

# A PALLIATIVE APPROACH TO CARE HELP SHEET



This Help Sheet aims to present the principles of 'A Palliative Approach' to care workers supporting people with MJD in general care settings: in the community, in respite and in residential care. It may be helpful to care staff, community workers and families as they learn effective ways to support people with MJD as a degenerative and life-limiting disease.

**Palliative Care** is defined by The World Health Organisation (2002) as an approach that improves the quality of life of people and their families facing the problems associated with life-limiting illness. Key elements are early diagnosis and impeccable assessment to prevent and relieve suffering. Palliative care:

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten nor postpone death
- integrates the psychological and spiritual aspects of care
- offers a support system to help people live as actively as possible until death
- offers a support system to families, including bereavement counselling

## **A Palliative Approach to Care**

Palliative Care is often associated with the specialist care and interventions at the end stages of life, but *a palliative approach to care* is beneficial from initial diagnosis and throughout the course of the illness or disease. A Palliative Approach acknowledges that death is anticipated although this may be months or even years away, and the focus is on quality of life and comfort.

A Palliative Approach to care applies to general care settings in the community and in people's homes. Direct Care services and their staff, work in consultation with health teams and specialist palliative care services to promote quality of life for people who have a life-limiting illness or who are becoming progressively frailer due to disease or old age. A Palliative Approach is multi-disciplinary and holistic, recognising that a range of symptoms may need to be addressed to improve overall comfort during life and towards the time of death.

## **Advanced Care Planning (NT)**

Advanced Care Planning (ACP) provides a process for the person to state their wishes while they are still able to express

themselves clearly. People with MJD face the loss of speech and capacity to use communication aids, so ACP is a significant step to initiate in the early stages of the disease. Key aims are to:

- establish a communication process that incorporates the person's care wishes
- create contingency plans to achieve those care goals

It aims to be a continuous, collaborative process throughout the course of a life-limiting illness.

Legislation and documentation frameworks vary across Australia. NT requirements are:

- a Statement of Choices which enables people to outline their health issues and wishes
- a Medical Enduring Power of Attorney which enables people to appoint someone to make medical and health decisions on their behalf if they are unable to do so

## **Cultural Respect**

Like all health care and support services, palliative care requires an awareness of cultural issues which are important to Indigenous people. It is important to consider and respect:

- Indigenous Australians may have beliefs and explanations for illness and death that differ from Western beliefs.
- Kin relationships which govern who the right/appropriate people are to make decisions, and to accompany and care for the person at different stages of the disease, including giving medications at end of life (without incurring blame for the death).
- Cultural needs and connection to traditional country in relation to wishes about where the person should be cared for, where they should die and where they should be buried. In Aboriginal culture, the spiritual connection to the land and the wish to remain on country is vitally important.
- The MJD Foundation experience is that most Indigenous people with MJD want to finish up

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(die/pass away) in their country and this would take precedence over the standards of care they receive in residential care but away from home. Principles of rights, choice and dignity of risk are important considerations in the planning. Family meetings may provide a culturally appropriate forum for decision making and practical care planning.

- The MJD Foundation staff may be the key contact in this process and can help make sure the 'right' people are involved.

## **Role of the Careworker/Direct Care Team**

Direct care staff work within the boundaries of their qualifications, role and organisational policies. You may be asked to contribute to a planning meeting, or support someone with MJD to attend a planning meeting. You may be the person present when visiting clinicians visit. In knowing the person well in the care setting, you will:

- implement the care plan on a daily basis
- maintain communication and connection with the person with MJD
- notice changes (physical, emotional, social, MJD symptoms)
- report changes or concerns to your supervisor
- record your observations in the required care plan/service documentation
- work as a team to consistently apply a palliative approach to caring for the person as their disease progresses
- communicate with therapists, clinicians and MJDF staff as required and within your role
- maintain confidentiality
- be aware of your own and team responses and issues of self-care and team-care as you accompany the person on a palliative pathway.

## **Who is involved?**

In the NT, direct involvement is likely to include:

- The person, their carer and family members
- MJD Foundation staff
- The person's primary health care service
- Professional care provider/s (residential/respice)
- Territory Palliative Care (specialist nurses, therapists, doctors)
- Medical specialists

- NT Department of Health, Aged & Disability (case manager, allied health staff).
- The following people may also be indirectly involved:
- Rehabilitation services (Northern Rehabilitation Network,)
- Specialists for other health issues the person may have, eg. a renal or respiratory physician)
- Visiting mental health professionals.

## **Territory Palliative Care**

Understanding the role of the specialist Palliative Care service is important so that the service is accessed appropriately.

Palliative Care physicians, specialist nurses and Aboriginal Health Workers support the work of primary health providers to support people in their place of residence, including residential care facilities. They assess needs, provide skilled advice, assist in coordinating community resources and are able to request additional services as required.

***Territory Palliative Care Hospice*** is a specialised 12 bed short-stay facility based at Royal Darwin Hospital. The hospice accepts admissions for active symptom management, transition from hospital to home or for care in the final stage of illness. There is limited access for respite.

***For more information on specialist Palliative Care services in NT:***

[www.health.nt.gov.au/palliative\\_care](http://www.health.nt.gov.au/palliative_care)

[www.nt.palliativecare.org.au](http://www.nt.palliativecare.org.au)

[pcnt@palliativecare.org.au](mailto:pcnt@palliativecare.org.au)

**Who can I talk to if I have questions or concerns?**

**MJD Foundation staff**

Phone: 1300-584-122

Email: [libby.massey@mjd.org.au](mailto:libby.massey@mjd.org.au)

Your Health clinic doctors, nurses and health workers.