MJD FOUNDATION

MEDICAL PROTOCOLS

Social and Emotional Wellbeing / Mental Health

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Background — Social and Emotional Wellbeing / Mental Health and MJD

Mental or emotional health refers to overall psychological wellbeing. It includes perceptions of self, the quality of relationships, and the ability to manage feelings and deal with difficulties (Smith et al., 2010).

The gradual deterioration of the nervous and musculoskeletal systems affected by Machado Joseph Disease (MJD) and, therefore, the capacity of the person with the disease to engage in all aspects of their life – self care, relationships and community, the need to progressively depend on others for all aspects of their care – all inevitably impact on the social and emotional health of those with the disease. Evidence shows that MJD patients have higher rates of depression, anxiety and apathy.

Studies have found that MJD patients have higher rates of depression (33.5–63.1%) and one study found that 34.6% had moderate to severe depression (Kawai et al., 2004; McMurtray et al., 2006; Saute et al., 2010; Zawacki et al., 2002). The majority of studies propose that depression in MJD patients is reactive to physical incapacities rather than neurological damage / or the disease itself. Several studies have found a positive correlation between Beck Depression Inventory (BDI) scores and motor incapacitation in MJD patients (Cecchinet al., 2007; Klinkeet al., 2010; Sauteet al., 2010). Klinkeet al. (2010), found that motor hand functioning is the greatest predictor for mood ($p<0.005–0.0001$), particularly in the dominant hand. Other authors suggest that depressive complaints and other neurological disorders 'may result from disruption of reciprocal connections between the frontal lobes and the striatum within the basal ganglia' (McMurtrayet al., 2006).

Other features of MJD reportedly exacerbate the patient's social and emotional wellbeing and/or their social and emotional wellbeing exacerbates other symptoms. Anxiety and depression in MJD patients reportedly aggravates executive dysfunction (Zawackiet al., 2002), excessive daytime sleepiness (EDS) (Chellappa, Schoder and Cajochen, 2009), REM behaviour disorder (Pedrosoet al., 2011) and weight loss (Saute et al., 2011). In addition, it is widely recognised that chronic pain, which 47% of MJD patients experience (Marcondes et al., 2007), is a common comorbidity with depression (Leo, 2005).

A survey of 360 non-MJD dysphagic patients found that 41% reported experiencing anxiety and panic during meals, 36% said they avoided having meals with others, 50% eat less and 33% stop eating even though they are still hungry (Ekberg et al. cited in Garcia and Chambers, 2010). The anxiety and panic experienced during meal times can reduce oral intake and consequently contributes substantially to nutritional deficiencies and weight loss.

> *For more information on dysphagia, refer to the Difficulty Swallowing Medical Protocol. For further information on nutrition and weight loss, refer to the Nutrition Medical Protocol.*

The association between depression and pain is well established. Pain predisposes patients to the emergence of depression (Langdon, 2004; Leo, 2005). Pain can be a

physical symptom of depression and the experience of pain can be intensified by depression (reduced pain thresholds and tolerance) (Williams et al., 2006). It can therefore be a perpetuating cycle. Pain can also exacerbate other symptoms of MJD such as sleep disturbance, loss of appetite and fatigue.

Chronic pain, which many MJD patients experience, increases the rate of depression among patients. The prevalence of depression among those with chronic pain is up to 55% (Koenig cited in Leo, 2005). One study of over 18,000 participants from the general population, found that 43% of those with a Major Depressive Disorder (4%) also had a chronic painful condition (Ohayon and Schatzberg cited in Williams et al., 2006). Using the same sample population, another study by Ohayon (2004) found that chronic painful conditions increased the duration of the depressive episode and its reoccurrence (cited in Williams et al., 2006).

> *For more information on pain and MJD, refer to Sections 3.2 and 4.2.1; and the Muscle Cramping and Pain Medical Protocol.*

Current practices to improve mental health, without or without a physical illness, include encouraging healthy living options – ensuring adequate diet, rest and exercise, relationship and community engagement opportunities, and building 'resilience'. Resilience involves maintaining flexibility and balance in dealing with stressful circumstances and traumatic events and is assisted by the maintenance of strong family and community bonds (Bernhardt et al., 2007).

