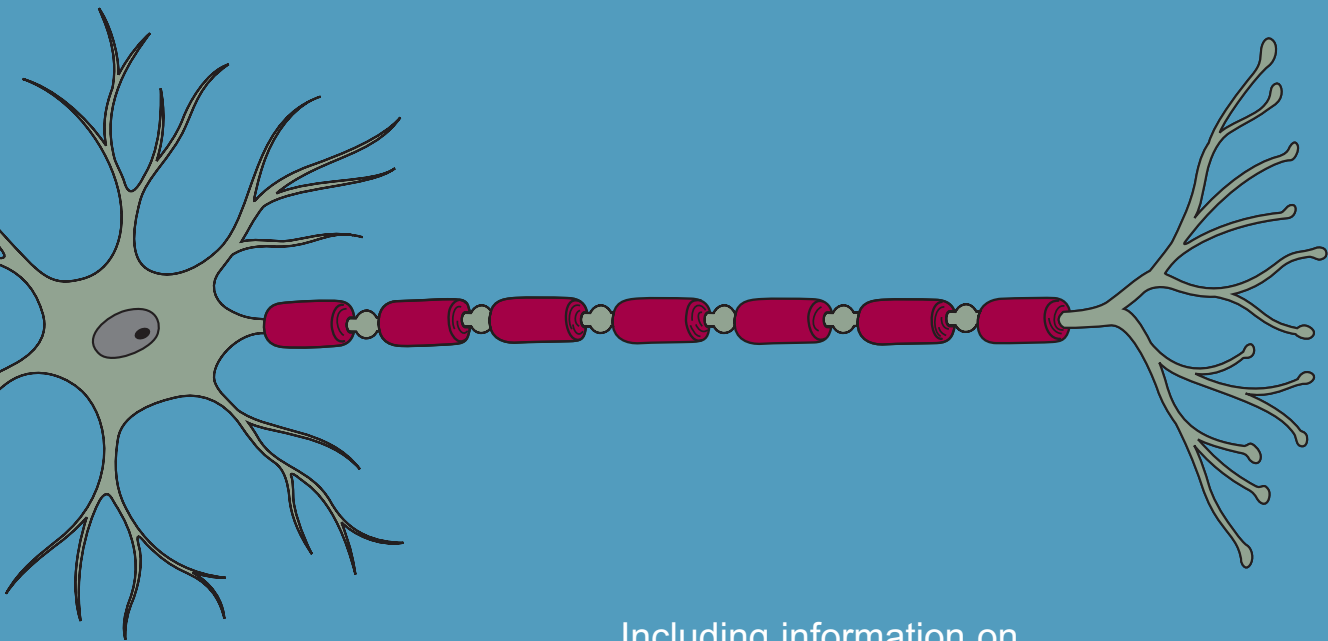


# MS and palliative care

A guide for health and social care professionals



Including information on

- palliative care for people severely affected by MS
- optimising quality of life during advanced phases of MS
- end of life care

## **MS and palliative care**

*A guide for health and social care professionals*

This guide is for health and social care professionals who are responsible for the wellbeing of people with advanced MS. To accommodate the needs of such a diverse readership, the content is designed to allow professionals to 'dip' into the chapters that complement their existing knowledge:

- The first chapter, **Overview of MS**, discusses relevant aspects of MS for professionals involved with specialised palliative care teams, general practice and community nursing teams.
- The second, **Palliative care explained**, explores the nature and provision of palliative care. It offers a care pathway that suggests potential trigger points for considering making referral or liaison with local specialist palliative care teams. It is aimed at MS teams, neuro-rehabilitation teams and community nursing teams.
- The third, **Palliative care challenges**, outlines some of the challenges faced in caring for people with severe or advanced MS, namely:
  - symptom management: pain, spasticity, bowel management and nutritional support
  - cognition and mental capacity
  - advance planning
  - end of life care

Further information about palliative care can be found at [www.mssociety.org.uk](http://www.mssociety.org.uk)

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# Introduction

It is increasingly recognised that people with advanced MS and other long-term conditions have unmet health and social care needs in the last years of their lives.<sup>2</sup> Many people with advanced MS represent a ‘silent minority’ who have fallen out of acute care follow-up and remain a collective mystery in terms of their palliative care needs.<sup>39</sup> With these concerns in mind, in 2003 the MS Society launched a three-year project to investigate the palliative care needs of people living with severe and advanced MS.

The project was a collaboration between clinicians at King’s College Hospital and researchers at the Department of Palliative Care and Policy, King’s College London. In-depth interviews were conducted with people in south-east London who were severely affected by MS, and with a diverse range of professionals involved in their care. From these interviews three themes emerged concerning unmet need:

- There was a potential role for **specialist palliative care services** to be involved in clinical care in addressing symptom control, advanced planning, end of life decision making and concerns about capacity and cognition.
- **Education** and professional discussion was needed for those involved in providing palliative care to people with MS.
- People affected by severe MS and the professionals involved in their care wanted **more information**, particularly about services, which they tended to acquire *ad hoc*, often through informal

contacts. Services varied and were difficult to contact or access depending on the locality. One interviewee described feeling they had to ‘fight for everything’.

This publication describes the work completed within the educational strand of the project. Ten study days were held throughout the south-east London area from March to May 2005, reaching an audience of 232 health and social care professionals. The sessions were case-based and interactive, the content evolving through the participants’ discussion and feedback. Some 95% of participants evaluated the sessions as both useful and relevant to their work.

While the work is grounded in the important issues highlighted by people severely affected by MS, it does not seek to represent the ‘patient’s voice’. People with severe MS are a diverse group of individuals, who have their own hopes, fears and challenges with which they face the future, and the purpose of this publication is not to make any judgements about their collective needs.

It is now more important than ever that, as professionals, we develop our skills and knowledge in our care of people with advanced disease. The National Service Framework for Long-term Conditions has challenged us to ensure that:

*People in the later stages of long-term neurological conditions are to receive a comprehensive range of palliative care services when they need them to control symptoms, offer pain relief and meet their needs for personal, social, psychological*

*and spiritual support, in line with the principles of palliative care. (Quality Requirement 9, page 51).<sup>32</sup>*

It is equally important that palliative care services need to be integrated more effectively with neurology and neuro-rehabilitation services in order to provide a comprehensive and holistic system of care for people living with advanced MS.

## **What is palliative care?**

**Palliative care is a service for people severely affected by advanced, progressive or life-limiting conditions. Its purpose is to maximise quality of life during the advanced stages of the condition. It takes a holistic approach and provides expertise in pain relief and symptom management. It also offers support for complex psychological and social issues to patients and families. All specialist palliative care services are carefully tailored to the needs of the individual. These services can be offered at home, in hospitals and in hospices.**

# 1 Overview of MS

This chapter discusses relevant aspects of MS for professionals involved with specialised palliative care teams, general practice and community nursing teams.

An estimated 85,000 people in the UK have MS. It is the most common disabling condition of the central nervous system (CNS: the brain and spinal cord) affecting young adults aged 20 to 40. The duration of the disease is protracted but the course is variable and, in individual cases, difficult to predict.

The prevalence of MS shows striking geographical variation, as the condition becomes increasingly more common with distance from the equator in either hemisphere. It is a disease of temperate climates, and as such is common in northern Europe, northern America and southern Australia. Even within the UK, prevalence varies from 115/100,000 in Surrey in the South East to 170/100,000 in the Orkneys.<sup>75</sup>

In MS, damage or scarring occurs to the myelin sheath – a layer of fatty protein that protects the nerves in the same way that insulating material protects an electric wire. This damage (called demyelination) disrupts the way in which messages, or nerve impulses, are carried to and from the brain, and so it can interfere with a range of the body's functions.

The term 'multiple sclerosis' comes from 'sclerosis', which means scarring and

'multiple', which relates to the sites of the scarring or 'plaques', which can occur in different places throughout the brain and spinal cord. Symptoms depend on the position and extent of the scarring within the CNS, and on how much damage has occurred.

## Types of MS

MS varies dramatically from one individual to another. Some people experience only very mild disease, others have particularly aggressive disease and develop profound disability within a few years of onset. The following types of MS were established in 1996 and give general guidelines to the pattern and types of MS disease:<sup>58</sup>

- **Relapsing/remitting**

In about two thirds of people diagnosed, MS takes the form of relapses or attacks interspersed with periods of remission. This is because the CNS can often compensate for areas of damage by repairing myelin or by re-routing messages around the problem area.

In a remission, symptoms that were disabling during a relapse can virtually disappear. Occasionally there is some residual damage after a relapse, leading to incremental levels of disability.

Exacerbations may be triggered by viral and bacterial infection but not by vaccination or immunisation.<sup>61</sup>

Exposure to heat and high humidity may amplify symptoms (Uhthoff's phenomena) as may strenuous exercise and menstruation. Pregnancy protects against exacerbation but the risk of relapse is increased following delivery.

The treatment for acute relapses is to treat any underlying infection before giving a course of oral steroids.<sup>70</sup> Steroids have been shown to influence the rate of neurological recovery but not the ultimate degree of recovery.<sup>61</sup>

For those with relapsing disease who meet the criteria set by the Association of British Neurologists, disease-modifying therapies (DMT) can be prescribed. These require (self) administration of a subcutaneous or intramuscular injection, given between once a week to daily, depending on the preparation chosen. These therapies modulate the immune response, causing a reduction in both acute attacks and accumulation of plaques within the CNS. Therapies currently on offer include interferon 1a, 1b and glatirimer acetate.<sup>69</sup>

- **Secondary progressive**

About 75% of people whose disease pattern begins with relapsing/remitting symptoms go on to develop secondary progressive disease. This heralds a gradual increase in disability irrespective of the presence of continuing relapses. For 50% of people this change occurs within the first ten years of diagnosis. This 'transition' can be quite gradual and may only be recognised in retrospect, as the awaited remission never happens. For others progression can be quite marked, and the loss of the improved quality of life previously experienced in remissions can be profound.<sup>17</sup>

This transitional period can be emotionally and physically difficult, as people fear the disease has 'finally caught up with them' and often worry for the future.

