

MND podcast number 8  
Maintaining hope in MND



Hello my name is Robyn Reid. Welcome. I am the MND Shared Care Worker in the Southern Region of Melbourne. This is the last in the series of podcasts on Motor Neurone disease. MND is a truly awful disease in its complexity and impact on those who have it. There is no cure. How do we help those with MND to maintain a sense of hope and not sink into despair as they lose their mobility, speech, identity, and independence and ultimately their life?

We may have little to offer in the way of mitigation of the prognosis and trajectory of MND but we can offer ourselves as a constant and unwavering source of comfort and support, undaunted by what lies ahead, and ready to do all that we can to understand, inform and empower people living with MND and their carers to endure and reach their goals. Health professionals are in fact the instruments of hope.

Hope may be defined in several ways. It can be a feeling of desire for something, and confidence in the possibility of fulfilment. Hope is a dynamic and multifaceted thing characterised by a confident, yet uncertain expectation of achieving good, which is realistically possible and personally significant. The opposite of hope is hopelessness or despair. Hope imparts a sense of the future and the possibility of future good. This attitude plays an important role in coping with illness and impacts upon a person's quality of life. Hope can exist even where there is life-limiting illness as it evolves and adapts, to include an appreciation of values, family relationships, the control of symptoms and the exploration of spirituality.

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Sources of hope include family, friends, health, carers and perhaps a spiritual belief system. It also includes the person themselves- their optimism, personality and character and their capacity to make meaning for themselves out of their reality.

Hope has enemies: powerlessness, isolation, pain, fear, social withdrawal, and personal devaluation. If we identify ourselves with what we do rather than who we are then when we cannot “do”, we can believe we have no worth. When all of our worth is tied up in external states such as our occupation, our possessions and financial status, our health, our relationships then these things are easily removed or challenged. If our worth is grounded in who we are, the values we live by and the way we express our authentic selves then we are more able to continue to hope in the face of tragedy, and to continue to add value to everyone in our path. Changing and reframing hope in the face of constant change means taking time to explore and have conversations, finding meaning and purpose and creating new ways to view the world and our place in it and having that ‘confident yet uncertain expectation of achieving good.’

When everything seems out of control and dark we can always cling to hope. My hope is that people living with Motor Neurone Disease and their loved ones and carers will take up all the assistance available to lighten their load. I hope Carers will also care for themselves with adequate respite and support and trust that others can also provide care for their loved one. While this will never be the same as at home- it may be enough to provide them with a break, so they can continue to care and reach the goals that they have set for

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themselves and their loved ones. In the face of our mortality and the fact that we will all die:

We can hope for a cure for Motor Neurone Disease and trust in the vast numbers of people working on all the factors involved.

We can hope that our strength and courage will not desert us.

We can hope that we have the dignity and grace to meet all the challenges that come every day.

We can hope for the love and support of family and friends.

We can hope for a peaceful death

We can hope for the expertise of health professionals to be available when we need it.

We can hope that we can realise our goals and wishes framed as they might be by circumstances.

We can hope that we can express our feelings freely and that they will be met with care and comfort and not judgement.

We can hope that what we need will come to us at just the right time

We can hope that in the daily rhythm of the ordinary the sacred reveals itself.

We can hope for kindness.

**There are many different types of loss experienced by people with MND, their carers and families**

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Grief is the response to loss. We respond emotionally, cognitively, psychologically, spiritually and physically. For people living with MND grief commences with the diagnosis and the shock. Few people understand the physical nature of the shock of bad news unless they have experienced it. With the news come a sense of depersonalisation, sometimes nausea, fatigue, crying, poor capacity for problem solving and making decisions, as well as confusion and inability to process communication. We become preoccupied with our internal world. As well we may experience difficulty with eating due to a sensation of a large ball in the throat, and there may be a decline in appetite, sleep disturbance, as well as anxiety.

It may take some days for the shock to subside. It is therefore important that any information given is repeated at a later stage to ensure that people have actually been able to hear it and understand it and they need time to get to the point of wanting more information and asking questions.

First there is the loss of health and functionality. These are ongoing and with constant deterioration there is little time to maintain any sense of emotional or psychological stability while adjusting to a constantly changing reality. There is the grief of understanding the prognosis and mourning of the life to be lived versus the one that is now a reality. There is the eventual loss of family and friends and the continuity of the self. There is the loss of identity. Who are they if they are unable to contribute and communicate, move or have personal autonomy and they are forced into dependency?

Then there is the loss of social visibility and participation. How do they continue to enjoy going out when lack of mobility creates burden for carers,

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lack of access, and symptoms such as drooling and coughing fits and poor communication create stigma, embarrassment or shame. There is also the response of others to this new identity: the person in the wheelchair, the person who struggles to participate in communication and social interaction. For the person who witnesses the disease they may feel powerless, helpless and uncomfortable, anxious about the fact that they might say something to upset the other person, and so their solution may be to avoid that situation by not visiting or coming into contact with the family, friend or relative. So, as well as suffering the consequences of the disease, people may lose their social connections, either through being confined in the home, or because their friends or family are unable to cope. The sense of powerlessness and helplessness can also affect health professionals and the treating team, faced with many complex issues and treatment needs and possibly little exposure to MND.