1.1. Pharmaceutical treatments

Antidepressant and anti-anxiety medications are also widely used for moderate to severe symptoms, usually accompanied by psychological or psychiatric treatment. There are seven different classes of antidepressants (extracted from BeyondBlue Fact Sheet 11):

1. Selective Serotonin Reuptake Inhibitors (SSRIs) are the most commonly prescribed antidepressants in Australia. They are generally well-tolerated by most people and generally non-sedating.
2. Serotonin and Noradrenaline Reuptake Inhibitors (SNRIs) are often prescribed for severe depression and have fewer side effects compared to older antidepressants (i.e. TriCyclic Antidepressants).
3. Reversible Inhibitors of Monoamine Oxidase – A (RIMAs) have few side effects and are non-sedating. They may be less effective for more severe forms of depression; however, are helpful for people who are experiencing anxiety or difficulty sleeping.
4. Monoamine Oxidase Inhibitors (MAO-Is) are seldom prescribed as people are required to keep a strict special diet to reduce serious side effects.
5. TriCyclic Antidepressants (TCAs) are effective but have more harmful side effects (i.e. low blood pressure) than the newer drugs such as SSRIs.
6. Nonadrenaline-Serotonin Specific Antidepressants (NaSSAs) may be helpful when there is difficulty sleeping and poor appetite.
7. Noradrenaline Reuptake Inhibitors (NARIs) are designed to act selectively on the noradrenline neurotransmitter. Side effects include difficulty sleeping.

If a patient's social and emotional wellbeing is strongly linked to a symptom of MJD, such as poor sleep, medications to alleviate those symptoms can be beneficial.

1.2. Pre-symptomatic testing and family planning

Due to the lack of effective therapeutic treatments for MJD, it is important that people receiving any form of genetic counselling (pre-symptomatic testing, prenatal diagnosis or preimplementation genetic diagnosis) are made aware of the symptoms, the limited number of effective treatments for those symptoms, how MJD is transmitted and how unstable the gene mutation can be. In 2012, it was confirmed that the MJD found in East Arnhem Land families is the Joseph strain of MJD which is associated with higher instability and more likely to result in expanded repeat lengths with each new generation (Martins et al., 2012).

International evidence shows that pre-symptomatic genetic testing can alleviate anxiety and the social and emotional burden for at-risk individuals regardless of the test result (Rolim et al., 2006). Reasons for this include: reducing the uncertainty and providing patients greater control to plan their future. However, it is important to note that in one study of Huntington's Disease (HD), 2–6% of at-risk individuals may have a severe psychiatric or suicidal response to a carrier result (Kessler et al. cited in Rolim et al., 2006).

A study of Azorean MJD families found that 'a large percentage of individuals were unable to comprehend the notion of "pre-symptomatic carrier" and, therefore, could not quantify the objective risk of inheriting/transmitting the disease' (Lima, 2001). In addition, similar to East Arnhem Land, some of the Azorean MJD families live in small isolated communities which can raise issues of stigmatisation (Bettencourt and Lima, 2011).

International evidence supports a three stage pre-symptomatic genetic counselling program provided by a multidisciplinary team (Rolim et al., 2006). Teams should comprise of a clinical geneticist, psychologist, neurologist and a social worker. Three stage genetic counselling for at-risk of MJD individuals would entail:

1) Engagement prior to genetic testing to support the individual and their family in the decision-making process
2) Support while the individual is awaiting their test result
3) Review after the disclosure of their genetic status, regardless of the result.

The delivery of clinical genetic services within the Northern Territory and particularly to the MJD population of East Arnhem is an ongoing problem requiring attention. The provision of pre-symptomatic testing for individuals at risk of MJD needs to be considered in the context of this lack of clinical geneticist oversight. The potential for adverse outcomes in such circumstances is higher than published data would suggest (see HD example above).

Recently in Australia, additional family planning options have been made available to people with inherited disorders whom would like to have children. Both options have

psychological and ethical issues which must be considered by the patient and their partner. Prenatal Diagnosis (PND) is able to analyse the mutation of *ATXN3* in the fetus and therefore enable parents to make an informed decision on whether they want to proceed with the pregnancy.

An alternative option is Preimplantation Genetic Diagnosis (PGD) which involves producing fertilized oocytes in vitro, which are then cultured. A single cell is removed from the embryo and tested. The embryos that have negative result for the disease are transferred to the woman's uterus. Patients should be made aware that multiple cycles may be required which may incur a significant cost.

