
MOTOR NEURONE DISEASE

FACT SHEET No 14

Stress Management For The Carers Of People With Motor Neurone Disease

Stress management is not a mystical technique but a few common sense ideas put together in a way to inspire you to begin to take control of your stress levels.

It is not a 'shoulds list'. You should do this, this and that. Try to think of it as a list of options, possibilities or "coulds" or indeed versions of what you may already be doing. If you are already doing some of the things I mentioned then pat yourself on the back and tell yourself – you're doing O.K.

Because this information is about stress management for carers, it will address itself to the carers of people with motor neurone disease (MND). By doing so, it by no means wishes to undermine or devalue the intense stress of the person with MND. However, this information may be of use to people with the disease or assist them to be aware of what their carers needs are.

From a book written by Melvyn Pohl & Deniston Kay - "*Staying sane when you care for someone with Chronic Illness*" comes this quote:

"Because the course and outcome of chronic illnesses are unpredictable, people with chronic illness often feel powerless at the mercy of the illness or as if they were living on a roller coaster. At the same time they can easily forget the other person who's along for the ride - their caregiver."

BASIC STRESS MANAGEMENT CONCEPTS

- Life is a stressful event
- We cannot avoid stress and stressful events but we can manage it and manage our reactions to situations and events to decrease its effects.
- Stress affects us physically and mentally.

General signs of stress & tension

It is a well-established fact that stress, especially prolonged or excessive stress, affects both our mind and body in a variety of ways.

If you experience two or more of these signs then it is time to take action.

- General irritability, hypersensitivity, being keyed up
- Pounding of the heart, palpitations
- Emotional instability, overpowering urge to cry, to scream, to escape
- Inability to concentrate or remember things
- Feelings of unreality, weakness or dizziness
- Tendency to become fatigued, feeling tired all the time
- Floating anxiety, vague fears
- Trembling, "the shakes", accident prone, clumsiness
- Easily startled by small sounds, sensitivity to noise and light
- Sleep difficulties, awakening tired, fitful sleep, insomnia, nightmares
- Feeling restless, can't sit still
- Excessive sweating
- Diarrhoea, indigestion, stomach churning or queasiness, vomiting or going to the toilet a lot
- Headaches
- Muscle tension, especially pain in the neck or lower back, general aches and pains
- Change of appetite – over-eating or not feeling hungry any more
- Smoking excessively, using drugs or alcohol to relax
- Anger and aggression, short tempered, frustrated
- Being susceptible to coughs, colds, the flu, cold sores

A few years ago, it was believed that if you measured the amount of stress someone was under you could predict who was heading for a major physical or emotional illness. Now the experts say it's not just how much stress or how long we are exposed to stress, it's how we perceive or react to the stress as well.

Factors affecting how we handle stress

- Our genetic make-up
- Our childhood experiences
- Parental messages
- Life experiences
- Our personality
- Our physical health
- Our emotional health
- How we perceive the stress
- Our coping mechanisms
- The amount of stress and the length of time it goes on
- Our support networks
- Our knowledge and understanding of what is happening
- The amount of control we perceive we have over the situation
- The predictability of the stress
- Self-esteem and confidence levels

All these factors affect how each individual reacts to stress and stressful situations. Unfortunately really stressful life events such as serious illness don't wait until you are in peak form and ready to handle the role of carer. These things can occur when you are feeling least able to cope.

Being a carer

For a long time it has been assumed that if a person debilitated by disease has a spouse, that spouse will care for and cope with the situation.

For some people being an automatically appointed carer is very difficult: just because you love someone doesn't mean you are automatically equipped to become a carer. For some it is like wearing their shoes on the wrong feet. I met a carer once who said to me as he struggled in this role, "*I'm a damn fine carpenter you know*". For others however the role of it is a natural extension of their love.

If any carer at any time struggles with the role it is little wonder. Being a carer can be like having nine or ten different jobs all at once: Nurse, Personal Assistant, Counsellor, Dietician, Transport Officer, Diplomat, Financial Manager, Estate Manager, Public Relations Officer, Trouble Shooter.

You are the best judge of your stress signs. Understanding your stress signs and how to act on them is the cornerstone of emotional, physical and mental health.

Cast your eye down the list of signs of stress and tension again. The most commonly reported symptoms on this list are:

- Irritability
- Sleep difficulties
- Headaches
- Muscle Tension
- Unexplained aches and pains

If you recognise a few of these symptoms in yourself, take note of them. Identifying or acknowledging that you are stressed is the first step.

So if life with MND or caring for someone with MND is stressful, what can you do about it?

You can't make the disease go away but you can change the way you perceive and react to the stressors involved.

Iris Barrows, a renowned New Zealander who writes and lectures on stress and stress management puts it this way - there are two kinds of sources of stress, external and internal.