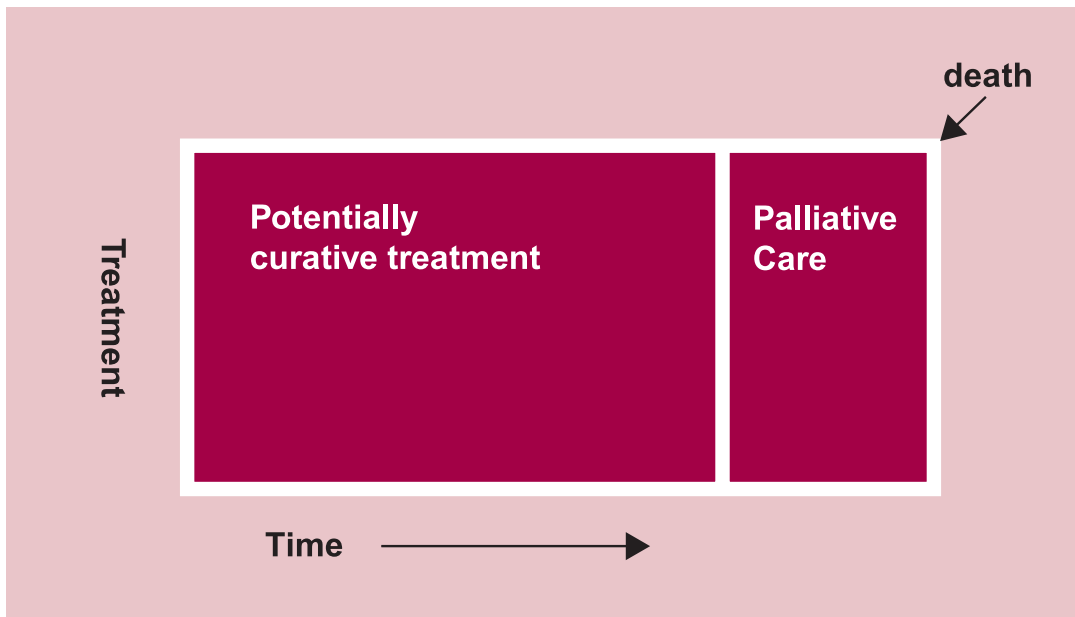
- **Primary progressive**

About 10% of people have this chronic condition from onset. Symptoms gradually worsen over the years, without relapse or remission. This form of MS is not amenable to the disease-modifying treatments that have received so much media coverage.

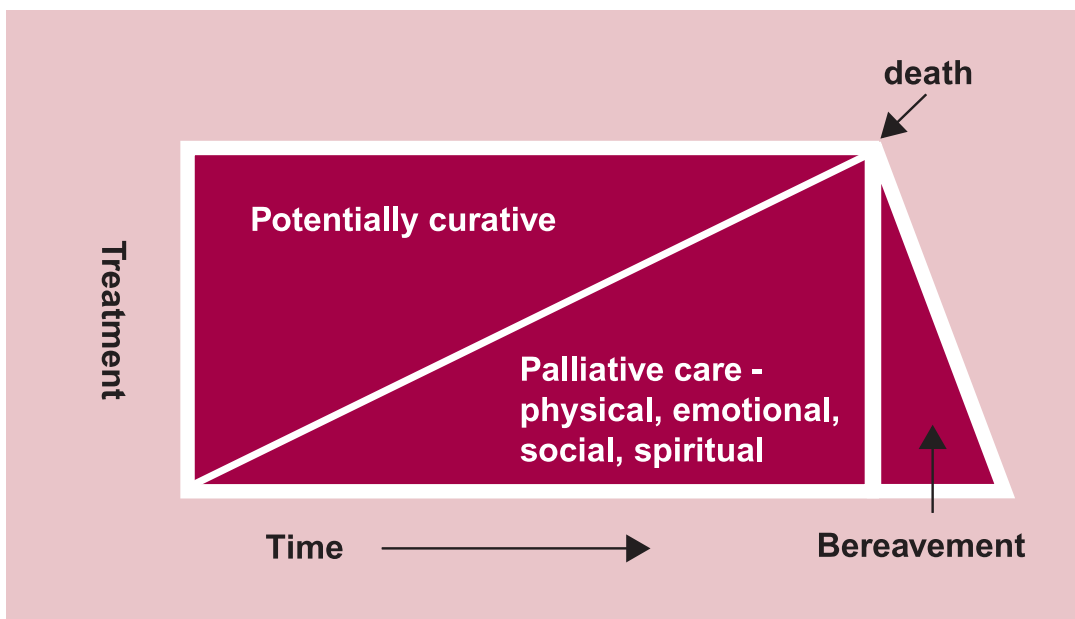
## Causes

The cause of MS is unknown, although there is increasing evidence that suggests an interplay between environmental factors (viral infective agents) and genetic susceptibility. This results in the triggering of the immune system to attack its own myelin sheath as if it were a foreign body. Thus, MS is said to be an autoimmune disease.

It is important to note that MS is not a hereditary disease. However, families that already have a member with MS show a greater risk of developing the condition than families that have no one with MS. If a parent has MS, their children are approximately 16 times more at risk of developing the disease than the general population. However this is still a very small risk. Studies of identical twins have shown that if one identical (monozygotic) twin develops MS there is only a 25% chance that their twin will also develop the disease.<sup>81</sup> Given that they have identical genetic make-up, genetic factors can only play a limited part.



**Figure 1** Traditional concept of palliative care



**Figure 2** New concept of palliative care

Adapted from Lynn & Adamson in *Palliative Care. The Solid Facts*, page15. WHO 2004.<sup>91</sup>



## Migration studies

The correlation of latitude on the prevalence of MS means that migration studies have proved particularly interesting. In 1997 Dean and Elian reported that, in general, an adult who migrates carries their original risk of MS with them.<sup>24</sup> However if a child (up to the age of 15) migrates, they acquire the risk closer to that of their host country. Obviously this will have implications for second generation immigrants from south-east Asian, West Indian and African states in northern Europe.

## Environmental factors

Given the evidence of the role of genetics and the strong links with latitude, many environmental factors have been investigated, including vitamin D, diet, sanitation and pollutants. Nothing conclusive has been found so far but research continues.

## Do people with MS have palliative care needs?

There is increasing evidence to suggest that people with advanced MS and other long-term conditions have unmet health and social care needs in the last year of their lives.<sup>3</sup> It is known that those with advanced MS represent a 'silent minority' who have often fallen out of acute care follow up<sup>39</sup> and may benefit from specialised palliative care services.<sup>73</sup> These services promote physical, psychological and spiritual wellbeing, and emphasise quality of life and good symptom control.<sup>89</sup> Research has shown that palliative care is effective in improving symptom management and quality of life care in cancer,<sup>71</sup> and that similar approaches are effective in the long-term management of neurological conditions.<sup>8</sup> There is evidence of the effectiveness of interventions to control pain,<sup>16</sup> spasticity<sup>11</sup> and breathlessness.<sup>56</sup>

Unfortunately the progression of the disease for people with non-relapsing progressive forms of MS is not amenable to disease-modifying treatments. It is therefore all the more important that appropriate palliation of attendant symptoms and psychological distress is given.

# 2 Palliative care explained

This chapter explores the nature and provision of palliative care. It offers a care pathway that suggests potential trigger points for considering making referral or liaison with local specialist palliative care teams. It is aimed at MS teams, neuro-rehabilitation teams and community nursing teams.

Palliative care offers a spectrum of provision, from a palliative (or supportive) approach through to specialist palliative care intervention from a dedicated team. A palliative care approach is an integral part of all clinical practice, whatever the illness or its stage. The World Health Organisation's definition of palliative care states that:

*Palliative care is the active holistic care of patients with advanced, progressive disease. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments.<sup>90</sup>*

Palliative care is based on these principles:

- affirming life and regarding dying as a normal process
- providing relief from pain and other distressing symptoms
- integrating the psychological and spiritual aspects of patient care

- offering a support system to help patients live as actively as possible
- offering a support system to help the family cope during the patient's illness and in their own bereavement

For many, palliative care has been synonymous with end of life and cancer care. People with advanced disease are often described as having reached a palliative stage of their disease. However, it is widely recognised that a palliative care approach has an important role **throughout the course of a non-curative disease, and can be delivered in conjunction with active disease modifying treatments.**

A key principle in the guidance on the commissioning of palliative care services for adults is that 'it is the right of every person with a life-threatening illness to receive appropriate palliative care services wherever they are.'<sup>26</sup> The National Service Frameworks for long-term conditions,<sup>32</sup> renal disease<sup>33</sup> and cardiac disease<sup>31</sup> have stated that specialist palliative care should be offered to people with advanced forms of these diseases. The clear message is that specialist palliative care should be available on the basis of need and not diagnosis.

Palliative care can offer guidance and support in:

- symptom control
- psycho-social factors, including cognition and capacity
- advance planning
- end of life issues

## Who provides palliative care?

All professionals involved in the day-to-day care and support of people with advanced MS may provide a palliative care approach. However, some people with complex needs may benefit from referral to specialist palliative care teams for one-off assessment or continued support.

