Chapter10

Depression

There can be few people with M.E. who have not travelled down into the dark valley at some time during their illness. Depression is a very common symptom in M.E. and CFS, and only those who have experienced deep depression can really sympathise with others so afflicted.

There is a difference between depression and unhappiness/sadness. The latter is usually the result of bereavement, difficult circumstances, or perhaps the inability to adapt to a situation.

If someone grieves for a deceased loved one, their sadness is normal; but if the sadness continues for a long time after one would expect the grief to have settled, it may turn into depression.

Depression as an illness affects most bodily functions.

The sleep pattern is usually disturbed, with early morning waking, and one's mood lowest at the beginning of the day, improving later. A depressed person may be cold and slow-moving, the appetite is poor, there is lack of motivation, and an inability to experience pleasure in anything - the symptom called 'anhedonia'.

However, with M.E., depressive symptoms are not constant, and may be present for a few days or a few hours only. As with MS, depression in M.E. usually correlates with disease activity, most commonly associated with general relapse, worsened by overexertion, and improving with rest. This is the converse to a depressive disorder with psychological origin (see chapter 8 - the bull-in-the-field test), where exertion improves one's mood.

People with M.E. suffering from *emotionallability* may experience black despair, non-stop weeping, and suicidal feelings for a few days, then wake up one morning feeling fine. Or they may be irrationally happy, laughing and excited (maybe over nothing more than waking up without pain) one day - this euphoria leads to delusions of ability and lots of activity such as housework, extra socialising and missing the afternoon rest . . . and what happens the next day? They crash with a bump into the state of weeping and exhaustion. This up-and-down emotional behaviour is not the same as a state of depression; it is more typical of organic brain disorder.

The best way to lessen the highs and lows is to live within a daily routine of rest and activity, so your energy is used wisely, as advised in chapters 7 and 8.

Another source of depression in M.E. is the natural grief reaction to the losses - of the former active self, of jobs, friends, sporting activities, maybe of a spouse. This loss is not unlike that of someone who retires or is made redundant after many active years in a fulfilling job. There is inevitably a sense of not being needed; the world carries on very well without you, a world in which we are judged by what we are seen to do and achieve.

This secondary depression is common to all chronic disabling conditions, especially when the future is uncertain, and is bound up with anxiety and fear about the future. And part of

the reaction to finding yourself ill with M.E. is, naturally, anger. Anger, if kept inside and not expressed, turns into depression, with loss of self-esteem. Of course you are angry at getting M.E., and at such a very inconvenient time, when there is so much you were planning to do. Because one is flattened, inactive, and maybe inarticulate, the anger is overlooked and very often suppressed.

Expressing anger in a constructive way is often used as part of psychotherapy for all sorts of mental problems; however, if you are flat on your back and saving your energy to do essential things you will not feel like hitting pillows or shouting to vent your rage. Some people are angry with themselves, if they are led to believe that they have developed M.E. because of bad living or past mistakes. You would be surprised to know how many people feel guilty about being ill. The belief that sickness may be some sort of retribution brought on oneself is common, though not openly admitted.

If you have M.E. and depression, the loss of self esteem is unfortunately reinforced by the loss of ability to work or function normally. Talking about these fears and grief with a trained psychologist or counsellor can help an ill M.E. person to come to terms with things.

However, sometimes there may be a more sustained period of severe depression, when short-term remedies do not help. The patient may be in a black despair for days or weeks, unable to see a way out of it, and while in this state has no chance of improving energy levels or other symptoms. There is commonly a feeling of isolation, that one is cut off from other people and from experiencing any contact with beautiful things. An unhappy person may be moved to tears by beautiful music or a glorious sunset. A really depressed person will hear or see such things and feel absolutely nothing except perhaps despair because his or her contact with them is gone.

With this sort of depression there is often lack of motivation, insight, or judgement. The general purposelessness of life is seen in contrast to the apparent industry and contentment of other people.

The really frightening thing about severe depression is that you hate being in that blackness but cannot climb out of it. Well-meaning friends suggest that you snap out of it, or read a good book, or think of the world's starving children. But when in this state, you often cannot read, listen to the radio, or speak on the phone.

