

Palliative Care

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Please provide any feedback on this Protocol to desiree.lagrappe@mjd.org.au



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1. Background - Palliative Care and MJD

Research and guidelines regarding palliative care for non-malignant diseases is sparse and despite indications of a recent increased focus on non-malignant diseases (and particularly neurodegenerative diseases) in the literature, as of mid 2015, no Machado Joseph Disease (MJD)/palliative care specific information was available.

Therefore, this Medical Protocol draws on research of palliative care for people with progressive long-term neurological conditions (PLTNCs) and palliative care more broadly.

There is a strong move towards palliative care services being incorporated much earlier in the disease stage for people with neurodegenerative diseases, as discussed in a study (Kaplan, 2015) with Motor Neuron Disease (or ALS) patients. In this study, a multidisciplinary team including palliative care services offered early in the disease helps guide terminally ill patients through their care options.

In Australia, Neurological Alliance Australia (NAA) which includes members such as the MJD Foundation, Huntingtons Australia, MND Australia, and MS Australia developed a "Palliative Care and Neurological Conditions" Position Statement in 2014 which basically states that palliative care services should be available to people with a neurodegenerative disease in a person centred way, and available when they want it, and that a multidisciplinary approach should be taken.

2. What is Palliative Care

Palliative care is providing quality of life for those whose illness is progressive, and terminal. Palliative care places emphasis on valuing autonomy and dignity for patients, and it addresses the individual physical, psychological, social and spiritual needs of the patient. In Australia, the national *[Standards for providing quality palliative care for all Australians](#)*¹ (2005) guide support and enhanced quality of care for patients who are at the end of their life, as well as that of their families and carers. Services and providers adopt the national standards on a voluntary basis (see Appendix A for more information).

¹ <http://www.palliativecare.org.au/Portals/46/Standards for providing quality palliative care for all Australians.pdf>

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. 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 patient care
- offers a support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patient's illness and in their own bereavement
- uses a team approach to address the needs of patients and their families, including bereavement counseling if indicated
- will enhance quality of life, and may also positively influence the course of the illness
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

World Health Organisation (2002)

Palliative care was traditionally considered as being required at the very end stages of life; however, planning palliative care is important from initial diagnosis of a terminal illness (Bede et al., 2011; Brown and Sutton, 2009; Bunting-Perry, 2006).

MJD generally shortens life expectancy, particularly for those who develop the disease early in life (mean life expectancy after the first symptoms are noticed is 21.18 years) (Kieling, 2007). Incorporating palliative care principles and documenting directives and wishes throughout the progression of the stages of MJD, can enable the patient and his/her family to maintain autonomy and dignity.

A systematic review of care options in 1998 (Hearn and Higginson, 1998), found that when compared to conventional care, the provision of specialist palliative care 'improves satisfaction of both patients and their carers, identifies and deals with more patient and family needs, and provides better pain control and symptom management. Furthermore, it reduces the overall cost of care by reducing the amount of time patients spend in acute hospital settings' (Hearn and Higginson, 1998).

MJD presents as a combination of the four most common PLTNCs – Motor Neuron Disease (MND), Huntington's Disease (HD), Parkinson's Disease (PD) and Multiple Sclerosis (MS). One of the features that practitioners who are unfamiliar with MJD patients have anecdotally commented on, is that end-stage MJD does not have the fast trajectory to death that other PLTNCs have (for example, MND). In addition, MJD does not substantially impair cognition and therefore, patients are able to actively make decisions regarding their care and the management of symptoms -

until they are physically unable to communicate their desires (i.e. unable to physically use augmentative and alternative communication techniques or aids).

Palliative care planning usually requires substantially known trajectories of disease progression to enable timed pathways into the different palliative care services/stages; however, there is no standard MJD trajectory. Despite having general degeneration in common, each person with MJD experiences different symptoms and severity of symptoms at differing times (which can partly be explained by the CAG repeat length²) (Saute, Jardim, 2015).

