

MND Podcast number six:

Carers of people with MND



Hello, my name is Robyn Reid. I am the MND Shared Care Worker in the Southern Region of Melbourne. Welcome. This is a series of podcasts on Motor Neurone disease. This podcast may help you to understand the issues for family and friends of those caring for people with MND. For specialist community palliative care agencies, carers are essential to achieving the client's goal of 'place of care' - especially if they wish to stay at home. Caring for a loved one can be meaningful and rewarding, but research shows that the burden of caring can impact on well-being and health. Carers are at risk of physical injury, anxiety and depression and may be socially isolated. Caring for someone with a life-limiting illness can threaten financial security and emotional, mental and physical well-being. The decision to care for someone, made in the early stages of the disease can have unexpected consequences.

Health professionals must be aware of the needs of carers, and service models need to include carer assessment and referral throughout the time of care, including post bereavement. It is important to recognise carer needs and issues, so that appropriate assessment, adequate monitoring and referrals are made to prevent carer burnout and poor carer health outcomes. The quality of life of the person with Motor Neurone Disease is dependent on the well-being and capacity of their carers.

Carers are under considerable stress at times. Research says that there is a relationship between the mental health of the patient and their carer. If a patient suffers from depression and anxiety, there is an increase in depression and anxiety in the carer. Carers of people with MND have increased rates again

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of depression and anxiety and also increased risk of complicated grief after bereavement. In a survey of carers 60% of carers said their health had been affected, 33% had been physically injured without any financial compensation, 70% had low energy levels, and 50% reported worse mental and emotional health.

The opportunity to talk to a health professional about what is happening, and in particular to anticipate what may happen during the illness and the dying process is very important. This discussion is difficult in the presence of the person being cared for, especially if there is conflict or differences in understanding of the fact that MND has no cure. It may be helpful for carers to have their own counselling support independently of those provided to the person receiving palliative care. It may be helpful to explain alternative or additional caring possibilities at the beginning of the caring role. These include:

- respite options
- inpatient palliative care service or hospice
- residential aged care

This can introduce the idea that changes can occur to care arrangements and that options are available.

Due to the ongoing deterioration of the person with MND, the carer has to continually adapt to more intensive care needs. This includes increasing

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dependency, understanding and using new equipment, decreasing mobility, changes to communication ability, Non- invasive ventilation and Peg feeding, and coming to terms with the end of life issues for their loved one and themselves. They must also adjust to changes in their relationship- intimacy, sexuality and roles, caused by the progression of the disease and its impact.

The person with MND requires the assistance of a multidisciplinary team and regular contact with a neurologist as well as specialist palliative care for optimal care. This means that the carer must juggle a very demanding schedule of appointments for interventions, assessments and treatments. This further increases the likelihood of carer burden and poor health outcomes.

In about 15% of cases the carers will also be dealing with behavioural issues due to frontotemporal dementia such as poor impulse control, being obsessed with things, loss of empathy and insight, food cravings and they may even be at risk due to aggression. Managing these symptoms sharply increases the chances of depression, burden and decreased quality of life for the carer.

Carers can struggle with the responsibilities of managing symptoms such as breathlessness in their loved one, which can create distress, anxiety and helplessness. The person with MND may not have the same views about their illness which may cause issues in the relationship and management of the disease. As end of life approaches, the person with MND may choose to refuse life sustaining treatments or even choose to end their life by withdrawing ventilation, or if they reside in Victoria, they may access Voluntary Assisted

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Dying. All of this can cause distress and complicate care. They may also be at risk of prolonged grief.

MND caregivers, particularly those providing prolonged care, face challenges seeking help from friends and family. Social support is an important factor in reducing the impact of caring for someone with MND and maintaining quality of life for the carer. Carers frequently have no time for their own needs and they often have interrupted or reduced sleep, physical exhaustion and fatigue.

Fatigue increases the risk of accident and injury, as well as understanding instructions, and the ability to carry out tasks such as driving and handling medications, etc. Fatigue and lack of sleep can cause irritability in the carer and this may lead to feelings of guilt. Household needs continue, and carers must continue with a range of other duties and responsibilities as well as care for the person with MND. Medications, appointments, dressings, special diets and feeds, toileting and hygiene needs are happening while the household cleaning, maintaining the environment, shopping and cooking still goes on. Then of course if there are children and pets, as well, there are added pressures on the time and energy available.

The person with MND will eventually need to give up work. The carer may have to reduce or stop work too. This affects the financial stability of the household. Those with MND over the age of 65 will be able to access Home Care packages to provide assistance with being cared for at home. Those under 65 will need

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to access the National Disability Insurance Scheme. It is important to include an expert in MND in the planning meetings to ensure that the NDIS funds are sufficient to cover future needs and that the plan is appropriate in its goals.

Transport, medication, equipment and treatments have significant costs and need to be considered. This is especially true for people who live in rural areas and who must travel to specialists and may need accommodation away from home on a regular basis. It is critically very important that people have conversations about the future impact of the disease as early as possible to enable wills, legal issues and insurances to be settled while communication is still possible. There is also the ever present time pressure of the possibility that cognitive capacity may be affected either mildly or by Frontotemporal dementia. Without steps to secure the financial future, such as ensuring the title to any owned home is in joint names, and that Enduring Financial Power of Attorney can be completed, there can be long term impact on the surviving partner. Superannuation can be used to provide funds due to the permanent disability created by MND. Some Gas or electricity providers will give one off reductions in bills and should be contacted to determine eligibility.

