

TIPS FOR PRINCIPAL CARERS

As the key person responsible for the care of a loved one everything is up to you.

The problem is, everyone's MND journey is different. MND can start anywhere in a person's body and the way the disease develops is unique. This makes it difficult for you, as their primary carer, so my suggestion is keep an open mind. Expect the unexpected.

You may not always get clear answers from everyone you talk to. This can be frustrating but the truth is, it's very difficult to predict how the disease is going to affect your loved one.

Some people with MND decline quickly, others can be well for a long time, and then suddenly decline. Again, expect the unexpected.

Some people with MND are told they don't have long left, but then live for months or years.

Getting support

Contact MND Association Connect helpline - 0800 802 6262 - to be connected with a local MND Association Visitor (AV). These volunteers are usually someone who has lost a person to MND. They are trained in providing support and signposting and will know how others in the community have handled various aspects of the MND condition. This makes them an extremely useful source of information for you.

Get as much help as you can from as many sources as possible. In addition to professionals, friends and family can lend a hand. Indeed many will want to help so they spend time with the person with MND, or because they want to relieve your burden.

You may have to be firm with those who are supposed to be serving your loved one. For example, you may have to talk frankly to the management of the care agency if carers are not up to scratch. If you apply for Continuing Health Care, you may have to appeal a decision that goes against you initially. Be strong and fight for your loved one.

Equipment

I recommend you get an occupational therapist involved, as soon as possible. They can assess what equipment will help your loved one remain as independent as possible for as long as possible.

Also it's a good idea to get a speech and language person involved, well before any signs of loss of speech or swallowing occur. Ask to see what equipment and tools are available and get trained on them as soon as possible. Practice with Eyegase well before your loved one's voice stops working.

Make videos when you are being trained to use any special equipment, for example, ventilator, cough assist machine, PEG flushing etc.

Communicating with your loved one

I recommend you keep having proper conversation with your loved one. Ask them what they want you to do for them, and what they want you to do for yourself. They may have views on how they want you to lead your life after they have gone. It can be comforting to them to give you guidance. In some cases, a loved one will feel very angry as they lose their functionality, or at how much work you have to do to help them. Remember, they are not angry at you. They are angry at their situation. It's not personal

Be prepared

There is no such thing as mild MND. Your loved one may think they are going to be okay, but you have to be prepared for the fact that parts of their functionality could change at any time.

You have to be prepared for the worst whilst hoping for the best.

You need to be two steps ahead of the progression of the disease.

You are likely to spend just as much time helping your loved one keep up their spirits as doing care duties for them, at the same time as being their advocate for everything they need.

If you are offered a meeting to discuss continuing health care (CHC), to create a package of care for your loved one, I suggest you do two things.

- Write a list of all the things your loved one can no longer do for themselves,
- Write a list of all the time it takes you to do various tasks for them. Such a list will include, washing, feeding, dressing, oral hygiene, etc.

Remember, what ever package you are awarded, in a matter of weeks or months, you may need to call another CHC meeting, to upgrade the package.

Humour

It important to keep a sense of humour. Make light of any accidents that happen so your loved one does not feel more guilty and angry that they already do. If they get angry, remember it's probably frustration coming out. Don't take it personally.

Practice self love

You need to look after yourself. It's very tempting to be there all the time for your loved one, but you are no good to them if you burn out. It may feel selfish to take time out, but you have to, for your own sake and that of your loved one.

It's okay to have duvet days. If you or your loved one feel the need, take time out. Chill. Do nothing. Lounge about. Watch back to back movies or a box set. Anything that helps you both escape from the daily grind and thinking about your situation, is good.

It's okay – indeed essential – to ask friends to help. They can sit with your loved one while you take a break.

Get out of the house if you can. Go for regular walks. Get your nails done. Go to the hairdresser. You need to be pampered so you stay strong.

Spend time pottering in your garden – I found being outside, and experiencing the sun's warmth made me feel calmer. Your loved one can sit and watch you while also taking in the fresh air. Suitable protection from harmful sun's rays – sunscreen, sunglasses, a hat – will be needed for your loved one, as well as yourself.

If you have a package of care, once you have trained the carers, and are satisfied they are confident, you will have time to go out shopping, or have coffee with friends.

Legacy

Consider recording conversations with your loved one, or making videos of them talking to you (with their consent). I have found it has given me joy to watch videos I made of Alan. Listening to his voice is especially comforting.

Consider making a video or audio legacy - <https://recordmenow.org/>

Please note: This article does not provide medical advice.

No content is intended to be a substitute for professional medical advice, diagnosis, or treatment. The views expressed in the book, Life's Good, are purely the views of the author. The author is not a medical expert and recommends readers affected by MND always consult their GP, MND specialist and other medical specialists appropriately.

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