There is the loss of communication. How do they maintain a sense of identity and self when others speak for them or talk about and around them as if they were not there? How do they make their wishes known if they cannot speak for themselves? They lose power and agency to affect their life. They cannot express themselves and the expression of emotions intense or otherwise, is difficult, both because they don't want to add to the burden of the carer, and because understanding them takes time and patience and perseverance. They may find it difficult to find an audience for their anger and frustration. How do they get people to listen to the multitude of small needs so that the daily tasks of living can be as independent as possible? They need the glass moved, the drink prepared just so, they need a certain position to be comfortable, mask

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on, mask off, toileting, lights on or off, heating up/ heating down. A hundred small activities that we take for granted to ensure our own comfort every day now require communication and requests. How do we mourn the loss of that?

In the face of overwhelming and continual losses, it is important that people living with MND have access to support and information, as well as really excellent care and assessment. In the light of the potential for intense emotion and clinical depression regular and careful monitoring is essential.

**So what are the potential strategies that people can adopt to manage these losses?**

In the face of continual devastating and cumulative losses how can people with MND manage? Firstly it's ok if they don't. We who help them can only listen, really listen, and help them to inform us of what is really happening to them in the process of the disease. They need adequate support from people who understand their disease and anticipate their needs as much as possible to reduce fear, anxiety and effort.

Accessing the best support, advice and treatment possible.

Providing alternative forms of communication through music, art and technology to enable the person to continue to express themselves as an individual and to maintain their connection to the things, people and places that give them pleasure.

Maximising their quality of life by living every day to the full despite the impact of the disease.

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Refusing to believe that because they can no longer “do” that they do not have value and worth to the people that love them and to themselves just by being.

Being able to accommodate the reality of living with a life limiting illness while not allowing it to dominate daily life. Planning and making all necessary decisions for the future.

Continuing to participate in spiritual and or religious life.

Continuing to explore and learn new ways of coping and adjusting.

Accepting what is and not looking backwards and wanting it to be different, being open to being cared for and receiving love wherever it can be found, being flexible.

Holding onto whatever independence and autonomy is possible even given the prognosis while at the same time surrendering gracefully those things that can no longer be held onto.

Finding blessings in the darkest moments and knowing that there are those who can accept them in whatever state they are in at any given time without expectations or judgement.

**How can health and community professionals foster hope in people living with MND as part of their work?**

**This disease of MND is bad enough without the secondary traumatisation that can be caused by health and community professionals who may respond and communicate poorly.**

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You are the instrument of hope. This does not mean not being truthful about the prognosis and presentation of the disease but communicating with empathy and skill.

It means remembering your humanity and bringing empathy and compassion into your contact with people living with MND. Make eye contact, don't appear rushed or in a hurry. Take time to create rapport. Consult and partner with the person rather than "do" things to them.

Ensure that you read as much information as possible to avoid asking questions that have been asked many times before or have been written down.

Prepare for contact by understanding the communication needs and function of the client.

Make extra time to spend with clients with MND to allow them to communicate.

Where possible use closed yes/no questions to reduce fatigue.

Where possible carry out assessments with more than one health professional to reduce fatigue and reduce the number of visits.

Get to know who this person is and what they enjoy, what their values and achievements are. Relate to the person not just the disease and its presentation.

Check their capacity for information and understanding. Go at their pace not yours.



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Create confidence in your care by communication with all those involved in their care and sharing information. Provide excellent clinical management. Have patience with carers and their expectations and demands.

Explore emotional and psychological adjustment and provide appropriate support.

**Care for the carers.**

The rate and progression of the disease means that carers have to adjust to their loved one losing mobility, having difficulty swallowing, breathing and communicating and coming to terms with a myriad of equipment. 50% will die within 3 years of symptom onset. Make sure they have access to counselling and their own support system separate from that provided for the client. Their role changes dramatically. Try to take time to acknowledge and validate their losses. Helping them to access social support can really help to mitigate the burden of caring. Provide information, respite and education sensitively and in a timely manner.

When we give hope to another, when we reinforce their worth and their value, when we provide a place of safety and comfort, we are performing sacred work. It is difficult in our busy lives to remember that.

The act of Blessing is intended to strengthen the human position and often draws on nature to do this. So as a nod to my Irish ancestry I leave you with this blessing:

**Beannact**

On the day when

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The weight deadens  
On your shoulders  
And you stumble,  
May the clay dance  
To balance you.

And when your eyes  
Freeze behind  
The gray window  
And the ghost of loss  
Gets into you,  
May a flock of colours,  
Indigo, red, green,  
And azure blue,  
Come to awaken in you  
A meadow of delight.

When the canvas frays  
In the curragh\* of thought

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And a stain of ocean  
Blackens beneath you,  
May there come across the waters  
A path of yellow moonlight  
To bring you safely home.

May the nourishment of earth be yours,  
May the clarity of light be yours,  
May the fluency of the ocean be yours,  
May the protection of the ancestors be yours.

And so may a slow  
Wind work these words  
Of love around you,  
An invisible cloak  
To mind your life.

John O'Donohue

\*A curragh is a small round handmade boat used by the Irish people.

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I would like to take this opportunity to give my thanks to staff at Bethlehem Calvary Health care and MND Victoria and VRSS for the support and training received in my role as MND SCW in the Southern Region. I also wish to thank everyone who has listened to this series of podcasts on Motor Neurone Disease. Please feel free to contact me should you wish to have an education session on MND for your agency or to receive a secondary consultation. You can contact me on: 0428264446 or email me at: [Robyn.reid@smrpcc.org.au](mailto:Robyn.reid@smrpcc.org.au)  
Thank you.

**References:**

- Dave McKay Is there hope in palliative care? NZFP Volume 31, Number 6 December 2004
- John O'Donohue To Bless the space between us. Doubleday publishers
- Cornelius J. Woelk Management of hope Vol 54: Septembre 2008 Canadian Family Physician Le Médecin de famille canadien