If a person who is not a permanent resident, is diagnosed with MND, they may not be eligible for Medicare. They may be required to pay for all the costs of medical treatment, however some public health services in Victoria will provide services without charge, if there is financial hardship. People who cannot speak English well, or have low health literacy may be less able to

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negotiate the health system. Working with professional interpreters is necessary to ensure clients receive and understand information and allows people to communicate their specific cultural needs.

Many carers are looking after children while dealing with a palliative care situation. Children's need for age appropriate information and support may be overlooked due to fatigue, exhaustion, lack of understanding or time. Parents may wait for children to raise issues, unaware that children are often acutely aware of the burdens that parents are carrying, and may not raise issues in order to be helpful, or not make further demands. Schools have access to their own social workers and psychologists. It is important to inform welfare staff in the school about the home situation to ensure optimal support of the child. This support is offered in school hours which reduces the need to travel to yet more appointments. Liaison with welfare staff in schools can reduce the workload for welfare staff in palliative care agencies. Some children may be carers and have reduced attendance at school, fatigue and isolation from friends. They may not be able to participate in activities due to changes in the financial situation of their parents or lack of transport or competing needs. Other community connections such as religious groups, clubs, schools and networks may be able to offer assistance with various needs. Social media applications (apps) and email can provide information for and connection to friends and family, minimizing intrusion through constant requests for updates. The carer may tell a small group of people about the daily status of the person

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who is ill and then those people can circulate the information ensuring it is accurate and up to date.

Given the long and difficult nature of caring, it is helpful to provide appropriate carer support. Much of the practical support can be provided by friends and family though the carer may be reluctant to take up offers of help. Due to the degree of disability and poor communication of the person with MND, carers may not want to take up respite or allow others to care for their loved one. It is important that Health professionals have knowledge and skills about the management of MND to give the caregiver and person with MND confidence in alternative care.

Carers are not able to freely discuss how they feel about being a carer in front of the person they care for, so it is important that the person has their own source of counselling and support. Given the rates of depression and anxiety, ongoing assessment and monitoring is very important to reduce the possibility of poor quality of life and negative health outcomes. The recommended tool is the CSNAT. '*Carer Support Needs Assessment Tool*' (CSNAT). It is an evidence-based tool, designed for carers supporting someone at home towards the end of life. The tool and more information can be located at <http://csnat.org>.

The positive impact of the clinical assessment tools is that the tool can open up conversations that otherwise would not have happened:

- it can be useful where a carer finds it difficult to talk about the impact of caring

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- it makes the carer's needs transparent and more legitimate
- it can cover the range of carer's issues quickly and thoroughly
- it may flag issues that reduce the need for crisis calls to the agency and reduce contact time overall

Because of the format, different health professionals may help the carer to fill it out so that it can be done at any contact time and the information used to refer to the appropriate person or agency.

Negative impact of the clinical assessment tool is that while some carers are gratified to see their issues raised, for others this can raise their awareness to issues they have not thought of. Health professionals may also rely only on this assessment tool rather than continuing to monitor the carer regularly.

Physical activity is important to maintain well-being. This may include a social game of sport, time at the gym or a walk around the neighbourhood. It can assist with the processing of emotions and provides a healthy outlet for frustration and sadness. Participating in hobbies and pastimes can be vital. Maintaining social connections with friends and family is also an important protective factor to help with grief after the death. When people keep up their interests and maintain a sense of self, they can cope better with the demands of caring. Many carers are reluctant to do something for themselves, however it is very important that the carer takes a break from caring and maintains social connectedness. It is important that they understand that accepting some form of respite can help them keep their ability to care for longer. Volunteers

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in palliative care agencies can be an invaluable source of support to enable carers to have a break or continue their desired activities. Respite provides a break from caring and is an important factor in making sure the carer role can be carried out for long periods of time.

Carers may have limited medical and nursing knowledge; therefore, it is important to discuss the tasks and issues of providing palliative care in the home. This is best discussed at the time of the referral. Carers may need education about nursing tasks, equipment, disease progression, medications, after hours care, the process of dying, emotional and psychological impacts on them and their loved ones, resources and services, financial and legal issues as well as funerals and care of the deceased. Best practice for caring for carers in palliative care currently includes a bereavement risk assessment. It is usually carried out and monitored by the palliative care team to ensure that the carer is provided with appropriate post-bereavement support.

The carer may also be of poor health, exhausted and overrun by the many demands before the bereavement occurs, reducing their ability to cope with grief. The financial state of the carer may mean a major change in lifestyle. They may need to enter or re-enter the workforce and need to acquire new skills and carry out tasks which they may never have attempted before. All of this takes place at a time of least clarity and confidence, as well as ongoing problems with concentration, sleep, social and family concerns. The period after bereavement may find the carer at a loss as they relinquish their caring

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role and readjust to once again having time on their hands. They may have become disconnected from their social groups or be significantly changed in terms of their lifestyle and needs. Carers may feel guilty about how they carried out their role, or about possible feelings of relief on the death of the loved one. They may be at a loss as to how to navigate as a single person after many years of being in a relationship.

The support of family and friends is important for carers to be able to cope with bereavement. MNDV has a number of support programs for people who are bereaved as a result of caring for someone with Motor Neurone Disease. Caring for the carers is a vital part of quality care and ensures that at the end of the caring role the impact of the tasks of caring can be reduced as much as possible.

Health professionals, who may have been part of the care team may also need to consider the impact of the death of the client and their relationships with their carers post-bereavement. They may need to take time to reflect or ritualise the end of these relationships in a way that optimises their well-being and reduces compassion fatigue.

I look forward to discussing more detail about various aspects of MND management in future sessions which will be available on the SMPPC website. 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

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received in my role as MND SCW in the Southern Region. 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

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