In addition, it is incredibly difficult for practitioners to predict trajectories because people can live with severe MJD for several years (Kieling, 2007) (unlike MND)³, and many of the signs and symptoms of severe MJD are consistent with the signs and symptoms that may occur in the very final stages of life for other conditions.

Evidence shows that across the spectrum of terminally ill patients, health professionals are generally poor at recognising dying and at predicting survival times (Murtagh, Preston and Higginson, 2004). To improve prognostic accuracy, an approach, which is patient-centred focused rather than disease-centred focus is recommended. (Murtagh, Preston and Higginson, 2004).

Anecdotally the MJD Foundation notes that many MJD patients appear to degenerate quickly during stressful or traumatic life events (particularly the death of a loved one) or while experiencing secondary illnesses such as a cold, flu or infection. Then they will then appear to remit, but not to the same level they were previously (a stepped pattern). Over time this pattern appears to change to a progressive decrease in function, but continues to be accelerated during times of adverse events or secondary infections. Aspiration pneumonia is the most common cause of death across all Spinocerebellar Ataxias (SCAs) (Rub, 2013).

As noted by McClinton (2010), 'progressive long-term neurological conditions may make care in the last stages of life ethically, practically and clinically challenging' due to the communication difficulties experienced. In the case of MJD, dystharia/anarthria has usually been present for a number of years (Saute, Jardim, 2015). Therefore, early discussion and planning for palliative care which appropriately engages the patient (and appropriate extended family members), including Advance Personal Plan (APP), is a vital part of the care continuum for a person with MJD.

It is important to recognise that people's circumstances are likely to change over the course of their life and as the disease progresses, and therefore their decisions about where they want to be cared for and where they die may also change overtime (McClinton, 2010). The MJD Foundation anecdotally notes that changes in preferences are most evident in the final stages of life, where carers are under significant stress and unable to provide continued care, and the person with MJD, together with their family and/or carers, chooses alternative care arrangements (such as relocation to a residential disability or nursing home facility or a hospice).

³ A person with MJD can be fully wheelchair bound and dependent for daily activities for 10 years prior to death (xx) whereas a person with MND has a life expectancy of 4-5 years from onset (xxx)

2.1. Settings of Palliative Care

Palliative care can be provided in:

- The home / community
- A Hospital
- An aged care facility
- A supported accommodation facility
- A hospice

Where palliative care occurs depends on a number of factors, including:

- The nature of the illness or disease
- How much support is available from the persons family and community
- Whether the person has someone who can care for them
- What the person and their family want
- Ceiling of Care – feeding, comfort
- Resuscitation status
- Symptoms
- Site of Care

2.2. Who is involved in Palliative Care

The patient, their carer and family are first and foremost at the centre of palliative care. Palliative care is about ensuring quality care and support that recognises the unique needs of the person and family is provided at the end of life. Research shows that palliative care for people with PLTNC requires input from a range of disciplines and the multi-disciplinary team (MDT) needs to have a strong commitment to teamwork and efficient and effective channels of communication which must be maintained throughout the progression of the disease (with each other and the patient and their family) (O'Brien, Welsh and Dunn, 1998; Bede et al., 2011).

Speck (2006) discusses the importance of all team members respecting and valuing the roles of other colleagues within the team; the importance of leadership coming from a variety of team members, not just one profession; that decision making is openly shared and that each person accepts their professional accountability for their role within that team. Byrne et al., (2009) further suggest that asking questions such as 'why are we doing this?' or 'what do we hope to achieve from this particular path or therapy?' may enable the MDT to act in a manner which is more closely aligned to the person's best interests and less dictated by the biomechanical imperative or habits of clinical routine.

A study in 2014 (Hussain, 2014) involving 62 patients with a neurodegenerative disease, showed that those patients referred to a specialist neurology palliative care service reduced hospital admissions, and increased the number of patients that died at home by 31%. The conclusion was that this model of service provision investing in specialist palliative neurology nurses is an effective model in delivering palliative care services to this group.