The National Council for Palliative Care states that those providing day-to-day care should be able to:

- assess the care needs of each patient and their families across physical, psychological, social, spiritual and information needs
- meet those needs within the limits of their knowledge, skills and competence in palliative care
- know when to seek advice from, or refer to, specialist palliative care services

Specialist palliative care services may be able to provide:

- assessment, advice and care for patients and families in all care settings, including hospitals and care homes
- specialist in-patient facilities (in hospices or hospitals) for patients who benefit from the continuous support and care of specialist palliative care teams to meet complex needs
- intensive co-ordinated home support for patients with complex needs who wish to stay at home

– this may involve the specialist palliative care service providing specialist advice alongside the patient's own doctor and district nurse to enable someone to stay in their own home

– many teams also provide extended specialist palliative nursing, medical, social and emotional support and care in the patient's home, often known as 'hospice at home'

- day care facilities that offer a range of opportunities for assessment and review of each patient's needs and enable the provision of physical, psychological and social interventions within a context of social interaction, support and friendship. Many also offer creative and complementary therapies
- advice and support to all the people involved in a patient's care
- bereavement support services that support the people involved in a patient's care following the patient's death
- education and training in palliative care<sup>67</sup>

Every area of the UK should have access to both inpatient (hospital) and community (home) palliative care teams. Specialist palliative care teams can include consultants in palliative care medicine, clinical nurse specialists and social workers, together with a range of expertise offered by physiotherapists, occupational therapists, dieticians, pharmacists and those offering spiritual support. Many areas also liaise with an extended team, including rehabilitation teams, pain specialists, anaesthetists, psychologists and counsellors.

## MS and palliative care

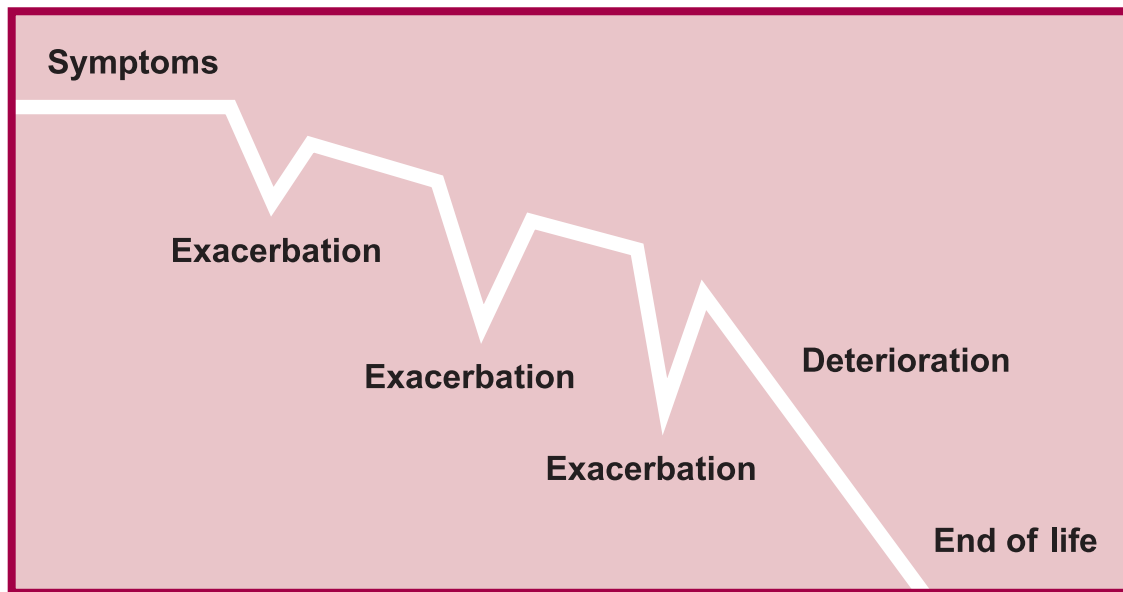
The NICE guidance for supportive and palliative care for adults with cancer (2004) sets out the benchmark for palliative care services.<sup>71</sup> While this guidance is oriented towards cancer, many of its principles and

recommendations apply to MS. Many of the symptoms experienced in the advanced stages of MS can be similar to cancer, eg. pain, nausea and breathlessness.<sup>72</sup> But some are specific to MS and require understanding of the disease itself, for example:

- the unpredictability and variability of the disease makes prognosticating on an individual basis extremely difficult
- MS is the commonest cause of chronic disability in young adults causing long-term challenges. The situation may be particularly difficult for young adults with extremely aggressive disease who are nearing the end of their lives

- managing pain arising from spasticity or neuropathic pain needs a different approach from managing cancer pain<sup>16</sup>
- cognitive and communication problems limit the ability to express choice and take part fully in counselling or other supportive interventions. Staff may also need further training in communication skills<sup>89</sup>
- there may be issues around mental capacity and consent and the need for advance directives

These points will be explored in greater detail in Chapter 3, Palliative care challenges.



**Figure 3** Characteristic disease trajectory of long-term conditions such as chronic obstructive pulmonary disease (COPD) and heart failure. This model may be adapted to some progressive forms of MS.

Adapted from Lynn & Adamson in *Palliative Care: The Solid Facts*, page 15. WHO 2004.<sup>91</sup>

The NICE guidance on palliative care emphasises the importance of co-ordinated planning and care across all agencies to provide continuity of appropriate care.<sup>71</sup> This guideline is reiterated in the NSF for long-term conditions which states:

*Professionals working within neurology, rehabilitation and palliative care need to work closely with primary care staff and care providers, including non-NHS care staff (social care, domiciliary and home care) combining their expertise to support people in the advanced stages of long-term neurological conditions. (NSF, page 52)<sup>32</sup>*

### **When to consider liaison with and referral to specialist palliative care services**

Making a prognosis of likely disease progression is notoriously difficult and often beset with problems for cancer patients, and more so for those with MS.

The protracted and unpredictable nature of the disease gives rise to concerns that patients will require long-term intervention stretching specialist palliative care resources to the limits. In contrast, the experience of the clinicians researching MS and palliative care in south-east London was that only a small number (15%) of people required ongoing specialist palliative care follow-up, although others benefited from one-off follow-up consultations or joint assessments and collaborative care planning.

It is important that people with MS benefit from the initiatives being implemented as part of the Department of Health's Building on the Best: End of Life Care Initiative.<sup>27</sup> In this, the government outlined its commitment to improve care for those coming to the end of their lives, regardless of diagnosis.

One of these initiatives, the Macmillan Gold Standards Framework or GSF,<sup>28</sup> is being used by primary health care teams to optimise the care they offer to patients in the last year of their life. Although developed for cancer patients, the GSF is being used increasingly for all patients with long-term conditions. This has led to a focus on unpredictable disease patterns (eg. with neurological disease, organ failure and coronary heart disease) and at what stage they can be considered to have reached the 'advanced stage' where palliative care input should be considered.

### **Care pathway**

Informed by the work being undertaken to extend the GSF to non-cancer conditions, the care pathway in Figure 4 on page 12 has been designed for those with advanced MS. It provides a tool for use by health care professionals to identify possible triggers for specialist palliative care referral or liaison.

