# A PATHWAY FOR THE MANAGEMENT OF PAIN IN MOTOR NEURONE DISEASE

**The UK Motor Neurone Disease Networking Group developed and published a Paradigm for disease management in Motor Neurone Disease (1). During the course of this work, the assessment and management pain was identified as one area that required greater attention. In order to provide guidance for other care professionals in their contact with people with Motor Neurone Disease this pain pathway has been developed.**


## The purpose of a pathway is:

- **To reduce variations in treatment**
- **Define care needs**
- **Provide a structure for patient care**
- **Enable the identification and assessment of patient needs**
- **Provide guidelines for decision making and care interventions**
- **Enable improved collaboration and efficiency in the provision of care**

## Motor Neurone Disease (MND) is a progressive degenerative disease of the motor neurons affecting up to 5,000 people in the United Kingdom.

It affects 1:12,000 of the population overall with an incidence of 1:50,000 per annum. The age of onset is usually between 40 and 70 years of age. Most cases of MND are sporadic in nature although familial MND accounts for around 5% of cases. Approximately 10% of familial cases have a mutation of copper zinc superoxide dismutase (SOD1) on chromosome 21. Survival from first symptom is on average 2-5years (14-16 months survival time from diagnosis). Three main forms of MND are identified but they may overlap. For example a person with PMA can progress to a state consistent with a diagnosis of ALS.

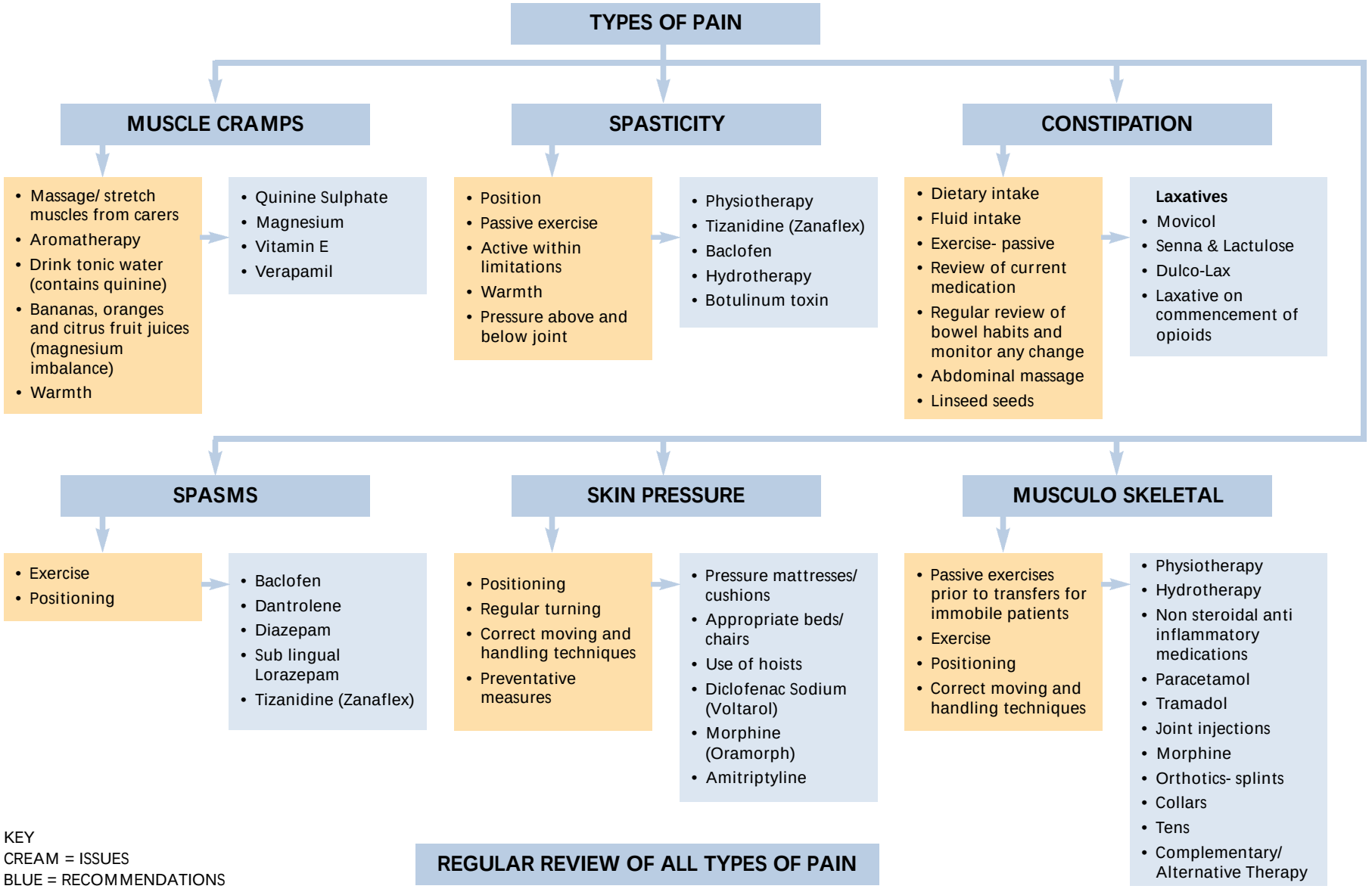
**Amyotrophic Lateral Sclerosis (ALS)**
This is the most common form of MND accounting for 66% of all cases and is characterised by muscle weakness, spasticity, hyperactive reflexes and emotional lability.