Examples of external stressors are

- Caring physically for a sick spouse
- Changes in roles and responsibilities
- Awaiting a diagnosis, test results, outpatient appointments, visits to specialist etc.
- Physical deterioration
- Constant interruptions to sleep
- Losing contact with friends and clubs or groups you belong to

These are the stressors we often have very little control of.

Examples of internal stressors are

- Unrealistic expectations placed on self
- Unrealistic standards to be maintained
- Fear - can I cope with this all
- Low self esteem and confidence
- Self critical thinking
- Inflexible thinking
- Maintaining a false public face - "no no everything is fine. We're coping well."
- Overwhelming feelings of
- grief and despair
- sadness and disappointment
- anger
- burden and responsibility
- lack of a sense of control
- guilt

Grief

Let's look at the grief issue briefly for a minute.

Grief does not just belong to death and the dying. We experience grief when we lose something important to us or when something changes. Losses and changes can happen slowly but that does not mean we don't grieve. Having someone you love diagnosed with MND is a major blow.

The image we have of them as a fit, healthy, active, indestructible person is destroyed. All those plans, dreams, schemes for the future go on hold - probably forever. All those practical changes like giving up work cause us to grieve.

When someone is first diagnosed with MND, they and their family will go through the whole gambit of grief reactions: shock, denial, anger and bargaining. As with any loss, then slowly comes acceptance, learning to live with it.

Accepting is not the same as giving up, it's a process of letting go of what can't be changed, turning the unmanageable into something more manageable, learning to live one day at a time.

Part of the accepting is learning to let go of the whys, and being able to say "*because it is so*". Being able to do this itself gives you the strength you need to move on. This is when you can begin to "*live within these 24 hours.*"

Pohl and Kay have this to say about acceptance:

"One of the keys to staying sane when caring for a person with chronic illness is holding on a healthy attitude and image about the illness. If you regard the chronic illness as a death sentence, then you commit yourself to sit in the very vestibule of death - listening for the death rattle - waiting for the end.

If you do this, you miss the best part: the process of living in the precious time available, whether days, months or years."

Just as you must allow yourself to grieve, you must allow yourself to accept.

Control

The other overwhelming feeling I wish to briefly talk about is a lack of a sense of control. Illness robs you of a sense of control. Terminal illnesses even more so. It's that old roller coast ride feeling, but this time you can't get off.

If any of you have been on a roller coaster ride recently you'll remember the first time round it's very frightening, as you don't know what's going to happen next. Second time around, it is slightly less frightening as you have a vague idea of what you've let yourself in for.

Third time around, you begin to anticipate the dips and sharp turns and it's not so scary. If you stayed on all day you would get to know every turn in the track.

A carer once said to me "*after about the fourteenth ambulance call-out in the middle of the night, I didn't get those panicky feelings any more, I knew what to do, I'd done it so many times before*".

If MND has robbed you of a sense of control, then you must in some perverse way take back a sense of control another way.

Steps to Managing Your Stress

1. Learn about the illness

Learn all there is to know about the illness. Knowledge empowers you. It takes away the fear of the unknown, helps you face the reality and understand what is happening. Become a professional MND roller coaster rider. Learn to anticipate the dips and turns, so when they do happen it is not like going on your first roller coaster ride with all that shock and fear. Education empowers you, takes away the fear of the unknown and gives you back a sense of control.

Every time you visit the doctor with the person you are caring for;

- Write down any questions you have before you go
- Write down what information the doctor gives you
- Re-ask the questions until you understand the answers
- Ask to have it explained to you in English not '*doctor speak*'

Collect all useful written material so you can read it at your leisure or when you are more able to absorb it. You do all this not to be super woman or man but for reassurance and a sense of regaining control.

Likewise learn about stress and stress management. There are literally hundreds of books, tapes and videos out there on the subject.

2. Learn to accept and to develop a coping philosophy, which allows you somehow to live in the eye of this hurricane.

3. Identify your support people

Write down your support network, making up your own categories, e.g. "*our social support network*"

1. Most significant - close, supportive
 2. Not so close - can be relied upon for help
 3. Have offered help - could be used
 4. Have offered help - use only when desperate
- Identify those who can offer physical help or emotional support
 - Record offers of help. You may not need them now but later on in the middle of a crisis when you are feeling overwhelmed

and completely stressed out, you can refer to your list and ring people for help.

- Learn to ask for help. This is the hardest bit for some people.
- Learn to be specific. "Oh yes please we would love some help with the ironing" or "great, we have so many visitors we would love some home baking, or some soup".

Many of your friends or family are at a loss as what to do they want to help but often don't know how. Write down some of these jobs - ironing, shopping, gardening picking up the kids from music, taking the kids out somewhere nice etc etc etc. Ask for help and take up all offers of help when they come.

4. Join a support group

This may be speaking to the converted. This helps with all the above issues and more.

