

TIPS FOR FRIENDS OF A FAMILY AFFECTED BY MND

Check out the MND Association website for loads of information

<https://www.mndassociation.org/app/uploads/2019/01/Introduction-to-MND.pdf>

Be proactive, instead of just offering help. There were loads of people who offered help to me, but I found it hard to call them when I needed support. It always cheered me up when people turned up out of the blue with something they had cooked, or a small gift, or offering to sit with Alan while I took a break.

Beware of assuming you know how people feel - they may be smiling, but that can be a mask for what they really feel.

Beware of saying "I know how you feel" unless you are living with MND day to day. Instead say "I can't imagine how you feel, is there anything I can do to help you?."

Give long hugs. Minimum of seven seconds is good.

Give people time and space to talk. Often they may not need you to respond. They may need to pour out all that's in their heart or on their mind. They may cry (a lot). Giving hugs, and listening to them is a very loving thing to do.

Beware of trying to fix problems. Often the family will have already considered all the different angles. If they ask for your ideas it's okay to ask them have they considered XYZ (rather than saying you should do XYZ).

Signpost people to professionals who could help them if they ask you something you don't know about (they should have access to an MND nurse, District Nurse, GP or palliative care team who can usually help with most issues).

Proactively arrange to sit with the person who has MND to give their principal carer a rest. You can read to the person with MND or watch television with them or just let them chat with you.

People with MND and their principal carers don't usually want sympathy. Treat them as if there is no MND.

Grand gestures are not necessary – it doesn't take a lot to help someone enjoy their day. A smiling face and some funny stories bring warmth.

An occasional small gift for the person with MND, or their carer, will make them feel special.

Help the person with MND to enjoy every moment – even if it's just watching TV together or reading to them.

Try to focus on the day, or happy memories from the past, rather than talking too much about the future.

Talking about your plans for holidays or house moving etc, may cause the person with MND, or their carer, to feel jealous or sad.
If the person is in a wheelchair, crouch or sit, rather than stand by them.

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.

<https://lifegoodbook.co.uk>