Living With Motor Neurone Disease (MND)

“The consultant’s actual words were: ‘Sorry, it’s MND. He then said: ‘I’ll leave you two alone to talk things over,’ and left the room. So there we were. I hadn’t a clue what MND was.”

The one thing that can be certain about anyone’s reaction to a diagnosis of MND is that the impact of the news will vary from person to person. The reaction, for example, of a young person with family responsibilities may well be very different to that of an older person looking forward to an active retirement. We are all in different circumstances that influence how we react to crises. Our concern and anxiety may not only be for ourselves but for those around us.

There are two important things to know: first, whatever reaction you have is normal; second, there is a whole range of help and support available. Whatever your circumstances, you need not be alone.

➜ See “Who to Contact When You Are First Diagnosed” section, for further information on your multi-disciplinary team

The diagnosis of MND inevitably means the beginning of a new journey - one that in all likelihood, you did not expect to be making but one that, in fact, you had already begun.

Normal reactions

‘Normal’ reactions to learning that you or someone close to you has a serious illness include:

- Shock
- Fear for the future
- Disbelief at the diagnosis
- Anxiety for loved ones and friends
- Grief for the loss of the future you expected to have
- Anger at the medical profession or family and friends
- Isolation because suddenly you feel ‘different’ from those around you
- Intense sadness
- Relief that you finally know what is happening to you

Some or all of these feelings may be overwhelming for a while and you need to work through them at your own pace. You may also find that you need to get the reality of the situation straight in your own mind first before turning to people for support. Others may find it easier to involve family and friends immediately. Gradually, though, most people will begin to ‘rethink’ and review their life and plans.

One of the most difficult things is to get a balance at this time between keeping a positive attitude and accepting that you have a serious illness. You may feel determined to face the disease head-on and fight it, or you may prefer to deal with it one day at a time.

Discussing and acknowledging feelings within the family is vital. MND affects not just the person with it but those close to them as well. Sharing the highs and the lows with your family and close friends, and allowing them to do the same, will mean that you can help each other. Bottling up feelings only leaves them to fester, causing far greater problems in the long term.

Depression

Depression is a natural reaction and it is quite normal to feel low at times.
Even so, it is important to be aware of signs such as:

- Insomnia
- Loss of interest
- Loss of appetite
- Lack of energy

If any of these persist for any length of time or become overwhelming, talk to your GP – they may be normal but that doesn't mean you have to go through them without help. Additionally contact the IMNDA to organise contact from the Nurse Specialist or ask about the counselling services provided in your area.

Emotions

You may find that you are laughing and/or crying at what might seem the wrong time and you are unable to control it. This may be due to how you are feeling but commonly it is because a part of your brain that is affected by the disease is causing it to happen. This may seem embarrassing to you and disturbing to those around you; be re-assured though, that this is normal and not a sign that your mind is affected. Some people have found that taking certain medication helps with these symptoms so you may want to talk to your GP or neurologist about it.

Sharing the diagnosis with others

Almost certainly, you will have undergone a variety of tests before the diagnosis is made.
You may have involved those closest to you in every stage, or it may simply not have been possible for someone to be with you at every doctor's appointment or hospital visit.
Either way, those closest to you will have been concerned for you and it is important that, at some point, they know what is going on.

It can be very helpful to make an appointment to see your consultant neurologist together so that your partner or close friend can ask their own questions and settle their own concerns as well as sharing the experience with you.

It does not follow that, just because someone is close to you, they will experience the same feelings as you at the same time. It may well be that when you are feeling anxious and distressed, your loved one is not and vice versa. Open, honest communication is vital to avoid possible friction or misunderstanding. Never make assumptions about how others are feeling.

Advice for family and friends

While feelings of anger, disbelief and anxiety are normal for someone diagnosed with MND, they are equally normal reactions of those close to them. Family and friends may feel guilty because they have reacted negatively or because someone they love and care about has been diagnosed instead of them. At the same time, they are trying to offer as much support and understanding as they can.

It may be that the person with MND is rejecting any attempt at support - their anger may be directed at family and friends. It may feel as though any help offered is simply not enough. Equally, they may feel some level of resentment that their lives and expectations have changed also.

It is important that friends, family and carers:

- Accept their own reaction as normal and that they too find a source of support and help, whether from professionals or friends
- Try not to over-react to any anger or frustration that may seem to be directed at them
- Know that any negative reactions from someone diagnosed with MND are usually temporary. Though there may be periods in the months and years ahead when these negative feelings overwhelm them again, these are natural, normal, understandable and usually transient.

Telling the children

How and what you tell children will depend very much on their age. However, a diagnosis of MND on any member of a family will affect everyone and often not knowing what's going on or feeling excluded from discussions is worse than having some idea of the full picture.