1.3. East Arnhem Land

In Australia, Aboriginal and Torres Strait Islander peoples have twice the rate of hospital separations due to intentional self-harm and the mortality rates for mental and behavioural disorders for Indigenous males and females were 5.5 and 2.2 times the rates of non-Indigenous counterparts, respectively. From 1999-2003, Aboriginal and Torres Strait Islander peoples suicide rate was twice that of the non-Indigenous population. A particular concern is young Aboriginal and Torres Strait Islander peoples (0–24 years) whose rates were 3 times the rate for males and 5 times the rate for females (AIHW, 2011).

There are local anecdotal reports of depression and 'challenging behaviours' among young people with MJD. Family carers and local medical professionals report some MJD patients self medicating with illegal drugs (e.g. marijuana) to alleviate the pain associated with muscle cramping.

Community discussions have indicated that 'role' ascertainment and maintenance within family and community is very important for those with, and those who care for, people with MJD. A report by a clinical psychologist working with East Arnhem Land MJD patients, has found, particularly in the young men, that empowerment, validation and strength are key issues. It is hypothesised that introducing projects or programs which increase the patient's sense of empowerment and strength, and validates their Kinship role within their community will improve social and emotional wellbeing (unpublished, MJD Foundation, 2010).

It is imperative that a Mental Health Plan is developed in conjunction with the patient, carer/s, and local Health Centre. It can be difficult to access specialist mental health services in remote locations, and fly-in fly-out (or drive-in, drive-out) practitioners have a limited capacity to develop a rapport and therapeutic relationship with the patient, thus emphasizing the importance of the local Health Centre.

Prescribing antidepressants requires considerable support from the medical practitioner and family/carers to ensure compliance with consistency of administration and dosages. Consideration must also be given to the patient's ability to swallow tablets, or determining if the prescribed medication is available in a liquid form compatible with a thickening agent. The sudden cessation of antidepressants can produce undesired side effects including: affective symptoms (low mood, suicide, anxiety, agitation, etc), sleep disturbance (insomnia and nightmares), somatic distress (flu-like symptoms, fatigue and headaches), gastrointestinal (nausea,

diarrhoea, abdominal cramps, loss of appetite and vomiting), loss of balance (dizziness, vertigo, ataxia and light-headedness) and sensory abnormalities (paraesthesia, numbness, blurred vision/diplopia, 'electric shock' and visual lag).

Recommended Guidelines for addressing Social and Emotional Wellbeing / Mental Health issues in MJD Patients

1. Establishment of an Individual Care Plan for each MJD patient, and where appropriate, his or her family members and/or carers.
2. The Care Plan should include:
    a) Referrals for genetic testing and genetic counselling for the patient and at-risk family members.
    b) A *GP Mental Health Care Plan* (Australian MBS item 2700, 2701, 2715 and 2717) and referral/s to a psychologist and, where appropriate, a psychiatrist.
    c) If appropriate, prescription of an antidepressant. Noting all other MJD symptoms, other medical conditions, and life style factors.
    d) A *GP Management Plan* (chronic disease) and *Team Care Arrangements* (Australian MBS items 721 and 723, respectively).
    e) If Aboriginal and/or Torres Strait Islander, a *Aboriginal and Torres Strait Islander Medicare health check* (Australian MBS item 715) and a *Follow-up for Allied Health Services for people of Aboriginal and Islander descent*.
    f) Referral to Access to Allied Psychological Services (ATAPS) (however, it cannot be at the same time as the GP Mental Health Care Plan).
3. Together with the treating Allied Health Professionals:
        1) An evaluation of appropriate therapeutic treatments such as Occupational Therapy, functional exercise programs, dietetics and nutrition, speech pathology, continence advisors, physiotherapists etc; and
        2) Empowerment and validation activities such as, inclusion in family / community activities, communication devices, educational activities, employment plan[1], and other social and emotional wellbeing activities.

[1] The Australian Commonwealth Department of Employment, Education and Workplace Relations has several workplace programs and subsidies which may assist the person to remain in their current role or seek new employment opportunities. http://www.deewr.gov.au/Employment/Pages/default.aspx

Pharmaceutical Treatments Options

A range of prescription antidepressants may provide benefits to MJD patients. The appropriate type of antidepressant may reduce or exacerbate other MJD symptoms such as sleep disturbances, appetite/weight loss, dry mouth, muscle spasms, pain, loss of coordination and loss of bladder/bowel control etc. Prior to subscribing any antidepressant, all other medical conditions and life style factors (such as drinking alcohol and the use of illegal drugs) should be taken into account. The side effects experienced will vary between each patient.