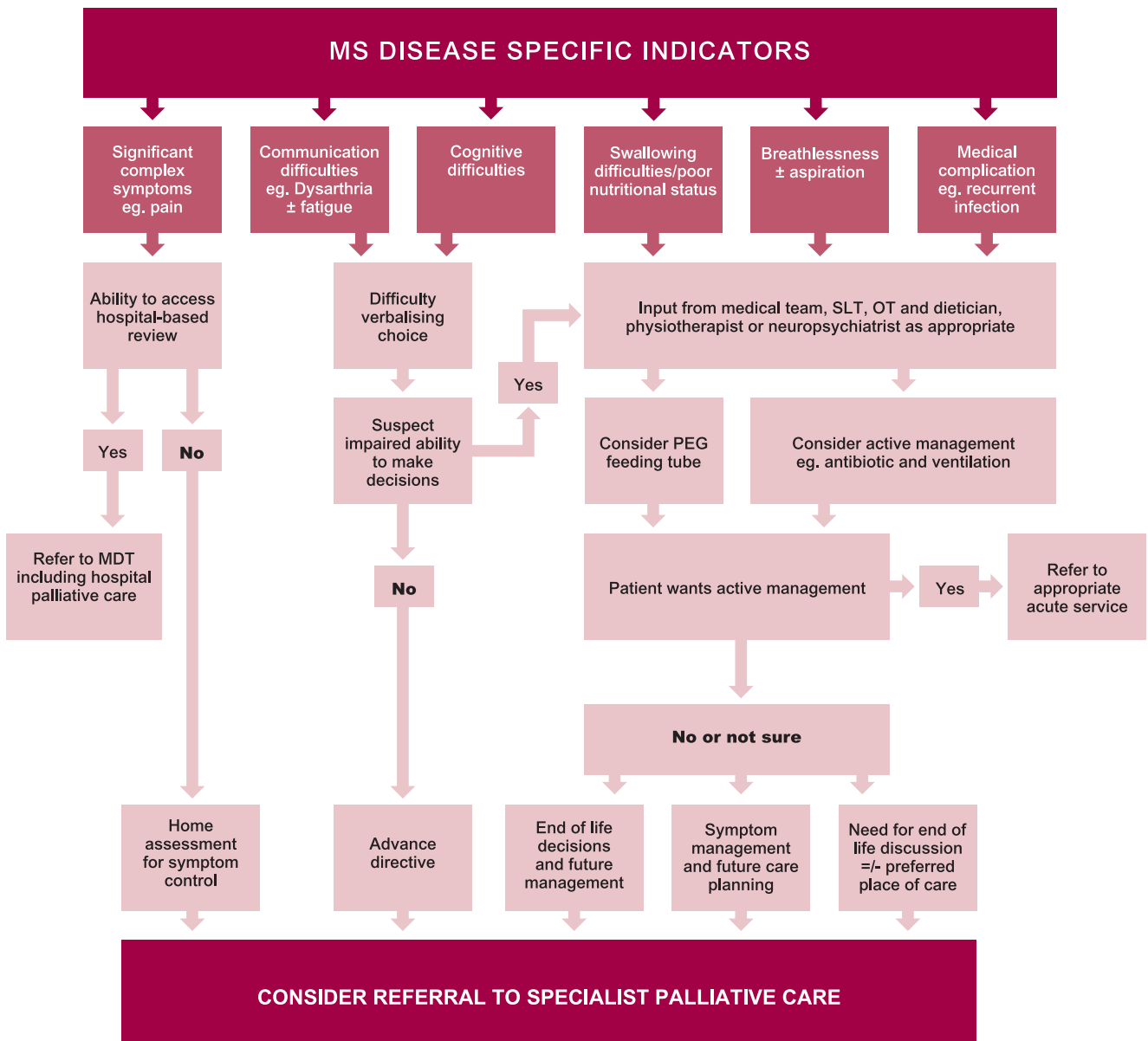
### CORE INDICATORS OF ADVANCED DISEASE

- Recent, significant functional decline (loss of ADLs)
- Dependence in three ADLs or more
- Multiple co-morbidities
- Weight loss
- Serum albumin <25
- Karnofsky score <50% (see Figure 5)
- Severe progression of disease over recent months
- Recent increase in infective episodes requiring hospitalisation

Consider holistic assessment using palliative care approach having regard to

- Quality of life
- Comfort
- Patient choice

### MS DISEASE SPECIFIC INDICATORS



Developed by Dr Rachel Burman and Sally Plumb. Based on Suggested trigger points for inclusion on GSF Supportive Register. Thomas, K et al. 2005

**Figure 4** Care pathway: could this person with advanced MS benefit from specialist palliative care?<sup>88</sup>

## General predictors of end-stage illness

	%	CRITERIA
Able to carry on normal activity and to work: no special care needed	100	Normal; no complaints; no evidence of disease
	90	Able to carry on normal activity
	80	Normal activity with effort; some signs or symptoms of disease
Unable to work; able to live at home and care for most personal needs, varying amounts of assistance required	70	Cares for self; unable to carry on normal activity or do active work
	60	Requires occasional assistance but is able to care for most needs
	50	Requires considerable assistance and frequent medical care
	40	Disabled; requires special care and assistance
Unable to care for self: requires equivalent of institutional or hospital care; disease may be progressing rapidly	30	Severely disabled; hospital admission may be indicated although death not imminent
	20	Very sick; hospital admission necessary, supportive treatment necessary
	10	Moribund; fatal processes progressing rapidly
	0	Dead

**Figure 5** The Karnofsky performance status scale<sup>38</sup>

# 3 Palliative care challenges

This chapter outlines some of the challenges faced in caring for people with severe or advanced MS, namely **symptom management** (pain, spasm and spasticity, bowel management and nutritional support); **capacity and consent**; **advance planning**; and **end of life care**.

The information may also provide a resource for training front-line staff caring for people in their own homes and in hospitals and care homes.

## SYMPTOM MANAGEMENT

*JK Wolf, a physician and person with MS, considered that depressive symptoms to be the most disabling, spasticity to be the most frequent, bladder symptoms to be the most confusing and bowel problems to be the most humiliating. Fallon 2004, page 931<sup>41</sup>*

Symptom management is the cornerstone of palliative care. The aims of effective symptom management are to:

- promote comfort
- provide emotional support
- prevent complication
- improve quality of life for the individual and family

The following list of common MS symptoms is by no means exhaustive and many people will experience only a few of them:

- bladder dysfunction
- bowel dysfunction

- cognitive dysfunction
- depression
- fatigue
- loss of balance
- mobility problems
- muscle weakness
- pain
- spasm
- sexual dysfunction
- tremor
- vertigo

It is the intangible or 'hidden' symptoms that are especially problematic. Fatigue is probably the most common symptom experienced in MS. In an MS Trust survey of 2,265 people with MS, 94% experienced fatigue with 87% reporting an impact on their daily activities that was rated as moderate or high.<sup>65</sup> Fatigue can be the major cause of disability, even early in the course of the disease, and is reported as



the most likely factor to precipitate early retirement from work.

***Sound symptom management is still the key to optimising quality of life for most people with MS.***<sup>65</sup>

## **PAIN**

As a symptom of MS, pain has been largely neglected. Until the 1980s there was little mention of pain in the literature and, in fact, many papers reported MS as painless. An estimated 80% of people with MS experience pain at some time in their disease.<sup>6</sup> A study conducted in 1995 at the National Hospital, Queen Square, London, found that 'discomfort' rather than pain was overwhelmingly experienced in their sample of people with MS.<sup>54</sup> One explanation is that pain can be an emotionally charged word with connotations of acute incident, whereas MS pain is often more subtle and difficult to describe.

Most pain results from normal activation of pain sensors that warn us of actual or impending tissue damage. Our protective response is to move away from the source of pain, so we move our hand away from the hot fire or finger from the sharp knife. Chronic pain does not serve any such purpose. It is not a warning to change our behaviour; it offers no biological advantage, and causes suffering and distress. The persistence of chronic pain, and associated depression and disability, has a devastating impact on a person's quality of life. Patients with chronic pain have been found to use the health service up to five times more frequently than the rest of the population.<sup>40</sup>

Pain is a complex multidimensional phenomenon affected by physical, psychological, social and spiritual factors. In a non-MS pain study, physical and emotional pain was shown to share a neuro-cognitive pathway. Both types of pain activated the same area of the brain, which means that

different types of pain may lead to more similar experiences than previously thought (Dowdall KC in Johnson & Hoffman).<sup>54</sup>

Despite a plethora of available pain assessments, health care professionals tend to underestimate pain.<sup>86</sup> A comprehensive pain assessment needs to include:

- location of pain
- duration of pain
- descriptors (type of pain)
- severity and frequency
- aggravating symptoms: what causes an increase or decrease?
- disability caused by pain
- effects of treatment
- psycho-social factors
- established pattern of coping<sup>49</sup>

The causes and types of physical pain in MS are varied, and include:

- neuropathic pain resulting from demyelination of the nerves
- musculoskeletal pain related to abnormal posture, immobility or possible osteoporosis
- headache
- spasm and spasticity

## **Neuropathic pain**

Neuropathic pain has been described as pain initiated or caused by a primary lesion or dysfunction in the nervous system.<sup>62</sup> It is suffered by about 1% of the UK population (500,000), and is common in a wide range of conditions including Guillan-Barré syndrome, nerve compression by tumours or nerve damage from radiotherapy and chemotherapy as well as phantom limb pain after amputation.

Neuropathic pain represents a huge challenge to health care professionals because it is difficult to recognise and treat. This could be attributed to confusing co-existing symptoms such as pins and needles, numbness or weakness. It may also be because the pain appears more severe and long lasting than would usually be perceived by the level of disability of injury.

Neuropathic pain is classically described as burning, pricking, tingling, electric shocks, cold and itching.<sup>12</sup> Patients also often liken their pain to a sensation, like 'insects crawling under my skin' or 'a tightening band across my middle'; Johnson says adjectives consistent with abnormal sensation such as 'cold water running down my (leg)' are indicative of neuropathic pain.<sup>54</sup> A detailed description is important where different types of pain co-exist. In MS, the person may experience musculo-skeletal pain around the shoulder girdle from self-propelling a wheelchair but also shooting neuropathic pains down the arms.

The complex mechanism of neuropathic pain means that conventional drugs cannot manage it, and patients often need to be referred to specialists in pain management: this may be a pain team or specialist palliative care team. It is useful to gain a history of the individual's normal patterns of coping, and which interventions have been successful. Their behavioural response to pain can also give clues for possible treatments. If rubbing the painful area relieves pain, then TENS (transcutaneous nerve stimulation) may be a suitable treatment. Gaining detailed information gives an assessment of previous understanding and compliance with dosages as well as expectations for success.

## Treating neuropathic pain

The aim of pain management may be to reduce the pain and help people cope, rather than eradicate the pain completely. Common neuropathic treatments are:

- **Antidepressants**

Tricyclic antidepressants such as amitriptyline are considered by some to be the drug of choice.<sup>79</sup> They are used primarily for depression, and people should be aware that it may be a few weeks before they notice a significant reduction in pain. The drug is often given at night, which is useful for those sleeping poorly because of their chronic pain.

- **Anticonvulsants**

The newer antiepileptic drugs are used alone or in conjunction with tricyclics. Gabapentin has been shown to reduce pain in patients with a wide range of neuropathic pain syndromes and induce better sleep, mood and quality of life.<sup>78</sup> Pregabalin also shows good efficacy in neuropathic pain.

