
MOTOR NEURONE DISEASE

FACT SHEET No 1A

Well, you have Motor Neurone Disease and...

The news is not good.
The diagnosis is clear!
What will happen now?
What about the family?

If you feel shock and despair at the news, that is quite natural. What you have to do is to decide what you are going to do about it. Are you going to

- (a) be an ostrich and not tell you friends
- (b) find out what it is all about
- (c) help yourself and your family cope as best you can – one day at a time?

Course (a) is pretty hard to sustain. Your friends will know sooner or later and they may be disappointed that you did not have confidence in them as friends.

Course (b) is at least a positive step – know all about it and prepare yourself for the worst. At least this is acceptance. The MND Association can help you with information (brochures, fact sheets, support, etc) that possibly your GP does not have. Contact the Association and get some information for yourself and your GP.

Course (c) is based on knowledge gained in (b) but the difference is that you are actively involved in managing yourself and helping others help you.

THERE ARE SEVERAL STEPS TO TAKE

1. With your General Practitioner

Ask your GP to refer you to a specialist neurologist. Use your specialist to advise both you and your GP how best to proceed. Ask your GP to refer you, if possible, to a rehabilitation centre and arrange regular visits.

There are rehabilitation specialists, physiotherapists, occupational therapists and social workers who function as a team to assess your progress and advise on use of equipment, exercise and all your needs.

2. With your family

Visit the Independent Living Centre (11 Blacks Road, Gilles Plains SA 5086 Ph 8266 5260 Country Callers 1800 800 523 Fax 8266 5263) to see what you may need at home. This is a free service and all you need to do is to ring and make an appointment. Take detailed notes when you visit. Check on equipment needs regularly and find out from the Association or the Independent Living Centre where equipment may be obtained.

Work out with the family just how they can help. Work out a daily/weekly schedule to fit in the things you like doing. Be sure to include rest periods when you can take a nap, perhaps morning and afternoon, as you may get very tired.

Get the family to organise visitors and outings so you are part of them. Your friends will support you. You need to be involved in a normal range of activities.

Plan your entertainment needs within easy reach with TV, radio, music, telephone, typewriter, and computer, so that you are able to control things yourself if you become less mobile. There is equipment to assist you if things get difficult.

Keep your hobbies and if you find you cannot manage, teach one of the children or grandchildren or friends to take over under your supervision and instruction.

3. In the community

Contact the local Domiciliary Care Service, making contact early so they can be aware of what you might need. The occupational therapist or social worker can drop in regularly to keep in touch.

Join the local library. If you cannot get there, many libraries have a book delivery service. If you live alone, survey the local services available to you, should you need them, such as shopping, cleaning or home maintenance. Some are available through government funded services. Knowing about things is half the battle!

MANAGE YOUR ILLNESS YOURSELF

Do regular GENTLE exercises. Stretching and relaxing are best. Remember – excessive or extensive exercise does more harm than good. Visit your physiotherapist, regularly for a check and also to get advice on appropriate exercises.

Relaxation and meditation can help. There are books and tapes on this subject and information on people who can teach relaxation and meditation.

Try to swim twice a week in a warm pool. When you are in the water do your stretching and relaxing exercises as well.

Learn to do deep-breathing exercises and learn to cough to remove congestion as this may help to avoid colds and chest infections.

Make sure you are comfortable when you sit or when you are in bed. Excellent cushions and mattresses are available.

If you have trouble getting in and out of the car, try a swivel cushion or even a glad bag on the car seat.

Be innovative and look for novel solutions to problems.

MANAGE YOUR EMOTIONS

Plan positively. There may be things you have always wanted to do and now may be your opportunity.

Make the most of the things and people you value, books, paintings, watching sport, friends, family – pets – and enjoy them!

Worrying about things never helps! Do what you can to tackle a problem and take one day at a time.

Learn to relax when you recognise that you are feeling tense. Discover what soothes you. Playing music, watching TV, having a warm bath, reminiscing? Try it.

Try to develop inner calmness. There may be family or friends who can help. Some people have the knack of a ‘no problem’ approach, meditation or religious faith. Whatever does it for you, try it. It makes things so much easier.

There are counsellors who can help you and the family come to terms with difficult situations. Contact the Association for advice and a recommended counsellor, experienced in such situations.

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