

+ Psychological care for people living + • with Motor Neurone Disease •

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Overview



Levels of psychological support



What makes us psychologically resilient?



Coping with negative emotion



Focus on values



Cognitive and behavioural change in MND



Summary and questions

Levels of psychological support



What makes us
psychologically resilient?



What makes us psychologically resilient ?

Psychological distress: being present, open and aware

It is normal and appropriate in the context of MND.

We need to sit with people's distress and not collude with their avoidance.

Need to make space to hear it and validate it. DO NOT UNDERESTIMATE VALUE OF THIS.

'you would be a very odd human being if you weren't overwhelmed by the news of your diagnosis – I'm profoundly sorry'.

Help people make space for it: what is going through your mind? What do you know about MND? What worries you most?

Notice the emotion that is being expressed and reflect it back to them, rather than feeling like you need to soothe or make them feel better.

- 'I can hear how sad you feel at thought of losing that' 'I see that you are very frightened about how you might die'. 'it's very sad and overwhelming. It's a lot to take in'.

Pay attention to their bodily felt sense: Where in your body do you feel that sadness? What do you notice in your body when you are anxious?

Psychological distress: Purpose, connection and values

In our pain we find out what matters to us.

‘Your sadness is really important to listen to – it tells me how important something is to you’ ‘you wouldn’t be sad if you didn’t care’.

Emotional pain is love. When you feel this pain it isn’t wrong or something to be pushed away, it is an expression of what you care about it.

Do they share how they feel with their loved ones? Encourage people to share how vulnerable they feel with others. Opening up their fear or sadness with loved ones builds connection vs protecting others from distress which disconnects. We can model these conversations with family members – encouraging them to open up and connect.

Values

What really matters to us in the end? Ill or healthy?

What is it about your hobbies/job/family that you really value?

How can you keep investing in these in these circumstances?

Help people focus on investing in the present moment versus outcomes.

Cognition and MND

Roughly 50% of people living with MND experience changes in their cognition or behaviour. Up to 80% by late stages of the disease

For about 15% of plwMND, these changes are significant enough to meet the criteria for a diagnosis of Fronto-temporal dementia

Cognitive and behaviour change

What it can look like?

- - not doing what they used to enjoy
- - Not accepting help
- - forgetting appointments/meds
- - lack of self care
- - behaviours that increase the risk of harm
- - behaving out of character / appearing inappropriate or rude
- - difficulties in conversations
- - asking the same questions over and over
- - lack of insight into decisions
- - seeming to disconnect/be unaffected

Assessment

- - Screening tool (ECAS)
- MiND-B carer questionnaire
- - Clinical interview
- - Observations
- - Formal Cognitive assessment

Cognitive and behavioural change – support/management

Psychoeducation

Change the environment, routine and/or use external aids

Increase others' awareness and encourage them to make adaptations

Support people with decision making.

Psychological distress is normal and appropriate in context of MND diagnosis. People are more resilient if:

- They are open to and aware of their own emotions
- They keep investing in what matters to them (not outcomes, but values)
- They show flexibility in their approach
- They share their vulnerability with others as it builds connection (which is often what matters).

Cognitive and behavioural change is fairly common and needs support/management

- listen to what the problem symptoms are and whom it is impacting most
- Offer psychoeducation or signpost
- Consider if further assessment would be beneficial
- Problem solve how the environment or routine could be changed/aids used to ameliorate the impact of these changes.

A sample of psychological resources, ideas & services



BOOK
The Reality Slap by Russ Harris

BOOK
Facing the Storm by Ray Owen

BOOK
With the End in Mind by Kathryn Mannix

[FURTHER TRAINING](http://contextualscience.org/)
<http://contextualscience.org/>
- introduction to ACT

[FURTHER TRAINING](http://www.praxiscet.com)
www.praxiscet.com
– access ACT training

CHARITY - MND
www.mndassociation.org:
• Emotional and psychological Support for people with or affected by MND
• Changes to thinking and behaviour with MND – a guide for people with or affected by MND
• Offer counselling for children via Barnardos.

CHARITY - Winston's Wish
www.winstonswish.org
UK child bereavement charity.

CHARITY - Widowed and Young
www.widowedandyoung.org.uk

End of Life Doulas. <https://eol-doula.uk>

[FREE ONLINE RESOURCE](http://www.psych.ox.ac.uk/talkingtochildren)
www.psych.ox.ac.uk/talkingtochildren
4 step guide to help you talk to your patients about telling children about serious illness

EXERCISE
Map out professional psychological network in your area?
Community neuro-rehab team?
Palliative care team?
MND Care Centre – nurses/OT/psychology?

BOOK
As big as it gets
supporting a child when someone is seriously ill. A Winston's wish publication.