Why is Depression so Common in M.E.?

There are a number of reasons why depression can afflict M. E. sufferers:

- All virus infections cause some degree of depression.
- Cytokines are the chemicals which help to limit a virus infection. When interferon (a cytokine) was used to treat patients for another virus, the side-effects complained of were fatigue, muscle aches, and depression. Therefore, many M.E. symptoms may be caused by continued production of interferon in the body as a response to a persistent virus.

- If the brain is affected in M.E., then quite a lot of neurological functions are interfered with. Transmission of impulses between nerve cells takes place via chemical messengers called *neuro-transmitters.* (Antidepressant drugs change the balance of these chemicals, and so influence mood.
- The brain's chemical reactions need various amino acids (derived from proteins), vitamins, and enzymes in order to work. A lack of any of these amino acids or of enzymes leads to a deficiency of one or more neuro-transmitters, and this can greatly affect mood. Therefore, nutritional deficiencies that are caused by a poor diet, poor digestion or malabsorption may contribute to depression.

If a person with M.E. has recurrent diarrhoea and poor food absorption, this will increase the risk of depression because of lack of amino acids and B vitamins. (Depression is an early symptom in cases of starvation, and beri-beri - vitamin B_1) deficiency).

No one has invented a way of doing a biopsy on the living brain. So, unlike muscle fibres, which can be biopsied and looked at with an electron microscope, brain cells affected by a virus retain their secrets, and we don't understand exactly what is going wrong. However, some of the brain tissues of people with M.E. who have committed suicide have been found to contain enterovirus.

Depression should be seen as yet another nasty symptom of M.E., rather than as something to do with the personality of the patient. Many M.E. sufferers are people with no previous history of depression, and their behaviour can change alarmingly with M.E. Uncontrollable tears, terrible, black depression, despair, panic, suicidal thoughts - all these can be felt by someone previously regarded as well-adjusted and in control of his or her emotions. Such a miserable wreck can also become cheerful, laughing, or manic, this transformation taking place overnight or even within a day. All these emotional ups and downs are quite devastating to patients, and also to their friends and families.

So there are two main causes of depression: one is the chemical imbalance in the brain interfering with normal brain cell function, the other is the reaction of anger and grief at developing M.E. In practice the causes cannot usually be isolated - what is important is to help the depressive symptoms.

There are other factors which may, if present, tip the scales between just coping and becoming depressed. These are:

- Exhaustion, which may precede a relapse
- Low blood sugar, which is treatable
- Candida overgrowth or sensitivity (there will probably be other symptoms to suggest this)
- Hormonal changes, for example premenstrual depression
- Food or chemical allergy reaction
- A personal upset
- Occasions like Christmas, which make many people depressed especially if they are lonely or ill
- Dark winter days

M.E. causes emotional fragility and a degree of paranoia.

When people or events make you upset, learn to say to yourself 'It doesn't matter, this can't hurt me'. Living with M.E. can *strengthen* our inner resources, and lead us to being less dependent on the opinions and approval of others. A friend with M.E. told me, 'I try not to react so much to upsetting things now, nor to get overexcited or overhappy. I have reduced the level of some of my emotional reactions and just let things wash past me, and it is easier to cope'.

It is easy for friends and family to cause hurt. You find out quickly who your real friends are; others melt away because they feel threatened by the illness. They do not know how to approach someone who has changed and whose mood may be unpredictable. The upset from such hurt can be lessened if you have a strong belief in yourself, and if you can realise that your *unique special self* (soul, spirit) *is still intact and special,* in spite of your being ill and losing friends.

Those with experience of depression can often recognise when they are going down-hill again. Before the thing has got hold of you and you don't have the will or insight to sort anything out, try looking to see if there is anything pulling you down which you can maybe change, or at least comprehend.