Research shows that services and staff need to create formalised links, agree on care pathways/ triggers for referral, agree on communication channels and establish ways of sharing skills and education (Sutton, 2008).

Palliative Care teams may include:

- Specialist palliative care doctors and nurses

- Local General Practitioners and nurses (pivotal to the palliative care experience for the patient)
- Specialist doctors
- Allied health professionals (social workers, counsellors, psychologists, physiotherapists, occupational therapists, speech pathologists, dieticians, hospital pharmacists)
- Pastoral care workers
- Grief and bereavement counsellors
- Volunteers.

2.3. Imminent death

Dying patients go through a stereotypical pattern of symptoms and signs in the days prior to death, often referred to as 'actively dying' or 'imminent death'.

Stages

Early

- Bed bound.
- Loss of interest and/or ability to drink/eat.
- Cognitive changes: increasing time spend sleeping and/or delirium.

Middle

- Further decline in mental status to obtundation (slow to arouse with stimulation; only brief periods of wakefulness)
- Death rattle – pooled oral secretions that are not cleared due to loss of swallowing reflex

Late

- Coma
- Fever – usually from aspiration pneumonia
- Altered respiratory pattern – periods of apnea, hyperpnea, or irregular breathing
- Mottled extremities

Time course

The time to traverse the various stages can be less than 24 hours or as long as ~14 days. Patients who enter the trajectory who are nutritionally intact, with no infection (e.g. acute stroke), are apt to live longer than cachectic cancer patients.

"The following signs of impending death may or may not occur, but if present, are indications that the patient will probably pass away within a day or two or even within hours:

- Breathing may slow. Periods of apnoea may be noticed.
- The lungs may fill with fluid, making breath sounds moist and rattly. This is often referred to as the "death rattle."
- Cheyne-Stokes respiration pattern may appear. This is a chaotic pattern of breathing with periods of apnoea followed by periods of deep and rapid respirations.
- Skin may feel cooler to the touch, and may appear bluish in the hands and feet.
- Mottling may increase especially in the knees, ankles, or elbows.

- Discoloration may travel down the legs, or other part of the body as circulation slows.
- The eyes may remain partially open and have a fixed stare without blink reflex.
- Pulses will become weaker and more difficult to locate.
- Body temperature can fluctuate between abnormally high or low.

Even when in this "actively dying" stage, some may linger for days and others for only hours. Continue to give physical and spiritual comfort to your patient at this time."

3. Palliative care for Indigenous Australians with MJD

Palliative care, like health care, requires an awareness of the cross-cultural issues which impact the patient. For Indigenous Australians, particularly those who practice their Aboriginal culture and religion (including ceremonies), decisions about palliative care will be influenced by:

- Different explanations for an illness or death from those offered by Western Doctors.
- Kin relationships which govern who the right (appropriate/correct) people are to help make treatment decisions, and to accompany and care for the patient at different stages of their illness, including giving medications at the end of life (without incurring blame for the death).
- Family considerations which will often determine where the patient will be best cared for and managed.
- Linkage to traditional country and patient and family wishes regarding where they should be cared for, where they should die, and where their body should be interred should be respected and facilitated, where possible.

Guidelines developed by the Queensland Government refer to the importance of family meetings to provide a forum for ‘...adequate information transfer, culturally appropriate decision-making and practical care planning’.

The importance of getting the ‘right’ family members involved in ACP is important for Indigenous Australian patients. This can be a difficult task compounded by the very limited physical and social resources available to remote Indigenous families with MJD. In Indigenous Australian cultures, the concept of ‘collective decision making’ means sensitive discussions must involve the ‘right’ people to make decisions for the person with MJD, and this will be different in different situations and for different families. These discussions need to take place over weeks and months in order to provide informed consent and content for the ACP.