About 30–40% of people find they cannot tolerate the side effects of the first antidepressant they try or it does not work for them. It is recommended that each new antidepressant is administered for 4–6 weeks or more before trying another one.

Below is a list of antidepressants and their common per day dosage.

SSRIs: sertraline (50–200mg), citalopram (20–60mg), escitalopram (10–20mg), paroxetine (20–50mg), fluoxetine (20mg) and fluvoxamine (50mg).

SNRIs: venlafaxine (75mg), desvenlaxafine and duloxetine (30–120mg).

RIMAs: moclobemide (300–600mg).

MAO-Is: tranylcipramine and phenlzine.

TCAs: nortriptyline (25–100mg), clomipramine (25–75mg), dothiepin (25–200mg), imipramine (10–300mg) and amitriptyline (50–150mg).

NaSSAs: mirtazapine (15–45mg).

NARIs: reboxetine (2–10mg).

Other: agomelatine (maximum 50mg).

1.4. Antidepressant trials for MJD patients

A trial of Fluoxetine (20mg daily) in 13 MJD patients for six weeks did not find any significant improvement in motor performance or alleviation of depressive symptoms (after using Bonferroni adjustment) (Monte et al., 2003).

In Arnhem Land, anectdotal / self-reported findings from the prescription of Mirtazapine (an NaSSA) for two young adults with moderate and severe MJD have provided benefits. Mirtazapine was prescribed with considerations for its side effects – excessive sleep and weight gain. Both people reported sleep disturbances and had experienced significant weight loss.

1.5. Pharmaceutical treatments for symptoms which exacerbate social and emotional wellbeing issues in MJD patients

A study by Loo, D'haenen and Hale (2002) found that the antidepressant *agomelatine* improves the quality of sleep (by regulating circadian rhythm) and therefore can be a form of management of depression associated with EDS.

For MJD patients experiencing pain, SSRIs may have limited efficacy in relieving pain symptoms (Iyengar et al. cited in Williams et al., 2006). However, SNRIs, due to the dual-action of blocking both 5-HT and NE reuptake, in randomised clinical trials have been found to be effective in treating pain and depression (Detke et al., Branna et al., Nelson et al., Goldstein et al., and Bradley et al. cited in Williams et al., 2006). Jain (2004) also found that TCAs and MAO-Is are more effective in treating both depression and pain than SSRIs (cited in Williams et al., 2006).

Therapeutic Treatment Options

A range of therapeutic treatments are beneficial to MJD patients who are experiencing depression and other social and emotional wellbeing or mental health issues. The Australian Government provides various Medical Benefit Scheme rebates and each state and territory has programs for people with chronic disease, disability and/or mental health illness.

1.6. Occupational therapy

Research supports non-invasive therapeutic treatments, such as occupational therapy (OT), reporting they are effective in improving the social and emotional wellbeing of MJD patients (Saute et al., 2010). OT can provide practical and functional solutions to patients and carers throughout the progression of the disease to ensure that patients maintain their maximum possible independence and autonomy in all domains of daily living, thus promoting their self-efficacy.

A study of OT intervention in MJD patients over six months (1 session per week for three months and then monthly sessions for the final three months) found significant reductions ($p<0.0001$) in depressive scores (Hamilton Scale). Greatest improvement in mental health occurred for those with the lowest baseline scores (Silva et al., 2010).

Physical exercise can significantly reduce depressive symptoms for people with chronic illnesses. A systematic review and meta-analysis of randomised control trials (Herring et al., 2012) found that patients with mild to moderate depression, and for whom exercise training improves function-related outcomes, achieve the largest antidepressant outcomes.

> *For further information on beneficial exercise programs refer to the Balance and Mobility Medical Protocol.*

1.6.1. Australian Government schemes and programs

In Australia, subsidised OT sessions or other allied health services are provided under the chronic disease *GP Management Plan* (MBS item 721) and *Team Care Arrangements* (MBS item 723). The GP Management Plans and referrals provide for up to five individual allied health services (MBS items 10950 to 10970 inclusive) per calendar year. Eligible allied health services include: Aboriginal health workers; audiologists; chiropractors; diabetes educators; dietitians; exercise physiologists; mental health workers; occupational therapists; osteopaths; physiotherapists; podiatrists; psychologists; and speech pathologists.