- **Opioids**

Tramadol, a weak opioid, has been found to be effective in neuropathic pain and is considered to have low addiction potential.<sup>84</sup> Increasingly, pure opioids such as morphine and oxycodone are being used because of mounting evidence of their efficacy. They are particularly useful when used in combination with tricyclics and/or anticonvulsants.<sup>93</sup> One study reported that gabapentin and morphine combined achieved better analgesia at lower doses of each drug than either did as a single agent.<sup>44</sup>

- **Non-pharmacological interventions**

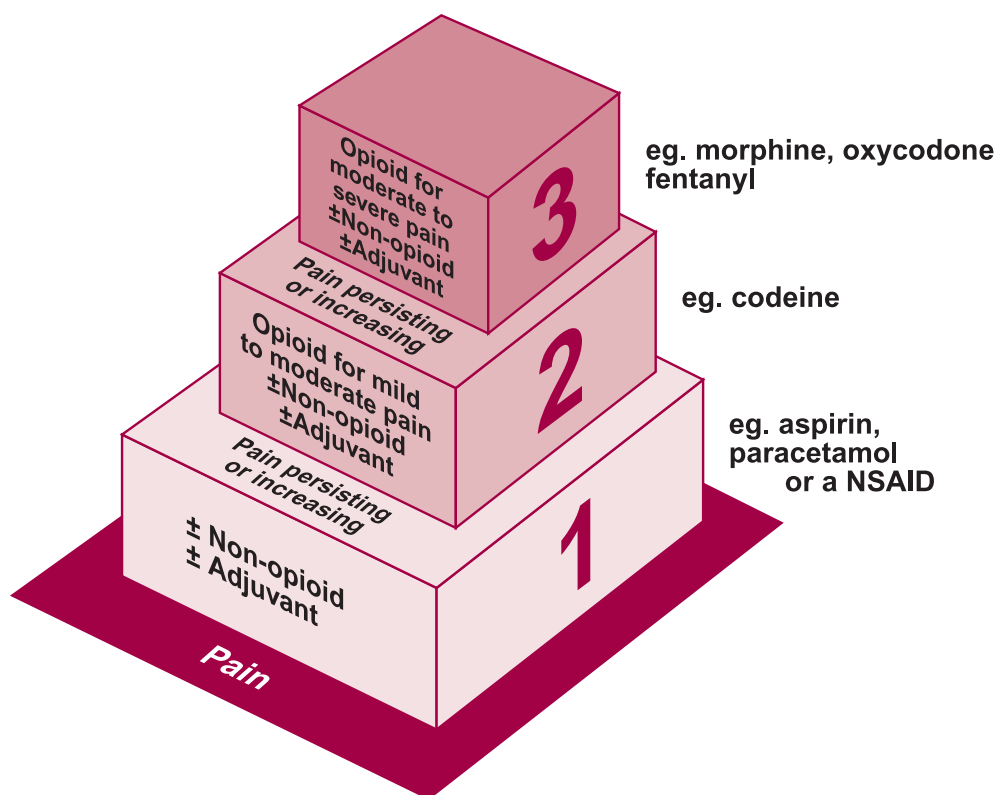
TENS and acupuncture, in the hands of experienced practitioners, represent safe therapies with broad anecdotal evidence of efficacy in neuropathic pain.<sup>52</sup>

● **Reflexology**

This involves stimulating points on the soles of the feet that are said to influence the physiology throughout the body. It has been investigated in MS on one occasion. Seventy one patients were randomised to either reflexology treatment with manual pressure on specific points in the feet and massage of the calf area, or to non-specific massage of the calf area only. Fifty three patients completed the study and there were significant improvements in the mean scores of paraesthesia (abnormal sensations such as pins and needles), urinary symptoms, muscle strength and spasticity.<sup>83</sup> Reflexology has no known serious side effects. Sessions usually last 30 to 60 minutes.

● **Massage**

Massage is very popular and anecdotally very helpful for some of the musculo-skeletal symptoms of MS. It also appears to help general wellbeing. One study involved 24 patients with MS randomly assigned to either a 45-minute massage twice weekly for five weeks or to no treatment. The massage group had significantly lower anxiety and a less depressed mood by the end of the study and had significantly improved in self-esteem, body image and image of disease progression. No conclusions however, were drawn about physical symptoms.<sup>47</sup>



**Figure 6** Analgesic ladder

Source: *Palliative Care: Symptom Management & End of Life Care*, WHO 2004.<sup>92</sup>

## Musculoskeletal pain

Musculoskeletal pain is caused by a variety of MS symptoms. It can be caused by lack of mobility due to muscle weakness, spasticity, poor sitting posture and continued periods of self-propelling a wheelchair. It can be exacerbated by the loss of protective muscles due to weight loss and stiffness. Whatever its cause, this type of pain is often overlooked in neurological conditions such as MS.

### Treating musculoskeletal pain

The importance of a comprehensive multidisciplinary assessment cannot be overemphasised. Physiotherapy and mobilisation may be extremely beneficial, while simple non-pharmaceutical interventions such as heat pads, topical anti-inflammatory treatments and TENS should be considered. Complementary therapies such as acupuncture and massage can also help.

Palliative care clinicians may be able to offer a wealth of experience in terms of pain management and are well versed in the pharmacological treatment of complex pain presentations.

Although the **analgesic ladder** (Figure 6, page 17) was developed for cancer pain, a stepwise approach using a limited number of drugs is probably equally acceptable for the management of chronic pain due to other causes.

- **Step 1 Non-opioid analgesics**

Paracetamol is a good analgesic and most people experience few side effects. However the maximum dose is restricted by hepatotoxicity. It may be sufficient on its own but more often it is used in combination as part of an analgesic regime.

Non-steroidal anti-inflammatory drugs (NSAIDs) have more side effects than

paracetamol, commonly ulceration of the upper GI system with pain, bleeding, nausea and renal impairment.

- **Step 2 Weak opioid analgesics**

Weak opioids such as codeine, dihydrocodeine and DF118 are used in combination with a non-opioid analgesic such as paracetamol in the second stage of the ladder. There is a ceiling effect with weak opioids, and if regular maximum doses are unsuccessful, you need to step up the ladder, ie. switch to a stronger opioid rather than an alternative weak opioid.

When using any form of opioid, it is important to discover if the person with MS or their carer has any concerns about these drugs that need to be explored. It is also important to consider any potential side effects such as nausea and constipation.

- **Step 3 Morphine and strong opioids**

Doctors may be concerned about giving opioids to patients with chronic non-malignant pain. This is a justifiable worry if a systematic approach to selecting patients has not been adopted. In non-cancer patients under-prescribing of opioids for pain is not uncommon. A series of 124 motor neurone disease (MND) patients admitted to a hospice were compared to cancer patients admitted to the same hospice.<sup>73</sup> Pain was less prevalent in the MND patients (57% versus 69%) while insomnia (48% versus 29%) and constipation (65% versus 48%) were more prevalent. At referral only 15 patients (12%) were receiving an opioid even though 71 of them (57%) had uncontrolled pain. During their hospice stay, 109 patients received an opioid on at least one occasion. This study demonstrated the safety and efficacy of morphine in the management of pain and insomnia in a hospice population with advanced MND. It also suggests

that established principles of symptom control could be applied to all patients with neurodegenerative conditions.

In 2003 the Pain Society published its recommendations for the appropriate use of opioids in chronic non-cancer related pain. These were deemed necessary due to the significant proportion of people worldwide who would probably describe themselves as severely disabled by chronic pain. Opioids have proved effective for some people but regular assessment and evaluation is needed. Interestingly, while there have been some high profile legal cases debating the appropriateness of opioid prescription for chronic pain, there have also been cases where patients have taken legal action against health care professionals because of inadequate analgesia.<sup>74</sup>

## SPASM & SPASTICITY

The true nature of spasticity is still not clearly understood but one of the most succinct definitions is that it is: 'the velocity dependent increase in resistance of a passively stretched muscle'.

This resistance to passive movement is caused by:

- abnormalities in the control of movement generated by the CNS
- biomechanical changes in the muscle and connective tissue possibly leading to contractures

In a recent survey of people with MS, 64% reported stiffness and 51% muscle spasm. Furthermore, 17% of those with stiffness and 14% of those with muscle spasm felt these symptoms caused them the most difficulty and distress on a daily basis.<sup>65</sup>

## Management and treatment of spasticity

The main principles of spasticity management include prevention of aggravating factors and effective multidisciplinary assessment.<sup>50</sup>

### ● Prevention of aggravating factors (noxious stimuli)

**EXTERNAL:** pressure sores, skin irritation, in-growing toenails, tight fitting orthosis, blisters

**INTERNAL:** incomplete bladder emptying, constipation, faecal impaction, urinary infection, pain

**PSYCHOSOCIAL:** stress, anxiety, bereavement

**ENVIRONMENTAL:** inappropriate wheelchair seating, poor posture, warmth

### ● Multidisciplinary assessment

This is essential to prevent or minimise aggravating factors and optimise an individual's environment. Opportunities for multidisciplinary working and team meeting are also vital for effective communication and spasticity management plans.<sup>50</sup>

**NURSES** can provide detailed assessment of skin care, bladder and bowel regimes.

**PHYSIOTHERAPISTS** may provide a stretching or standing programme; advising on posture and positioning throughout the day.

**OCCUPATIONAL THERAPISTS** play a key role in environmental and seating assessment.

### ● Oral medication

The majority of people with advanced MS will have tried anti-spasticity medication at some point. Those presenting with spasticity problems have invariably found the drugs unhelpful and may be searching for alternatives. A detailed

history is useful to tease out the circumstances around previous treatment attempts. The individual may not have had access to a comprehensive spasticity plan from a multidisciplinary team. Care must be taken in treating spasticity in a person who is still able to weightbear and therefore carry out activities like transferring. The extensor spasm in their lower limbs may be the reason they can still carry out such activities because the rigidity compensates for their loss of strength. Using antispasticity drugs at this time may make them feel 'floppy' and cause a loss of mobility, which could leave them with negative feelings about the medication. Should they become a wheelchair user, dependent on a hoist, a previous negative experience may prevent them from re-considering antispasticity drugs. Doses can be started low and titrated to give a feeling of control over possible side effects.

**BACLOFEN** is the most commonly used antispasticity drug. To counter side effects the dosage should be low and increased slowly, stopping at a dose that does not cause too many side effects. It works best if taken regularly. Extra doses may be needed, for example during exacerbation of urine infections that may cause a temporary increase in spasticity, but this should be reviewed once the underlying infection has been treated. Many people find an extra dose can be effective before sex if increased tone in adductor muscles is a problem; however they need to be cautioned that an unwanted side effect is drowsiness!