**Progressive Muscular Atrophy (PMA)**
Characterised by muscle weakness and wasting, weight loss and fasciculation this is the least common affecting 7.5% of diagnosed cases.

**Progressive Bulbar Palsy (PBP)**
Affecting 25% of cases this form predominantly affects the muscles of the bulbar region and is characterised by dysarthria and dysphagia. Depending on which motor neurones are affected the patient may develop nasal speech, tongue atrophy and fasciculation, pharyngeal weakness or tongue spasticity and emotional lability.

**Treatment**
There are a range of pharmacological interventions that provide symptomatic relief for people with MND (PwMND) but currently Riluzole is the only drug licensed for the treatment of individuals in the UK. Riluzole is a disease modifying therapy, which may extend the length of time to death or mechanical ventilation. The National Institute of Clinical Excellence (NICE) recommends that: "Riluzole therapy should be initiated by a neurological specialist with expertise in the management of MND. Routine supervision of therapy should be managed locally agreed shared care protocols undertaken by GP's" (NICE Health Technology appraisal No.20 January 2001).

# Motor Neurone Disease Pain Pathway - Physical Pain



# Motor Neurone Disease Pain Pathway - Psychological Pain

The approach to psychological pain may not be as simple as: Identify pain – treat pain – absence of pain.

'Psychological Pain' can take many forms, e.g. fear, grief, anger, frustration, stress, loss of control, anxiety, depression.

Psychological pain varies greatly between individuals, it may not be expressed as openly as physical pain due to cultural restraints & it may be difficult for people with MND to admit fear or depression.

It must be accepted that a certain amount of pain may be unavoidable, and may need to be worked through before improvement.

It is also necessary to consider the psychological pain of both family and lay and professional carers.

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| Pre-morbid personality, character and family dynamics.<br><br>Previous experiences in life and with illness, coping strategies. Expectations and implications of illness | Prepare the ground for bad news eg condition difficult to treat or cure. | Education and information about MND to reduce anxiety and improve psychological wellbeing. | • Assess & provide appropriate level of information<br>• Discuss with the patient what level of information and education e.g. MNDA leaflets, Internet (advise about accessing 'safe' sites).<br>• Identify gaps in knowledge e.g. fear of choking, end of life issues and offer support.<br>• Financial advice regarding benefits may resolve fears about future finances |
| How diagnosis is given may affect future psychological wellbeing<br>E.g. tone, who tells diagnosis, where patient is told, level of empathy, etc | Follow agreed guidelines of giving of diagnosis (local guidelines, (2)(3)) | Hope based on realistic and accurate information may improve psychological well-being. | Strategies to foster hope: e.g.<br>• Clinical trials<br>• Disease modifying medication (Rilutek)<br>• Information about research and conferences.<br>• Complementary therapies<br>• Information on MND |
| Providing ongoing support to enable reduction of psychological pain. | • Offer explanations - support at diagnosis.<br>• Give contact details of MND Associations<br>• Address any initial fears<br>• Facilitate discussions | Acknowledgement of the difficulties of coping with MND & discussion of coping strategies may help the patient | • Provision of equipment & advice to enable coping strategies and maximisation of independence.<br>Discussion of<br>• Denial / Acceptance.<br>• Short term / Long term strategies. |
| Psychotherapeutic & Pharmacological interventions may be helpful | • Antidepressants<br>• Anxiolytics<br>• Counselling<br>• Refer as appropriate | Support for children & carers concerns. | • Provision of information for families/ carers including children<br>• Facilitating discussion within family/carer networks |