Residents of aged care homes whose GP has contributed to a care plan prepared by the residential aged care facility (MBS Item 731) may also have access to the allied health items. Under the *Aged Care Act (1997)*, approved providers of residential aged care have an obligation, where an assessed care need has been identified, to provide allied health services to high-care residents at no additional cost to the resident.

The development of a GP Management Plan and Team Care Arrangements and the associated reviews are bulk-billed items (i.e. no out of pocket cost for the patient). For more information on GP Management Plans and Team Care Arrangements, visit the Department of Health and Ageing website[2].

Aboriginal and Torres Strait Islander patients are also eligible for an *additional* five subsidised allied health services under the *Follow-up Allied Health Services for People of Aboriginal and Torres Strait Islander Descent* (MBS items 81300-81360). Follow-up services are available when in conjunction with the *Aboriginal and Torres Strait Islander Medicare health check* (MBS item 715). For more information on Follow-up Allied Health Services, visit the Department of Health and Ageing website[3].

Each state and territory disability program may provide access to Allied Health professionals who can implement programs to improve social and emotional wellbeing. See *Help for all Australians with MJD* booklet for more information[4].

1.7. Psychological counselling

Psychological counselling and other psychological interventions are effective in treating depression. Research supports that the effectiveness of a psychological intervention, such as cognitive behavioural therapy (CBT), is comparable to antidepressant medication in mild to moderate depression (Hollon cited in Williams et al., 2006).

1.7.1. Pain management and CBT

Pain, particularly chronic pain, should be viewed as biomedical, psychosocial, and behavioural factors (Dysvik et al., 2010). CBT is seen as generally effective in addressing psychosocial problems associated with chronic pain. CBT offers an opportunity to consider the cognitive and behavioural factors that can influence the pain experience and focus on learning and coping strategies (Dysvik et al., 2010). After controlling for physical impairment, one study found that catastrophising contributed significantly to disability (Arnow et al., 2011). The modification of catastrophising and other depressive features may reduce disability and increase participation in daily life activities (Arnow et al., 2011).

One study of 202 non-MJD patients found that a nurse-led CBT program focusing on enhancing self-efficacy aids and reducing cognitive distortions (such as catastrophising), was effective in reducing pain intensity (by 22%; $p<0.001$), disability (by 18%; $p<0.001$) and depression symptoms (by 29%; $p<0.001$) (Wells-Federman, Arnstein and Caudill, 2002).

[2] http://www.health.gov.au/internet/main/publishing.nsf/Content/mbsprimarycare-chronicdiseasemanagement-ganda#1_2

[3] http://www.health.gov.au/internet/main/publishing.nsf/Content/factsheet_health_ATSI_descent

[4] Currently under development

1.7.2. Australian Government schemes and programs

Under the Australian Medical Benefits Scheme, a *GP Mental Health Treatment Plan* (MBS items 2700, 2701, 2715 and 2717) provides up to 10 subsidised individual psychological therapy sessions and up to 10 group therapy sessions per calendar year. Until 30 December 2012, under exceptional circumstances, an additional six sessions are available. For more information on *GP Mental Health Treatment Plans*, visit the Department of Health and Ageing website[5].

The subsidised sessions under the *GP Mental Health Treatment Plan* are in *addition* to subsidised sessions under the *GP Management Plan* (chronic disease), *Team Care Arrangements* (chronic disease) and *Follow-up Allied Health Services to people of Aboriginal and Torres Strait Islander Descent*.

The *Access to Allied Psychological Services* (ATAPS) program is a component of the *Better Outcomes in Mental Health Care Initiative* funded by the Federal Government and coordinated and managed locally by Medicare Locals or Divisions of General Practice. ATAPS provides access to effective low-cost treatment for people with mild to moderate mental disorders that can respond well to focussed psychological strategies. ATAPS is designed to enable groups who are less able to pay 'out of pocket' fees associated with the *GP Mental Health Plan*. For more information visit the Australian General Practice Network website[6].

[5] http://www.health.gov.au/internet/main/publishing.nsf/Content/factsheet_health_ATSI_descent

[6] The current contract to manage ATAPS expires on 30 June 2012. The details of this program may change after this date. http://www.agpn.com.au/programs/primary-mental-health2/overview

Other Treatment Options

The MJD Foundation is trialling a range of activities to improve the social and emotional wellbeing of MJD clients. Activities include increasing independence, such as communication devices and mobility aids; educational and employment activities; respite and 'a holiday of a life time'; and social activities.