If baclofen or gabapentin do not manage the pain associated with spasticity, NICE recommends using Tizanidine, diazepam or dantrolene.<sup>70</sup>

**CANNABIS** A recent multi-centre trial demonstrated that although people with spasticity reported improved spasticity, pain and bladder function, their

experiences did not correlate with the outcome measures chosen for this study. It still cannot be prescribed.<sup>7</sup>

## OTHER TREATMENTS

- **Botulinum toxin injection**

This is used where there is focal spasticity. The botulinum is injected directly into the muscles and acts as a neuromuscular block causing paralysis in the targeted muscle. It can take 10 to 14 days to take full effect. It needs to be used in conjunction with a stretching programme and physiotherapy input to be fully effective and to see a change in the muscle once the toxin has worn off.

- **Intrathecal baclofen pumps**

For severe lower limb spasticity, a small pump is inserted into the abdomen and filled with baclofen. It has a small catheter that transmits the baclofen around to the intrathecal space of the spinal cord. Delivering baclofen locally into the intrathecal space allows small doses to be used, which accentuates its antispasticity property and minimises troublesome systemic side effects. This intervention requires commitment to a number of in-patient stays within a regional neurological centre for trial of the drug and implantation of the device as well as future pump replacements. Many patients may also have to attend the centre for regular refilling of the pump reservoir with baclofen. Some local MS or rehabilitation services now offer a local pump refilling service.

- **Phenol blocks**

Phenol is injected into the intrathecal space to chemically sever the nerve impulses to the lower limbs. Once thought to be a permanent procedure, it is now known that repeat procedures may be necessary. Although every care is taken (by careful positioning of the patient) to select only motor nerve cells,

## CASE STUDY

Six years ago, 35-year-old CB was diagnosed with primary progressive MS. While still mobile she fell and broke her hip. Although it had been pinned, she developed osteomyelitis in the joint, which caused pain and discomfort. Her hip dislocated on two further occasions, once due to severe lower limb spasm. CB is now bed-bound, suffers much pain on movement and has developed two grade four pressure sores that require daily dressing. She is dehydrated, nauseous and in some degree of renal failure but she is well supported by a dedicated community nursing team and a devoted family.

A palliative care consultant who assessed her needs diagnosed the immediate problem as pain, which caused her discomfort and an inability to maintain personal hygiene. As an interim measure Actiq (fentanyl) lozenges on a stick were prescribed: the preparation is rolled around the mouth to allow absorption of the fentanyl through the oral mucosa. Manufacturer's studies suggest it takes between three to 15 minutes to be absorbed (mean eight minutes). This proved sufficiently effective for CB to access the pain clinic at her local hospital.

In the meantime, CB was seen by a physiotherapist from a local community rehabilitation team. While she was unable to tolerate any passive limb movement, the physiotherapist was able to advise on better positioning and provide a TENS, which, with the fentanyl lozenge, provided short-term background relief.

At the pain clinic various treatments were discussed, including nerve blocks and

intrathecal local analgesia. A trial of local analgesic was given but was fraught with procedural problems and gave only partial relief. A phenol block to chemically sever the sensory nerves serving the hip and lower limbs, which could be performed at a local hospice, was discussed. (The complexity of CB's disease suggested that she would benefit from the psychosocial as well as clinical expertise available at the hospice rather than at an acute hospital.) Unfortunately these plans were superseded by an acute episode of renal failure, which meant an acute admission to a renal unit. On discharge from the unit, CB decided not to go ahead with the planned phenol block. She was concerned about the irreversible nature of the procedure and felt that her pain could be controlled with her existing pain relief interventions if they were used before purposeful movement and intervention. The teams have also introduced topical analgesia into her dressing and entonox administration for dressing changes.

CB continued to have ongoing support of the local specialist palliative care team and regular reviews from their consultant. She was able to talk about her fears for the future and concerns for her family. The palliative care team has also engaged with her family, offering support to her two teenage sons who are now linked into a young carers' group. This has eased CB's concerns for them and her feelings that she has become a burden on her family.

CB now has the option of inpatient care at the hospice for symptom control and respite care whenever she needs it.

this cannot be guaranteed and sensory nerves are usually affected as well. This obviously has a huge effect on sexual function and bladder and bowel management. Careful patient selection and information is vital. Effective bladder and bowel regimes need to be in place already, and the spasm needs to be severe and otherwise untreatable.<sup>51</sup>

- **What can palliative care offer?**

Palliative care is characterised by the systematic and meticulous monitoring of symptoms and their pharmacological management. A holistic palliative care assessment also identifies spiritual, social and psychological distress that may exacerbate the experience of many MS symptoms such as pain.

## **BOWEL MANAGEMENT**

Bowel management in advanced MS has received scarce attention yet remains intrinsically important to comfort and quality of life. Bowel problems are a common source of distress. Toilet habits remain one of society's taboo subjects, and such problems are massively under-reported and neglected.

### **Prevalence**

Seventy per cent of people with MS experience constipation or faecal incontinence, which frequently co-exist. A study by Sullivan and Ebers reported that 53% of people with MS suffered constipation,<sup>87</sup> while another study suggests that 53% suffered faecal incontinence.<sup>65</sup> Bowel control is complex, involving the co-ordination of many different nerves and muscles. Overall bowel and bladder control has been linked to lower limb dysfunction. The following factors may contribute to the problem:

- **LOSS OF NEUROLOGICAL CONTROL**  
To control bowel actions, it is necessary to be aware of the 'call to stool'. This occurs as the faeces moves into the rectum, causing it to expand and send messages via the sensory nerve pathways of the need to pass the stool. It is important to be able to distinguish whether the rectum now contains liquid, gas or solid, as we may need to take different actions depending on the stool type. In MS, there is often loss or distortion of these signals leading to the loss or reduction of rectal sensation altogether.
- **PREVIOUS MEDICAL HISTORY** such as anal sphincter damage during childbirth: this occurs in 80% of mothers having forceps-assisted delivery.<sup>65</sup>
- **REDUCED MOBILITY** appetite and ability to 'bear down'.
- **CONCURRENT MEDICATIONS**
- **LACK OF TIME AND PRIVACY DURING 'TOILETING TIME'** There is a huge psychological component to the performance of any of our private bodily functions. For many people with advanced disability, their reliance on others to 'toilet them' at a specified time is a huge barrier to being able to perform. Similarly, carers often stay in the bathroom while the person with MS is trying to use the toilet. Many of us would have extreme difficulty evacuating on demand, to tight time constraints and often with an audience.
- **WESTERN DIET** It is estimated that 2% to 20% of people experience constipation without the added complication of neurological damage.
- **A DEFINITION OF WHAT IS NORMAL**  
Tradition and culture play a huge part in determining people's expectations of what is normal. Many older people have a strong belief that bowels must be opened at least once a day, and the use



of laxatives to enable this is common. In fact bowel habits vary greatly from two or three times daily to twice weekly or less.<sup>77</sup>

The NICE Guideline on the management of MS identifies bowel problems and makes four key recommendations:

- 1 each professional in contact with a person with MS should consider whether they have any problems with bowel function
- 2 anyone who appears to be constipated should be offered advice on changes that would help
- 3 anyone with faecal incontinence should be assessed for constipation with overflow
- 4 routine suppositories or laxatives should be considered if difficulties are ongoing<sup>70</sup>

### **Bowel management and advanced MS**

For people at an advanced stage of MS, bowel management options may be limited. Bowel difficulties are likely to have been a problem for some time, with the involvement of the district nursing and continence advisory service.

The NICE guidelines recommend that patients are advised to increase fibre and fluid intake as well as the level of physical exercise.<sup>70</sup> While this advice is important, it may be compromised by the individual's level of disability and personal preferences. Someone with swallowing difficulties who chooses not to have a PEG feeding tube may find increasing fluid intake tiring and problematic. Conversely, having a loaded bowel will cause general discomfort and possible exacerbation of spasticity, which can be painful and troublesome to the wheelchair user. The inter-relationship of symptoms on an individual's general wellbeing and quality of life should not be underestimated.

### ● **Bowel assessment**

Detailed re-assessment is of paramount importance and a number of assessment tools and pathways are in use.<sup>65, 30</sup> An assessment of stool consistency, of which the Bristol Stool Form Scale is probably most widely used, and a bowel diary can help establish whether constipation or incontinence is a problem.<sup>46</sup>

### ● **Diet**

Diet is clearly an important factor in bowel management. Any assessment should be individualised and consider dietary changes as well as the need to increase or decrease fibre and fluid intake. Fluid intake is dependent on weight: as a rough guide a person weighing 9 stone (57kg) requires 3 pints (1.7 litres) of fluid a day, while someone weighing 13 stone (82.5kg) requires 4.5 pints (2.5 litres) a day.<sup>1</sup> Similarly if the appetite is poor it may be unrealistic to expect a significant daily bowel action.

### ● **Concurrent medication**

Many medications can have an impact on bowel management. Anticholinergics, used to decrease over-activity of the bladder, and antidepressants are commonly prescribed to people with MS. Both are associated with constipation.

### ● **Laxatives**

The management of constipation extends well beyond the use of laxatives. The aim of laxative therapy is to achieve comfortable defaecation rather than frequency of evacuation. Although most laxatives are not very palatable, oral laxatives should be used whenever possible. Bulking agents should be avoided but the use of a stool softening aperient is important. Movicol is preferable to lactulose as it does not cause the same degree of flatulence and bloating. Stimulants such as senna or sodium docusate may be required.