Early Signs of Depression Checklist

- Are you overdoing things? Extra rest and sleep, and letting go of striving, may help.
- Are you eating enough, and the right foods?
- If you are female, is your period due soon? If so, you know this bad bout will not last forever. Premenstrual depression is very common in women with M.E.
- If you have had symptoms pointing to candida overgrowth, could you be having a flare up, and need to take an antifungal agent and check your diet?
- Have you eaten something you normally avoid and to which you may be hypersensitive, such as wheat? If so, this reaction will pass.
- Is there some extra chemical around, such as gas or new paint? If you cannot avoid it, take extra vitamin C and wait for the reaction to settle, or consider removing yourself from the new chemical, if possible.
- Is it a time of year when you have felt bad before? Many sufferers seem to find a seasonal pattern to their ups and downs. There is not much you can do about the earth turning, but at least. you know it will go on turning and bring you to a better month. If it is winter, maybe a full-spectrum lamp will help if you cannot get outside.
- Weather can also influence mood. Damp weather seems to affect a lot of people; low pressure is associated with an increase in negative ions, and of moulds and fungal spores in the air.
- Is your low mood the result of some personal upset?

If so, try and talk about it to someone you trust, instead of bottling it up.

It can happen that just when you think that the M.E. is receding, or that you have really got this illness sorted out and are coping wonderfully, then crash, down you go into a spell of depression and nothing you do seems to pull you out.

This happened to me last year, when I was trying to increase my exercise tolerance, and thought I was doing very well! I was very depressed for weeks, but came through it.

What now helps me most is (a) getting more physical and mental rest, (b) using either sleeping pills or low dose tricyclic antidepressants to ensure me a run of nights of sleep.

Each bout of depression I get *always* follows a period of extra activity, mental or physical, and comes with other symptoms of relapse - fever, sore throat, sweating, muscle twitching and pain, etc. This leads me to believe that most M.E. depression is a symptom of brain disturbance due to the disease.

So what encouragement can be offered to people going through a low patch? The following ideas may help carers as well as patients, and if you have M.E. and are at present well enough to read and understand this, then store this information up against a future bad time:

- Remember that *you,* a unique special person, are the same person underneath the depression. The essential you is intact, even when you feel disintegrated and cut off from the world. Try to see the depression as an awful symptom to be borne patiently until it passes.
- *This time of blackness will pass.* Be very patient with yourself, remember that seasons come and go, and so do moods.
- *Do not feel ashamed of being as you are.* Depression is a symptom of the illness, and may need treatment.
- Make a list (on paper or in your head) of all the people you have ever known who love you, and care about what happens to you. Do this while you are less depressed, and take this list out and refer to it if you have a bad time. Those people *still* care about you while you are depressed.

Allow those people who love you to give you their affection even if you cannot give anything back at the time. The thoughts and prayers of others can sustain you during a long bad patch. Michael Mayne, present Dean of Westminster and M.E. person, said 'When I was depressed I found I could not even pray, so I had to allow others to do the praying for me'.

Some of you may live alone, and may feel that you have no one who cares about you. There is probably someone, maybe at a distance, who could be contacted by phone or a written note. Could any friend fail to respond to a simple plea, such as 'I'm going through a very bad patch just now - please think of me, or phone me, or come and see me'? The British 'stiff upper lip' serves no purpose; admit you are low, and ask for help and reassurance.

The majority of those other people out there who appear to be happy and stable have probably gone through depression at some time in their lives. Those most able to understand and give support are those who have been in the dark valley and know what it is like. Such people may be contacted through your local support group, local church, or one of the national M.E. societies' telephone help-lines.

Try and give yourself treats, or allow others to pamper you. For instance, a nice warm bath with essential oils in, a new nightgown, something very good to eat, a visit from a hairdresser and some make-up, a new book or record, some beautiful flowers, or an outing if someone can take

you. A problem of course is that if you have depression *and* M.E., you may be in physical relapse and not strong enough for outings. A trip to a garden where you can just sit and take in the gifts of nature might be more appropriate.

One of the classic features of depression is the loss of self-esteem. By trying to give yourself treats, you are reinforcing your affection for yourself. *There is nothing wrong with loving yourself.* Loving yourself is not the same as selfishness, it means accepting and caring about your individual personality with all its faults and weaknesses, just as you accept the imperfections of a loved friend.

Laughter is good medicine for any illness. In his book *Anatomy of an Illness,* Norman Cousins tells of how, when confronted by sudden, severe, life-shattering arthritis, he withdrew from life and watched comedies on videos for days. He laughed his way back to health.