1.8. Promoting independence

Research shows that depression in MJD patients is reactive to physical incapacities rather than neurological damage / or the disease itself (Cecchinet al., 2007; Klinkeet al., 2010; Sauteet al., 2010). Improving a patient's independence will have positive effects on their social and emotional wellbeing. For example, as the disease progresses, dysarthria (slurred speech) reduces a person's independence in communicating effectively with others. Therefore, the provision of a communication device such as an *Apple iPad* and its associated communication application *Proloquo2Go*[7] can increase their independence and enable the person to participate in conversation and communicate their needs and desires.

> *For further information on dysarthria and treatment options available refer to Communication Difficulty Medical Protocol.*

A range of mobility equipment and assistive devices can reduce the impacts of physical incapacities and fine motor dysfunction and increase independence. The correct prescription of mobility items is essential to improving the longer-term outcomes for people with MJD. For example, a correct wheelchair prescription or splint can increase the person's independent mobility or range of movement as the disease progresses and/or reduce the risk of comorbidities such as joint contractures.

> *For further information mobility issues and equipment items available refer to Mobility and Balance Medical Protocol and Equipment per Stage of Disease Medical Protocol.*

[7] http://www.assistiveware.com/product/proloquo2go

Appendix A – Genetic counselling resources for MJD patients

The following resources have been developed in conjunction with Associate Professor John MacMillan, Genetic Health Queensland, and families affected by MJD.

1. **MJD genetic education books** – is a series of simplified English[8] and local language (for example, Anindilyakwa[9]) books which explain in words and pictorially how MJD is transmitted.

2. **Genetics in Primary Healthcare lecture** – is a recorded presentation[10] by Associate Professor MacMillan to remote General Practitioners in East Arnhem Land. The presentation includes:

    a) Knowledge in the area of genetic medicine.
    b) Describes Mendelian inheritance patterns and their use in evaluating an individual's risk of being affected/a carrier of genetic disorder.
    c) Describes features suggestive of an inherited form of common cancers (breast and bowel) so that an appropriate referral to appropriate specialists is expedited.
    d) Describes recent advances in the application of laboratory investigations in genetic medicine with specific relevance to general practice.

3. **MJD in Primary Healthcare lecture** – is a recorded presentation[11] by Associate Professor MacMillan to remote General Practitioners in East Arnhem Land. The presentation includes:
    a) How MJD is passed on
    b) The features of MJD
    c) Experiences in East Arnhem Land
    d) Genetic testing options and counselling available.

4. **MJD Genetic Counselling Checklist** – is a checklist[12] for General Practitioners who are providing genetic testing to at-risk individuals. The checklist has been devised to enable clients who are unable to attend genetic counselling with a Geneticist (i.e. currently all at-risk individuals in the Northern Territory) to receive adequate support prior to the test and after the result is disclosed.

[8] http://www.mjd.org.au/cms/file_library/Other/Other_281.pdf
[9] http://www.mjd.org.au/cms/file_library/Other/Other_282.pdf
[10] http://vimeo.com/31948180
[11] http://vimeo.com/32066438
[12] http://www.mjd.org.au/cms/file_library/Other/Other_471.pdf

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Appendix C – Definitions

Beck Depressive Inventory (BDI) measures the emotional distress rather than major depression. The test consists of 21 questions reflecting the most frequent symptoms of depression (Klinke, 2010). BDI is usually interpreted: 0–10 (absence or subtle depression); 11-18 (mild depression), 19-29 (severe depression) (Saute, 2010).

Catastrophising refers to focusing on the most extreme negative consequence that may be possible in a situation (Arnow et al., 2011).

Medical Benefits Scheme (MBS) is an Australian Government funded initiative which pays the 'Schedule' fee for a medical consultation, procedure, laboratory testing etc. The Schedule fee may not cover the full fee charged by the medical practitioner or laboratory, therefore, the 'gap' fee is borne by the patient.A list of MBS items is found at: www.mbsonline.gov.au.

Pharmaceutical Benefits Scheme (PBS) is an Australian Government funded initiative which subsidies certain prescription medications. The schedule of medications covered under PBS is found at: www.pbs.gov.au.

Preimplantation geneticdiagnosis (PGD) is generally defined as the testing of preimplantation stage embryos or oocytes for genetic defects.

REM behaviour disorder (RBD) is where patients verbally and physically act out dreams usually with violence.

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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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