**EVACUATION DIFFICULTIES** The gastro-colic reflex is the normal urge to open your bowels after eating, especially 30 minutes or so after breakfast or hot liquids. Most people who rely on paid morning carers attempt to open their bowels without eating or drinking first. The problem may be compounded by lack of privacy and fear of being under a time constraint. Subtle improvements to a care regime, however, could include having a warm drink or some breakfast before getting up. Of course an individual risk-assessment would be necessary to ensure safe swallowing when reclined in bed, but it would also provide an opportunity to take any pain relief or antispasmodic medication that might make hoist transfers more comfortable.

Assisted manual evacuation, involving perineal support, digital stimulation and manual evacuation, is suitable for a small number of people with MS. It is indicated for faecal impaction, incomplete defaecation, inability to defaecate, and neurogenic bowel dysfunction. The RCN<sup>80</sup> and the National Patient Safety Agency<sup>68</sup> have published guidance on risk assessment and procedure.

**STOMA FORMATION** For some people, stoma formation may be a means of maintaining independence, privacy and dignity. While this extreme intervention needs careful and informed consideration, it should not be dismissed out of hand. Requests for consideration of a stoma are often ignored or even refused before specialist opinion has been sought.

**FAECAL INCONTINENCE** The Department of Health publication *Good Practice in Continence Services* estimates the prevalence of faecal incontinence as 1% of adults living at home, with 17% of the very elderly reporting symptoms.<sup>30</sup> Neurological dysfunction affects the mechanism involved in normal

continence. MS can cause problems with this neurological integrity and the sensation required to maintain continence.<sup>23</sup> As part of any assessment, it is important to consider whether there is overuse of laxatives, or constipation with faecal impaction and resultant overflow. Overflow accounts for half the cases of diarrhoea and such patients require rectal laxatives together with a stool softener.<sup>42</sup> Care is required with stimulant laxatives as they may cause colic.

Consideration should be given to the underlying cause but, with the exception of the scenarios above, symptomatic relief is generally achieved with non-specific antidiarrhoeal agents such as loperamide (up to 16mg daily) or codeine (10 to 60mg every 4 hours). Codeine may cause drowsiness or sedation but this is rare with loperamide.

- **Containment advice and products**

The containment of incontinence can improve home care and there are many products available. Medication, pads and anal plugs may be available on prescription through the district or continence nursing service. Non-prescription items such as bed protection and commodes can be bought privately or loaned through an equipment loan store.

## **NUTRITIONAL SUPPORT**

***Before you can blink a PEG is inserted and there hasn't been a lot of discussion around the long-term implications***

*Health Care Professional, MS/Palliative Care Project, King's College, London*

Many people with advanced MS develop some degree of dysphagia. This is often compounded by the presence of excessive saliva, weight loss, fatigue and loss of appetite. It is important that the patient has

regular assessments by a multi-professional team involving speech therapists, dietetic specialists and occupational therapists. There is also a role for palliative care specialists.

The goal is to maintain nutrition by an oral route for as long as possible. This period may be extended by appropriate eating aids, achieving better head positioning through use of collars and head supports, as well oral food supplements. The decision to have a gastrostomy tube inserted does not necessarily herald the end of oral feeding. It can form an important part of future planning and take some of the pressure off arduous and fatiguing mealtimes. A gastrostomy tube can then be used to supplement hydration and nutrition when necessary. However it is important to be aware of the optimal timing for placement of a feeding tube.

If a patient becomes too emaciated and weak they are less able to withstand the gastrostomy procedure and may have to undergo the insertion of a nasogastric tube or no feeding at all. Not only does this deny an individual choice, it can also cause ethical dilemmas. If a patient has entered a terminal phase of their illness it may be obvious that to proceed with artificial hydration and nutrition is inappropriate but it is a more difficult decision for those with only a limited prognosis.

As well as the individual's ability to undergo a placement procedure, there are practical issues about the community and carer support that may or may not be available. Of paramount importance is whether the benefits of starting feeding outweigh the likelihood of complications during the procedure, or post-procedure infection, regurgitation or aspiration. Indeed, the patient may not always see prolongation of the prognosis as a good thing. Advance planning and discussion, with or without writing a formal advance directive, ensure that the patient's wishes are known.

Any decision is made in their best interests, taking into account their own assessment of their quality of life, wellbeing and spiritual or religious beliefs. This is a highly individual set of considerations for which a specialist in palliative care has appropriate experience to facilitate.

## CAPACITY & CONSENT

***This person I care for, is not the wife I knew.** Carer of person with advanced MS, MS/Palliative Care Project, King's College, London*

## COGNITION

Up to 65% of people with MS have some cognitive impairment and 5% to 10% suffer global cognitive impairment. Contrary to previous belief, a recent longitudinal study by Amato in 2001 has found a significant relationship between severity of cognitive impairment and duration of MS.<sup>5</sup> Cognitive impairment places an enormous strain on carers, most usually the spouse, who has to adapt to new roles and sometimes also to profound personality changes in their partner.<sup>20</sup> The implication of these findings is that choices need to be discussed much earlier in the disease trajectory so that there can be no challenge to a patient's capacity in making these choices and everyone is clear about their wishes.

The incidence of depression is also greater in advanced MS. This is due to organic brain changes that are part of the disease itself as well as reactive depression, caused by the challenges and demands of disability. Bipolar disorder is increased twofold and treatment of relapses with steroids not infrequently unsteadies the mood. Suicide rates are more than seven times higher than the 'normal' population.<sup>81</sup> Emotional lability can affect 10% to 25% of people but may be contained by taking low dose SSRI (such as Ciprimil).

## Competency

Cognitive impairment or changes in the mental health of people with advanced MS may lead health care professionals to be concerned about their ability to make sound decisions. Formal testing of cognitive impairment is generally carried out by a neuropsychologist but depends on the setup of the local service. An assessment is likely to involve:

- psychometric testing
- IQ
- memory

## CAPACITY

Capacity is a legal term and part of the three-point test for consent. Any health care intervention requires consent and this can be given as implied or explicit consent. A patient visiting their GP who proffers their arm to have their blood pressure checked is giving implied consent. Consent for surgery tends to be in a formal written and explicit format.

For consent to be valid, an individual must:

- have mental capacity
- be informed
- be free from coercion

## Mental capacity

Unless there are concerns or evidence to the contrary, the law assumes that a person has mental capacity. There are three stages in determining whether someone has it:

- 1 Can they comprehend and retain the necessary information? This is obviously important in any disease that causes memory impairment or intermittent competence such as Alzheimer's disease.
- 2 Can they believe in it (within their own belief structure)?
- 3 Can they weigh up the information, balancing the risks and arrive at a choice? This last stage requires cognitive abilities to make a decision on the basis of the information presented.

## CASE STUDY

*Doctors advised patient C, who had chronic paranoid schizophrenia, that he had gangrene in his foot. C suffered delusions of grandeur, believing he had a successful medical practice himself. Vascular surgeons believed he would die unless he had a below-knee amputation. His chances of survival were assessed as no better than 15% if he had conservative treatment only. C stated that he would prefer to die rather than lose his leg. He refused to give his consent*

*and sought an injunction from the High Court to stop the amputation going ahead. The judge applied the three-point test to C and decided he did have the mental capacity to refuse the amputation. This case shows that a person can suffer from a specific form of mental disorder yet still have the requisite mental capacity to give or refuse consent.*

(Re C 1984 1 WLR 290, legal case quoted Kennedy & Grubb)<sup>55</sup>

The capacity must relate to the decision being made. There are obviously different levels of decision making, from deciding what to wear to whether to donate a kidney. Some people suffering from learning difficulties, for example, may be able to make sound decisions on day-to-day matters but unable to make more critical decisions.

### **Irrational decision making**

Disagreeing with an individual's decision or believing they are making a decision which is against their best interests is not a determinant of mental capacity.

### **Be informed**

Information should be given to individual patients in an appropriate medium and language. Health professionals have a:

*...duty to inform patients according to the reasonable standards recognised by accepted practice.<sup>34</sup>*

Patients must also be informed of significant risks that are likely to cause substantial harm. The courts have not defined when a risk is 'significant' and they have been reluctant to rely on percentages, such as patients needing to know about all risks higher than 10%. However it is clear that even a small risk that could be devastating, such as a 1% risk of paralysis, will be of more concern than a 50% chance of bruising. Risks that have special significance for a particular individual also need to be given, for instance a violinist may be more concerned than anyone else about a 25% risk of losing sensation in their fingers. Of course this cannot be assumed, and highlights the importance of impeccable assessment and communication skills.

### **Be free from coercion**

Consent needs to be given with free will and without deception. A Department of Health guide to good practice in consent implementation warns against patients being pressurised by parents and family members or health and care professionals who might unknowingly exert pressure through a sense of duty or awareness of resource constraints.<sup>29</sup>

### **Lasting power of attorney**

'Lasting power of attorney' was created by the new Mental Capacity Act in 2005. This allows someone to legally appoint a person to take decisions on their behalf if they subsequently lose the capacity to do so themselves. The Act, which comes into force in April 2007, extends the current 'enduring power of attorney' to cover decisions about personal welfare, including health care and consent to medical treatment, in addition to decisions about property and financial affairs.

An attorney can be given general authority to make decisions or authority over specific decisions such as refusing artificial feeding, hydration and other life sustaining treatments. Attorneys can only refuse life sustaining treatment if there is a clear statement to this effect in the legal document that gives them power of attorney. Anyone can be appointed as an attorney, they do not have to be a lawyer. They can be family members or friends, and there can be more than one attorney. In Scotland a separate Adults with Incapacity Act 2000 applies, but the provisions are similar.