One way to boost self-esteem is to manage to complete a small task each day. There is no point in setting impossible goals that you cannot achieve without collapse, so the task needs to be something within your grasp. Perhaps writing a short letter, tidying a drawer, or doing a small patch of weeding, according to your ability.

The positive feedback from accomplishing something, especially if you see the result, can give a small boost each day. A certain degree of apathy may need to be overcome, but it is amazing how once the initial effort is made, the concentration required overcomes the misery for a time. Do not set a goal which is beyond your powers; if the task is unreasonable you will give up halfway through, and this can be counterproductive.

Antidepressant Drugs?

Some M.E. sufferers have been helped by antidepressants; others have been unable to tolerate them, or have found no benefit. Often when they are not tolerated, the drug has been prescribed in too high a dose.

The antidepressants called *tricyclics* (because of their chemical formula) were originally developed as antihistamines to treat allergies. The chemical formulae of the tricyclics and of the antihistamines used to treat hay fever and skin allergies are very similar. For this reason tricyclic antidepressants are sometimes used to treat chronic skin problems. Both of these formulae also closely resemble the formula of the phenothiazines used to treat schizophrenia and mania.

Tricyclics work by altering the available levels of some neuro-transmitters, with effects not only on mood, but on the transmission of other nerve impulses. So it is not surprising that brain functions in general may improve, such as memory, concentration, sleep patterns, and sensitivity to pain and noise. As these drugs also have antihistamine effects, they may modify some allergic symptoms as well.

Do not dismiss antidepressants if your doctor suggests this treatment, unless you have already tried them and were made worse.

Some may find their depression is helped by a nutritious diet, plus extra B vitamins, zinc and magnesium, and perhaps amino acids as a supplement. If antidepressants are prescribed, then those with the least side-effects should be used, and the smallest dose used to begin with.

The important thing to remember about antidepressants is that they do not work overnight like aspirins or sleeping pills. It will be at least two weeks before you see any real improvement in your depression. But better sleep and lessened anxiety will come almost straight away, which can be a great relief if there is marked insomnia and agitation as well as depression.

The possible side-effects of tricyclics are: dry mouth, blurred vision, difficulty passing urine, constipation, low blood-pressure, dizziness, an irregular or slow heartbeat, and nightmares.

Most side-effects settle after the first week or two, especially if the dose is increased gradually.

The starting dose should be much smaller for an M.E. patient than would normally be prescribed.

For example: Dothiepin 25 mg at night, increasing to 50 or 75 mg. Amitriptylene 25 mg at night, increasing to 50 to 100 mg.

If you have unpleasant side-effects at the start of treatment, especially any heart symptoms or missed beats, tell your doctor. Some of the newer tricyclics have fewer side-effects.

Another group is called *5-HT reuptake inhibitors,* eg fluoxetine and sertraline (Prozac, Lustral). These are stimulating rather than sedative. They can cause unpleasant side effects, which can be minimized by taking them only every 2 or 3 days.

The other main type of antidepressants, MAOIS, are not used as first choice. They interact with any foods that contain tyramine or other amines, and alarming rises in blood-pressure can occur. If you are put on MAOIS you will be given a list of all the dangerous foods, which include cheese and broad beans. This is one more hazard for an M.E. patient to contend with, and life is complicated enough without yet more foods to avoid.

From my own experience and that of many others, I find that the main benefit of tricyclic drugs in people with viral onset M.E. (rather than 'chronic fatigue') is that they help to improve sleep, and achieving this requires only a low dose. When the dose was increased, we felt worse and more depressed. What is urgently needed is a trial of tricyclic therapy for people with M.E., compared with the same treatment for people with depressive disorder but no M.E. features.

If you are getting better on antidepressants *do not suddenly stop them.* Even if you think you don't need them any more, you need to reduce the daily dose very gradually, under regular medical supervision. Sudden withdrawal could put you right back to where you started from, or even worse.

Sadly, there is a small but steady toll of people with M.E. who find they just cannot bear life any more, and take the only route left to them. Perhaps they would not have committed suicide if they had had someone who believed and supported them; if they had a sympathetic employer; if they had seen a doctor who had recognised the risk, placed them under supervision and started antidepressant treatment.