Every family situation is different and every person diagnosed with MND must do what feels right and comfortable for them.

➜ See Talking with Young People about MND section

Telling other people

How much detail you share with others is a very personal thing. Some people find it helps to 'get it straight' with everyone from the start. Others prefer to keep such information closer to home.

People have no automatic right to know anything about your personal life and you may not want to have to explain the situation over and over again. On the other hand, as the disease progresses, you may want people to understand that how you are affected.

The reactions of others

The more people know, the easier it is for them to offer help and support. Having said that, people may feel awkward in coming forward and think it best to wait to be asked. So don't be afraid to ask for help.

Some people find it very difficult to accept or be around illness. They may be frightened or nervous of committing themselves to helping in a serious situation and so become distant.

Talking and listening

One of the most important things is to talk and listen:

- To those who are qualified to give you more information and professional support
- To family and friends - they need to know how you are feeling so that they can support you and you need to know how they are reacting
- To the IMNDA

It is important to remember that your feelings and those of people around you will change - there will be highs and lows.

Changes in life roles

Everything becomes different with MND. Remember, that living with change is part of normal life and we are good at adapting to these changes.

How you feel

Family and friends will no doubt be struggling to support you through the emotional roller coaster that is living with MND. People often tell us that their feelings are in such chaos that it is difficult to explain how they feel. The many life adjustments that become necessary can lead to sadness and loss, guilt and frustration, and even fear and resentment. All of these can be mixed in with feelings of hope and optimism and a fighting spirit.

Keeping these feelings to yourself can lead to misunderstanding and isolation from those around you. Try to share your feelings with someone, because this will help you to organise your thoughts and banish the chaos. This does not need to be someone close to you, although it's best if it is. Many of the professionals helping you will have some training in emotional or psychological support and you can ask them where you can get a 'listening ear' to help you get your thoughts in order. Research tells us that getting the best out of living with MND relies on being open about your feelings and not allowing guilt and resentment to build up.

How other people feel

We know that MND affects the whole family. Normal routines and life styles can be turned upside down and lead to significant emotional changes for everyone.

Some may take on tasks that were traditionally yours. Careers may have to be put on hold and resulting money worries may increase. Many will try to hide their own feelings of loss and helplessness to protect you.

As MND progresses, the nature of your usual relationships may shift bringing you closer together in many cases. Whether you live in a family unit, as a couple, or within a friendship network, hold on to what was unique about those relationships before you had MND. Try to avoid everyone becoming your 'carer' by accepting outside help for some of your physical care. Above all, try to recognise when those you love need to share their feelings and be prepared to encourage it.

Intimacy and sexuality

"I enjoy my partner holding me in her arms
closely while in bed with our favourite music on."

Physical intimacy is core to any loving relationship: we need to feel and be close to others. Although MND does not affect sexual ability, when other movements become affected, sexual expression may be more difficult.

This is the time to talk openly about these changes and discuss alternatives. Consider talking to healthcare professionals, such as a counsellor, if necessary. Living life to the full with MND is what it is all about.

Sex itself may become less of an issue for some couples, but do show your love in other ways like cuddling and kissing. Some members of your family may be worried about showing they care - if they would normally give you a hug and a kiss, encourage them to do so.

Planning ahead

"In my view, mental and physical aspects of MND go hand in glove - if one has the right frame of mind, one can almost achieve the impossible."

A diagnosis of MND may interrupt the best-laid plans but that does not mean you should stop making any new ones. Rather, you need to become informed about the disease and learn to manage it as best as possible.

Why plan, - how it can help?

The urge to deny the impact of a diagnosis of MND may be overwhelming, swiftly followed by the thought of, "Why me?"
It is normal and perfectly understandable to ask, but if you remain focused on this, you put off learning to live with MND and being able to take control of how you manage the illness.
It is important to become informed about the types of decisions that you may have to make in the future.

The following coping strategies offer a positive way of dealing with the diagnosis:

Accommodating change

- Means adapting to change, being able to recognise what was and what now is
- Is proactive - turning "Why me?" into "What can I do?"
- Acknowledging that MND is a real part of your life can take considerable time

Accepting change

- Takes however long you require - it may be months; for others it may never happen
- Means, changing how you achieve things for example, using a walker or wheelchair for safer mobility
- It does not mean giving up or giving in

Making decisions

- Can be improved if you talk with family and friends - but you have the final decision
- Will be on-going as your symptoms change - decisions will need to be revised or sometimes reversed

Staying in control

- Remain involved in the world around you
- Organise your own healthcare - choose a GP and healthcare professionals you like and trust
- Retaining a sense of humour is life-enhancing
- Deal with MND one day at a time

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Notes