The Queensland Health publication [*Sad News, Sorry Business - Guidelines for caring for Aboriginal and Torres Strait Islander people through death and dying*](#)⁴ highlights that when working in a cross-cultural setting, it is important to remember that every community and family will be different and an Aboriginal Health Worker or appropriate Elder for the family you are working with should always guide conduct.

3.1. Place of Care

In Aboriginal culture, the spiritual connection to the land and the wish to remain on country is vitally important. It has also been well documented for well, sick and elderly people. Anecdotal MJD Foundation experience is that most Aboriginal people with MJD want to remain in their country and be cared for by family. They also want to ‘finish up’ (die/ pass away) in their country and it is for this reason people are often willing to endure sub-standard care (when compared to the care they could

⁴ http://www.health.qld.gov.au/cpre/indig_pc.asp

receive in supported accommodation or a nursing home in city) and the concepts of respecting patient choices and dignity of risk come to the fore.

As noted in the Central Australian Rural Practitioners Association (CARPA) Reference Manual regarding palliative care in the community:

...raises very practical issues for care including the training and support of community care workers, and availability of medications, care equipment, suitable accommodation and transportation. With appropriate resources and adequate support of both lay carers and primary health care providers, most people should be able to be cared for in the manner they wish, in accordance with contemporary standards of palliative practice. (Fried cited in CARPA,2009).

3.2. End of life

A key element in palliative care is addressing the spiritual needs of the patient, therefore 'cultural and religious beliefs about death and dying (including family participation, gender roles, communication rules guiding decision making and the breaking of bad news, and rituals) should be respected'.

There will be many and varied cultural differences between Indigenous and non-Indigenous Australian beliefs within the context of death and dying (DoHA, 2004).

For example,

- Traditional beliefs surrounding the sacredness of the land and the Indigenous person's relationship to it through the Dreamtime, totems and songlines are central to end of life needs and practices for many Indigenous people.
- The importance of being in country at the time of death is therefore a common theme and of paramount importance to traditional Indigenous people. Providing culturally appropriate responses to meet the needs of Indigenous people is, therefore, extremely complex.

Financial resources and the remoteness of some locations are barriers to some Indigenous Australians wishing to return to country but as noted in CARPA 'while logistically it may be enormously challenging for the patient, family and community to achieve, it has the potential to realise the greatest gain for patients, their families and communities at the end of life'.

3.3. Palliative care in the Northern Territory

Although it is widely accepted that adopting a palliative care model early in the course of a serious illness is preferred, referral to Territory Palliative Care in the Northern Territory must be carefully considered because of the complex practical and financial implications for the client. For example, clients previously catered for under the general NT Office of Disability when transferring into the care of Territory Palliative Care (TPC) are unable to access funding through the Northern Territory Government's Disability Equipment Program (DEP) and consequently are extremely restricted in the assistive technology options they can access. This is a significant concern because specialised postural support systems and customised equipment is often required for the optimised care of people with MJD as a result of their trunk

ataxia and low body weights (most people in the severe stages of MJD live with body weights between approximately 23-30kgs for many years) Similarly, TPC are limited in the number and length of remote community visits they are able to conduct, whereas the NTG Office of Disability has designated community allied health professionals who are funded to spend 1-3 days in every community every 4-6 weeks pending need.

A list of Australian and Northern Territory specific services and support agencies can be found in Appendix A.

3.4. Who is involved in Palliative Care for people with MJD in the Northern Territory

In the Northern Territory context, the following people are likely to be directly involved:

- The patient, their carer and family
- The patient's local health centre (nurses, doctors and Aboriginal Health Workers are pivotal to the palliative care experience for the patient)
- The residential care provider in their place of residence
- The MJD Foundation
- Territory Palliative Care (specialist nurses and doctors)
- The Northern Territory Department of Health Office of Disability 'Key Contact'
- Neurologist
- Aboriginal Liaison Officer or interpreter (preferably with palliative care / Advanced Care Planning experience / familiarity).