5. Care for yourself

It is vital that in all the turmoil, carers learn to provide care and love without losing themselves in the process: caring without being consumed. If you give all of what you have all of the time, what is left of you?

Take care of yourself so you can take better care of the person with MND. Eat well, try to do some form of exercise - swim, walk. Take time to learn a relaxation technique, meditate, pray, read, listen to music, write, paint or just watch a sunset. Do one of these at least once a day!

Don't say "I don't have time for all of this". You need to make it a priority. You will be of little help to the person you care for if you collapse with exhaustion or end up flat on your back in coronary care.

6. Take time out on a regular basis

In basketball, the exhausted players are substituted out for a rest. They come back into the game with more vigour and energy. Use your support network and organise a sub on a regular basis for several hours. Then do something refreshing and relaxing (not the housework). Go out for lunch with a friend, walk along a beach, garden. Give this time

priority like you would a doctor's appointment.

It is also worth remembering that in normal circumstances you would not spend 24 hours with each other anyway. Work, interests, hobbies, and other events gave you time apart on a regular basis. Both of you will benefit from time apart from each other.

7. Set your priorities and lower your standards

Make 3 lists

1. Most important
2. O.K. to let slide and get around to it sooner or later
3. Doesn't need to be done at all

The bed does not need to be made straight away, a bit of dust never hurt anyone (except asthmatics). Anyway, if you leave it long enough, a relative or friend is bound to notice it needs doing and do it.

8. Laugh, cry and express your emotions

Over the next few months or years you will experience the whole range of emotions known to man or womankind. Identify what it is you are feeling - anger, guilt, frustration, sadness, despair - accept its O.K. and appropriate to feel this way.

Don't feel guilty about emotions such as anger; just don't take it on the one you are caring for.

Don't bottle it up

- Talk with someone
- Write a journal
- Chop wood
- Go for a long walk on a beach and yell at the seagulls
- Throw a dozen eggs into the bath
- Hit a pillow.

Once you've done that, then laugh. Learn to laugh more. Use a sense of humour to see the funny side of things.

9. Use professional help and advice

If and when your MND case worker, your GP or any other health professional tells you. "You need a break" then take it. The person

you are caring for may hate the idea. Yes, no one knows how to care for them as well as you do and there's no place like home. But for you to last as an effective carer and to survive as a human being, you must.

Not even superman leaps tall buildings all day, every day. In fact he is a perfect role model for stress management as he regularly takes time out from the stress of being faster than a speeding bullet, to be an ordinary human being.

When you are out there on the edge, it may be difficult for you to objectively see the crisis looming. An outsider maybe the one to say that you need to take some respite time out - now.

10. Plan for a crisis

Plan together what will happen if you get sick, the kids get sick, the person with MND is hospitalised etc. A crisis plan made in advance is not only useful if and when one comes along but it sure helps at 2.00am while you're lying awake worrying about the "what ifs". Tell your support people, so they know what to do if you do ring in a crisis.

11. Do something creative with the waiting times

Lots of time is spent waiting; waiting in doctors' rooms, waiting for home visitors, waiting for results of tests etc. Together you can play 'do you remember games', intellectual quizzes, read aloud, learn something new, read about philosophy, sociology, other cultures, go on a visual fantasy somewhere together - whatever.

If you sit waiting for long periods of time, you could take up tapestry, embroidery or patchwork. Create something and when it's finished frame it as recognition of your courage and endurance.

12. Learn to live each day as it comes

When you have taken all the previously mentioned stress management possibilities into account then try to learn to live each day as it comes; one day at a time; move away from asking "why", stop worrying "what if" - Live within these 24 hours.

Worry is one of the most useless emotions known of man or woman. Worrying constantly about the future will not change what is going to happen - it just makes you feel sick.

Pohl and Kay state:

"Living one day at a time means avoiding playing mental games that can make you crazy. Your only obligation is to this 24 hours. Your only task is to be as patient, competent and compassionate a caregiver as you can for this 24 hours."

One of the caregivers I spoke with said the best piece of advice she was ever given was NEVER underestimate your children's ability to understand and cope. After I listened to her story it seems to me that the advice could be wider - don't ever underestimate your own ability to cope. After this is all over you will be a richer, wiser, stronger person than you could ever imagine now.

HUGS

Hugging is healthy

- it helps the body's immune system,
- it keeps you healthier,
- it cures depression, reduces stress, induces sleep,

Adapted from a talk given by Rhonda Preston-Jones Occupational Therapy Advisor, Waitemata Health at the New Zealand Motor Neurone Disease Association Conference July 1995

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- it's invigorating,
- it's rejuvenating
- and it has no unpleasant side effects.

Hugging is natural

- it is organic
- naturally sweet
- no pesticides
- no preservatives
- no artificial ingredients
- and 100% wholesome

Embracing is virtually a miracle drug.



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