So please, if you, as a person with M.E., or if someone you know with *M.E.* is seriously depressed and has. thought or talked of suicide, *do get medical help,* and don't refuse treatment or hospital admission if this is advised.

If you are not taking any nutritional supplements already, consider the following, all of which are necessary for good brain function:

Vitamin B complex, (or as part of a multivitamin), containing at least 20 mg each B_1, B_2, B_6; vitamin C, zinc, and magnesium; and amino acid complex, if you have poor food absorption.

Psychotherapy

The term psychotherapy is used here rather loosely, and refers to the sort of skilled help that can be given by a psychiatrist, a psychotherapist, a counsellor, or anyone else trained in this field.

Psychotherapy proper is not suggested for someone in the early acute stage of illness, nor during a relapse, because there just is not the energy available for the talking and self-understanding that is part of the therapy. Digging up past painful experiences does not help an ill person; better help comes from a skilled listener, and by dealing together with problems of the present moment.

Learning to live with a debilitating illness is difficult.

One of the first steps to coping is accepting the illness and coming to terms with the limitations it imposes.

Anger and grief are perfectly normal reactions to developing a condition such as M.E. If these emotions can be expressed and admitted, instead of being suppressed and driven inside, then the patient has a better chance of maintaining a degree of sanity, and of coping with further relapses or depression.

Often, family and friends really want to help the M.E. sufferer, who they see is devastated by the symptoms and loss of normal life, but they may not have the skills needed to help psychologically. So seeing an outsider who has these skills (when you are not acutely ill or starting a relapse) is worth thinking about.

Loneliness

I have talked about grief and anger and their roles in contributing to depression. Loneliness is a feeling that hurts a lot of M.E. people, even those living in a family situation. Chronic illness may lose you friends, but it need not: a lot depends on how you view your friends and family. For example, if you become jealous of the health of others, this shows, and drives them away.

Self-pity, moaning about how unfair life is, and seeing yourself as a victim all lead in the end to resentment. *Much of life is unfair and difficult for every human being!* You and I have a strange illness, other people have different problems. Many people in the world are starving to death as you read this. Feelings of resentment, envy and self-pity can only make the illness worse, and they get between you and friends and lead to loneliness.

Past hurts and grievances, if they are hung onto, eat away inside and also cause resentment. All sorts of barriers that stop you loving other people, and keep their affection from you, can spring up from jealousy and resentment. Loneliness is partly a state of mind. People can feel lonely surrounded by a crowd in a city, or not feel lonely while apparently isolated in a deserted landscape.

The key to this is being content with yourself, liking yourself enough to want to have *you* as your friend.

I do not write these things as an outsider with no understanding - believe me, I *still* experience loneliness, envy of relatives who are fit and active, and anger. However, I think it is natural to feel these things. What is destructive is either not acknowledging these emotions, or feeding on them. Once you are aware of them, express them - on paper or out loud when alone! - then throw them away and replace them with more useful thoughts.

Here are some words by the writer Kahlil Gibran, taken from his little masterpiece *The Prophet.* They speak clearly about unhappiness and the pain of depression:

. . . Of Joy and Sorrow . . .

When you are joyous, look deep into your heart and you shall find it is only that which has given you sorrow that is giving you joy.

When you are sorrowful, look again in your heart, and you shall see that in truth you are weeping for that which has been your delight.

Some of you say, 'Joy is greater than sorrow', and others say, 'Nay, sorrow is the greater:

But I say unto you, they are inseparable.

Together they come, and when one sits alone with you at your board, remember that the other is asleep upon your bed.

. . . Of Pain . . .

Your pain is the breaking of the shell that encloses your understanding.

Even as the stone of the fruit must break, that its heart may stand in the sun, so must you know pain.

And could you keep your heart in wonder at the daily miracle of your life, your pain would not seem less wondrous than your joy;

And you would accept the seasons of your heart, even as you have always accepted the seasons that pass over your fields.

And you would watch with serenity through the winters of your grief.

Suggested Further Reading

Michael Mayne, *A Year Lost and Found,* (Darton, Longman and Todd, 1987).

M. Scott Peck, *The Road Less Travelled,* (Arrow Books, 1990).