The following people may be indirectly involved:

- Rehabilitation Specialists, Northern Rehabilitation Network (Royal Darwin Hospital and Alice Springs Hospital)
- Specialists for any co-morbidities the person may have (for example a renal or respiratory physician)
- Visiting mental health support teams.

3.5. Transitioning from Community to Supported Accommodation

The decision by a person and family with MJD to move away from their community and into supported accommodation is not made lightly. It is likely to leave one or both parties with feelings of guilt and/or abandonment. It is generally preceded by cycles of carer burnout, recurrent secondary infections and/or substantial functional deterioration in the person with MJD. All usually countered by attempts to increase informal and formal community supports, until care needs surpass what can currently (and realistically) be provided in community.

The MJD Foundation provides, where possible, Kin Connect trips back to country for clients who have relocated to urban centres for care.

4. Advanced Personal Planning

Advance personal planning (APP) is considered the corner stone of palliative care as it provides the patient the ability to achieve autonomy. APP is a continuous collaborative process that starts at the time of diagnosis (Bunting-Perry, 2006). Teno (2003) outlines the two overarching goals of APP:

1. Establishing a communication process that incorporates the patient's care desires
2. Creating contingency plans to achieve those care goals (cited in Bunting-Perry, 2006).

For people with MJD, early and sensitive advanced personal planning is paramount because of the ultimate loss of speech that people will experience. APP allows the patient to express their wishes for their future care while they are still able to express them clearly. It is important to note, that unlike other common neurological diseases such as Huntington's Disease and Parkinson's Disease, MJD patients do not experience intellectual loss. Their intellectual capacity remains intact throughout the progression of the disease and therefore, the patient in the later stage of life are still able to make an autonomous decision. However, the ability to communicate that decision, particularly during the final weeks may be limited as physical strength to using an AAC device (iPad or alphabet board) may be not be present.

APP is a process that enables the patient to discuss and decide what treatments they may or may not want carried out in the event that they become unable to make decisions or unable to communicate their wishes. In addition, it enables discussion on withholding or withdrawing treatment at the end of life.

This process requires continual/regular, sensitive updating and rechecking, amending as necessary as the directions may change as the circumstances of the person change.

4.1. Advanced Personal Planning in the Northern Territory

In Australia, State and Territory legislation and delegated/secondary/associated documentation oversees advanced personal planning.

The Advanced Personal Plan document is available on line:

www.advancepersonalplanning.nt.gov.au

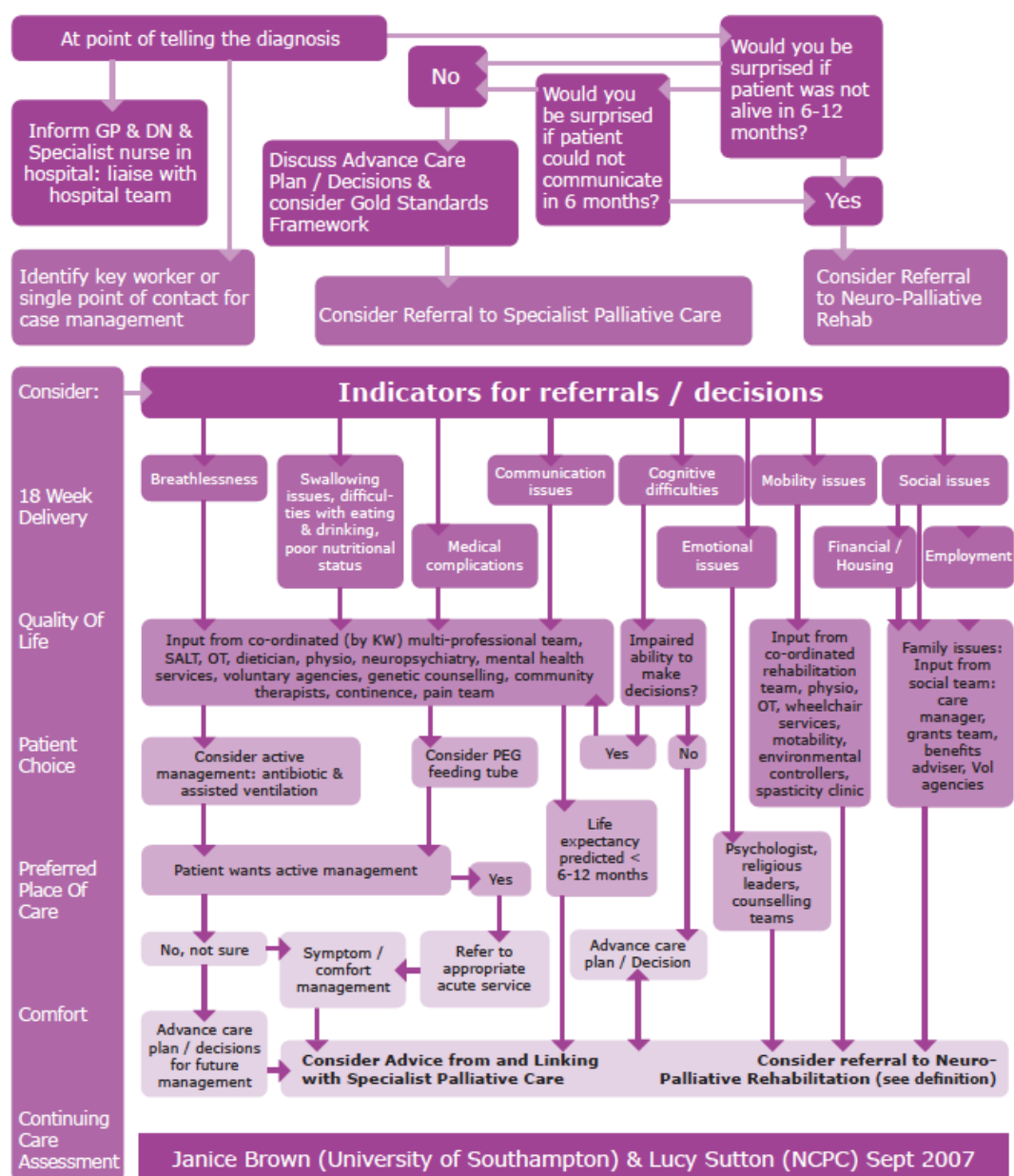
The APP enables the person to have some control over their :

- Consent decisions about future health care
- Advance care statements about how they want to be treated in relation to any future health, financial or lifestyle matter
- Appointment of substitute decision maker

Once documentation is completed, copies should be given to relevant people, including the patient's carers, family, local GP and hospitals. The patient should endeavour to keep a copy with them in the event that they are admitted to hospital.

5. Recommended Guidelines for addressing Palliative Care for people with MJD

Pathways from diagnosis to palliative care – indicators for referral and attention to policy (adapt NCPC diagram – Brown and Sutton 2009 paper)



From diagnosis, the following guidelines are recommended:

1. Coordinated and explicit method of communication between the MDT and the patient and their family or other care provider.
2. A designated point of contact for each stage of the 'pathway' (such as a case manager or General Practitioner)
3. A needs assessment identifying the individual patient's symptoms (which

needs to be constantly revised as disease progresses) and referral to appropriate specialist and service. Specialists include:

- a. Geneticist
 - b. Genetic counsellor
 - c. Neurologist
 - d. Psychologist
 - e. Speech Pathologist
 - f. Physiotherapist/ Occupational Therapist
 - g. Dietician
 - h. Gastrologist
 - i. Optometrist/ Ophthalmologist
 - j. Social Worker
 - k. Sleep Technician
 - l. Palliative care physician
4. An assessment of the care needs and the availability of support services, if the majority of care is provided within the home:
 - a. Home and Community Care (HACC)
 - b. Respite services
 - c. Day programs
 - d. Assisted transport
 5. Discussion of and the establishment of an Advance Care Plan including, an Advance Care Directive and a Enduring Power of Attorney (which needs to be revisited as a patient's circumstance change or their preferences change)
 6. Referral to specialist palliative care services if the patient is expected to die within 6-12 months or distressing symptoms such as pain, vomiting and breathlessness which fall within the remit of the palliative physician or the patient expresses the desire for end of life planning.
 7. Referral to or increased access to religious and/or spiritual support services
 8. Bereavement planning and counselling.

6. Caring for Carers

Caring for people with severe MJD is a full-time, highly demanding job (physically, mentally and emotionally). Because MJD is an autosomal dominant genetic disease, and also has an 'anticipation effect', the informal care network so heavily relied upon, particularly in Indigenous Australian and remote communities is frequently also impacted by the disease and effectively decimated (Massey et al., 2013).

An Australian study into the care needs of people with PLTNCs (503 people with Huntington's Disease (HD), Motor Neuron Disease (MND), Multiple Sclerosis or Parkinson's Disease and 373 carers) found extensive unmet needs for support, particularly for patients and carers with HD and MND (which are the two most similar to MJD) (Kristjanson et al., 2005). MND carers reported the lowest quality of life across all four groups, largely because of fatigue and tiredness.

Palliative Care Australia's *What can I say – What can I do? When someone I know is living with a terminal illness* outlines strategies to prepare family, friends and carers to help someone who is living with a terminal illness.

The Carers Association of Australia found that up to three quarters of primary carers for terminally ill patients have a chronic health problem (cited in PCA, 2005).

6.1. Respite for Carers

In Australia, the federally funded, program *National Carers Respite Program* (NCRP) can provide support and respite for carers. NCRP funds community-based respite service that are delivered to carers and the people they care for in a variety of settings, including homes, day centres, host families and residential overnight cottages. Information about respite services in your local area can be obtained by phoning Commonwealth Respite and Carelink Centre on free call 1800 200 422 during business hours or, for emergency respite support outside standard business hours, free call 1800 200 422. A list of funded NRCP projects can be found on the [Aged and Aged Care Statistics](#)⁵ page.

⁵ <http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-rescare-aac-stats.htm>

APPENDIX A – National Standards for the Provision of Quality Palliative Care

The national *[Standards for providing quality palliative care for all Australians](http://www.palliativecare.org.au/Portals/46/Standards%20for%20providing%20quality%20palliative%20care%20for%20all%20Australians.pdf)*⁶ (2005) are:

1. Care, decision making and care planning are each based on a respect for the uniqueness of the patient, their caregiver/s and family. The patients, their caregiver/s and families' needs and wishes are acknowledged and guide decision making and care planning.
2. The holistic needs of the patient, their caregiver/s and family are acknowledged in the assessment and care planning processes, and strategies are developed to address those needs, in line with their wishes.
3. Ongoing and comprehensive assessment and care planning are undertaken to meet the needs and wishes of the patient, their caregiver/s and family.
4. Care is coordinated to minimise the burden on the patient, their caregiver/s and family.
5. The primary caregiver/s is provided with information, support and guidance about their role according to their needs and wishes.
6. The unique needs of dying patients are considered, their comfort maximised and their dignity preserved.
7. The service has an appropriate philosophy, values, culture, structure and environment for the provision of competent and compassionate palliative care.
8. Formal mechanisms are in place to ensure that the patient, their caregiver/s and family have access to bereavement care, information and support services.
9. Community capacity to respond to the needs of people who have a life limiting illness, their caregiver/s and family is built through effective collaboration and partnerships.
10. Access to palliative care is available for all people based on clinical need and is independent of diagnosis, age, cultural background or geography.
11. The service is committed to quality improvement and research in clinical and management practices.
12. Staff and volunteers are appropriately qualified for the level of service offered and demonstrate ongoing participation in continuing professional development.
13. Staff and volunteers reflect on practice and initiate and maintain effective self-care strategies.