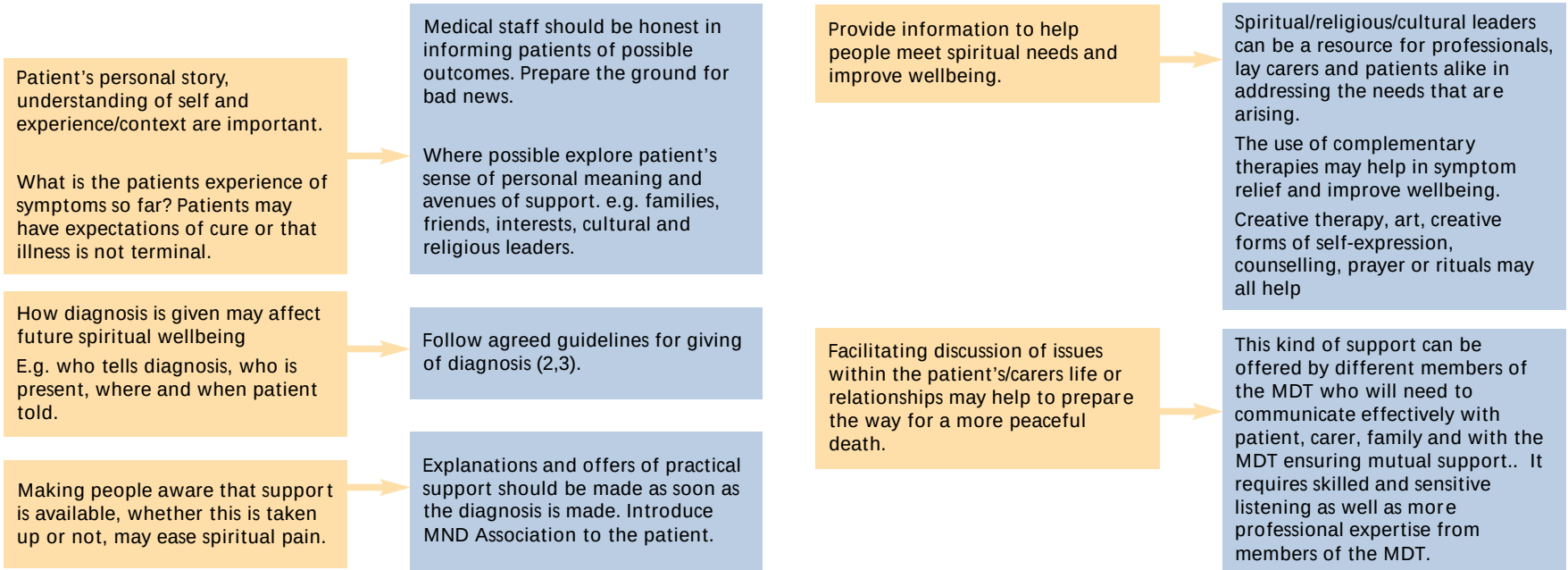
# MOTOR NEURONE DISEASE PAIN PATHWAY - SPIRITUAL PAIN

## Spirituality may be defined as, a search for meaning within a life experience and will encompass a patient's understanding of self in relationship with others (for example people, nature, God)

There is an overlap with psychological and spiritual pain. Spiritual pain may take many forms and can be voiced to any member of the team both lay and professional. It may be expressed in the question, "Why me?", but may also be manifested as fear, grief, anger, regret, stress, loss of control, anxiety, depression, as well as specifically religious or cultural concerns. In times of crisis/vulnerability, a reassessment of one's spiritual values is common.

Spiritual pain varies between individuals and may be expressed in different ways according to culture and background.

Unlike physical pain a certain amount of spiritual pain may be unavoidable, and spiritual pain may need to be worked through in order for personal growth/integration of the experience to take place. Thus the approach to spiritual pain may not be as simple as: Identify pain – treat pain – absence of pain. It is also necessary to consider the spiritual pain of family, lay and professional carers.




**References:** 1. Motor Neurone Disease Working Group. A paradigm for disease management in MND RCN London 2001 2. Miller RG, Rosenburg JA. et al Practice Parameter: The care of the patient with amyotrophic lateral sclerosis. Neurology 1999;52:1311-1323 3. Excerpta Medica MND Advisory Group, Guidelines for the management of Motor Neurone Disease (MND). Endorsed by ABN,1999
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