⁶ [http://www.palliativecare.org.au/Portals/46/Standards for providing quality palliative care for all Australians.pdf](http://www.palliativecare.org.au/Portals/46/Standards%20for%20providing%20quality%20palliative%20care%20for%20all%20Australians.pdf)

APPENDIX B – Palliative care services and support

MJD Foundation

The MJD Foundation's *A Guide to Living with MJD for all Australians*⁷ provides comprehensive information on relevant Australian state and territory services, including palliative care support agencies.

Territory Palliative Care

www.nt.palliativecare.org.au

pcnt@palliativecare.org.au

Darwin- PO Box 41326 Casuarina NT 0811

Ph: 08 8922 6761

Fax: 08 8922 6775

Alice Springs- Community Care Centre, Alice Springs 0870

Ph: 08 8951 6762

Fax: 08 8951 67774

Have a series of brochures including

- Bereavement support
- Pastoral care
- Understanding grief
- Practical matters
- Grieving children

Centrelink

The Carer Payment is available to full-time carers providing support to someone who would otherwise require full-time professional care. This payment is subject to an income and asset test.

Carer Allowance is available for all carers in the home setting and may be paid in addition to the Carer Payment. This is not means tested, and recognises the additional costs of home carer.

If the deceased person was partnered and in receipt of the partnered rate of a Centrelink pension/payment, the deceased persons partner may qualify for a Bereavement Payment (equivalent to six pay periods for the deceased) to assist in funeral costs. Or, if a partner was receiving a Carer's Payment, the carer is entitled to a Bereavement payment.

Central Australian Aboriginal Congress

25 Gap Road Alice Springs 0870

Ph: 08 8951 4457

Fax: 08 8953 4515

⁷ <http://www.mjd.org.au/> resource tab

Booklet: "Loss and Grief for Aboriginal People"

www.caac.org.au

Other Key Organisations

Australian Centre for Grief and Bereavement: 1800 642 066 www.grief.org.au

Lifeline: 13 11 14

Crisis Line: 08 8981 9227

Kids Helpline: 1800 55 1800

Mensline: 1300 78 99 78

Beyond Blue: 1300 22 4636

Respecting Patient Choices: www.respectingpatientchoices.org.au

Palliative Care Australia: www.pallcare.org.au

Appendix D – Contributors and Reviewers

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Appendix E – Definitions

Advance Care Plan (ACP)

Specialist Palliative Care Provider is a medical, nursing or allied health professional, recognised as a specialist by an accrediting body (or who primarily works in palliative care if an accrediting body is not available), who provides primary or consultative care to patients with a life-limiting illness.

Specialist Palliative Care Service is a service provided by a cohesive interdisciplinary network of specialist palliative care providers.

Multi-Disciplinary Team (MDT)

Neuropalliative rehabilitation is a relatively new concept which focuses on a 'holistic approach to the care of neurological patients with significant disability, complex needs and a potentially shortened life span. It is patient-centred and involves diagnosis of clinical problems at all stages; rehabilitation to maintain function, care coordination and appropriate palliation to relieve symptoms' (NCPC cited in Brown and Sutton, 2009).

Appendix F – References

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ⁱ 'Nothing contained in this protocol constitutes medical or other advice and is only intended for use by qualified healthcare providers. Healthcare providers considering this protocol must use their own clinical judgment, knowledge and expertise when deciding whether it is appropriate to apply this protocol or other guidelines to any particular patient or treatment scenario.

The recommendations set out in this protocol are a guide only and may not be appropriate for use in all situations or with all patients. The decision whether to adopt or not adopt any of the recommendations set out in this protocol must be made by each healthcare provider on a case-by-case basis.

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