## ADVANCE PLANNING

Everybody should have the right to make choices yet some people with advanced MS are denied this. It may be because a discussion about their future wishes has never been initiated or because speech difficulties, caused by weakness of the muscles or fatigue, have become a barrier to communication. Palliative care specialists may be able to support or facilitate discussions about advance directives, future management and place of care.

## ADVANCE DIRECTIVES & LIVING WILLS

*It is a basic principle of law on consent that a mentally competent adult can refuse treatment for a good reason, a bad reason or for no reason at all.*

*Re MB 1997 2 FLR 426, legal case quoted in Dimond 2004, page 986<sup>36</sup>*

A mentally competent adult can express their wishes about their medical care to guide doctors should they lose the mental capacity to make decisions or the ability to communicate them. These earlier declared views are known variously as a **living will**, an **advance directive** or an **advance refusal of treatment**. An important point to note is that these constitute statements about refusals not requests for possible treatments.

Law in the UK is made by statute (parliament) or derives from decided cases (judge-made or case law). Cases such as Airedale NHS Trust vs. Bland 1993 have established the legality of advance directives. In the case of Mr Bland, a victim of the Hillsborough disaster who was in a persistent vegetative state, the House of Lords decided his artificial feeding could be discontinued in his best interests. They said if he had set out an advance directive, that directive would have been binding upon the health professionals caring for him.<sup>36</sup>

A typical example of an advance directive is the card carried by Jehovah's Witnesses. This states the treatments or care that is being refused, and is signed by the person refusing the treatment and a witness.

In Canada an unconscious Jehovah's Witness who was given a life-saving blood transfusion, despite the fact that she was carrying a card, won compensation against her doctor (Malette vs. Shulman 1990). The doctor was deemed to be guilty of battery in treating her against her express instructions. The House of Lords in the Tony Bland case referred to this Canadian one, saying: '...respect must be given to the patient's wishes where the patient's refusal to give his consent has been expressed at an earlier date, before he has become unconscious or otherwise incapable of communicating it.'<sup>36</sup>

## How should they be drawn up?

Living wills and advance directives are subject to the same three-point test required for determining consent.

- 1 The individual must be over 18 and have mental capacity at the time they express their advance refusal
- 2 They need to be informed, and should understand the nature and consequences of what they are refusing
- 3 They need to be free from coercion

At present there are no statutory provisions governing the validity of a living will. This means judges still have the discretion to decide whether decisions are valid or not. However the BMA Code of Practice on advance statements says:

*An unambiguous and informed advance refusal is as valid as a contemporaneous decision. Health professionals are bound to comply when the refusal specifically addresses the situation which has arisen.*<sup>14</sup>

The difficulty is that a circumstance may arise that the living will has not foreseen. A person with MS, for example, may decide to refuse ventilation and artificial feeding should their disease progress and they are unable to communicate their wishes. However if they sustain a severe head injury in a traffic accident and require ventilation there would be concerns about operating their advance statement and withholding ventilatory support. Clearly, these circumstances do not meet the situation that the individual had envisaged when drafting their living will. If there is uncertainty about the validity of an advance directive, a declaration should be sought through the courts and, in the meantime, the patient given all necessary support.

The BMA suggests the minimum data that should be contained in a living will:

- 1 full name
- 2 address
- 3 name and address of GP
- 4 whether advice sought from health care professionals
- 5 signature
- 6 date drafted and reviewed
- 7 signature of witness
- 8 clear statement of the person's wishes, either general or specific
- 9 name, address and telephone number of any nominated person, if there is one

## CASE STUDY

*AB, a 36-year-old woman with secondary progressive MS, lived at home with her partner who was her main carer. She had three school-age children fostered and awaiting a court ruling. She had become bed bound and was not eating or drinking. She showed a high level of personal neglect and had begun to refuse the help of paid carers. She would not engage with rehabilitation professionals but had a good relationship with her social worker. She was adamant that she wanted to remain at home despite her environment and personal care needs.*

*A palliative care consultant offered a joint home visit with her social worker. AB was anxious that she would not be allowed to remain at home in the long term. A short-term hospital admission was negotiated with the express aim of achieving better symptom management and an assessment of her mental capacity.*

*AB demonstrated that she was fully competent in her decision to remain at home. She understood the risks and could weigh up the pros and cons. She was also aware she would not always get the care she needed from her partner.*

*Confident that she would not be 'taken away' she now allowed paid carers into her home to deliver a minimal care package. She was adamant that she wanted conservative future treatment to minimise hospital admission and engaged with the local specialist palliative care services. They were able to provide a period of respite care and, as a result, she elected to have future infective episodes treated at the local hospice. AB died during her second admission to the hospice from overwhelming sepsis. Her partner and children continued to receive support through the hospice's bereavement counselling services.*

An advance directive does not have to conform to any particular form or be drawn up by a lawyer to make it legal.

Consultation with a doctor is not essential but may be useful to explore treatment options and demonstrate that an informed decision-making process has occurred. However, it should be in writing because casual remarks about health care cannot be used as the basis of an advance directive, and it needs to be reviewed regularly.<sup>14</sup> It only comes into force when a patient is unable to make or communicate a decision; it offers guidance only and should not be a barrier to communicating directly with the person about their contemporaneous wishes, which may have changed or no longer concur with their advance directive.

## Relatives

In the UK the views of relatives can be taken into account, but they have no legal right to decide treatment.<sup>14</sup> In the case of an adult who lacks mental capacity refusing medical treatment, Lord Donaldson cautioned against relying on the wishes of relatives:

*'There seems to be a view in the medical profession that in...emergency circumstances the next of kin should be asked to consent on behalf of the patient and that, if possible, treatment should be postponed until that consent has been obtained. This is a misconception because the next of kin has no legal right either to consent or to refuse treatment.'* (1992 4 All ER 649)<sup>37</sup>

## CASE STUDY

*DF was a 63-year-old woman with very advanced secondary progressive MS who had lost the use of her arms and legs. Although she was no longer able to communicate verbally, she used mouth-controlled assistive technology very effectively. She still managed an oral diet, although her swallow was poor and she was at repeated risk of aspiration.*

*Consequently, she developed a chest infection and was admitted to an acute hospital to be treated with intravenous antibiotics. However DF's condition continued to deteriorate, necessitating ventilatory support to survive. She was referred to specialist palliative care by nursing staff who were concerned that ventilatory support was not in her best interests, given her level of disability.*

*DF was fatigued and breathless at the time of her palliative care assessment,*

*and unable to communicate her wishes effectively. However, in a recent full and frank discussion with her husband she had expressed her firm desire to consent to all life-prolonging measures. She considered herself to have a good quality of life and wished to 'be around to boss him for a little longer'.*

*DF was ventilated and made a good recovery. She continued to suffer recurrent chest infection and on her third admission decided to have more conservative treatment of antibiotic therapy instead. On her next admission she took up the offer to move to the hospice where time was taken to discuss her end of life issues. During a subsequent chest infection she died peacefully at the hospice, despite the use of antibiotics to palliate its symptoms.*



## Advance directives, living wills, euthanasia and assisted suicide

Advance directives and living wills are often confused with debates about euthanasia and assisted suicide. This is partly because the Voluntary Euthanasia Society was one of the first to launch a living will pro-forma. Advance directives allow people to take some control over end of life decisions, which may involve life-prolonging treatment. They do not permit illegal actions and are not concerned with taking measures to end a person's life. At present euthanasia and assisted suicide are illegal under British Law.

## ADVANCE PLANNING & MS

Living wills and advance directives have the advantage of promoting discussion and sending a clear message that difficult subjects can be broached. There are a number of interventions that may become appropriate for people with advanced and severe MS such as supra-pubic catheterisation and PEG feeding, which are often offered too late to allow time for explanation or to improve quality of life.

Conversely, when a team approach to offering information, open discussion and demonstration of any equipment has resulted in a refusal to consent to any intervention, those wishes should be respected. Morally and ethically it can be difficult to support a decision that you know will deny the patient a better quality of life, but the team approach gives you the support of your peers.

## Ventilation

The need to discuss ventilation becomes apparent for the individual with swallowing difficulties, who suffers from the respiratory risks of aspiration. This is often marked by chest infection increasing in frequency, if not severity as well. Any discussion requires

an explanation about the risks of chest infection and possible treatment options. It is possible to have a tiered approach to treatment, considering at what point the individual would like to stop active intervention at each episode. The question is to treat or not to treat, and individuals may wish to consider their views on:

- intravenous antibiotics and chest physiotherapy
- tracheostomy
- artificial ventilation

Edmonds suggested that the complex needs of people severely affected by MS are not always adequately met in an acute hospital setting.<sup>39</sup> Although the MS/Palliative Care Project was a small-scale study, sub-optimal hospital conditions were a strong concern of people affected by MS in south-east London. While this cannot be extrapolated into a widespread experience, it does beg the question whether treatment can be provided in alternate settings and places of care. For those with comprehensive care packages, oral antibiotic therapy may be given at home, and district nurses could attend those with PEG feeding tubes and administer antibiotics using this route. Alternatively, hospice admission for intravenous antibiotics could be considered for those who have had specialist palliative care input.

There is a range of alternatives that can increase the choices offered to patients although they will depend on local resources and services.

## Cardio-pulmonary resuscitation

*A patient has a right to be resuscitated if the procedure is reasonably likely to be successful and if s/he has a reasonably good prognosis following resuscitation.*<sup>36</sup>

This right is enshrined under Article 2 of the Human Rights Act: 'Everyone's right to life

shall be protected by law. No one shall be deprived of life intentionally...<sup>36</sup> and by the duty of care owed by the medical and nursing staff to their patients.

Guidance drawn up by the BMA, RCN and Resuscitation Council, and commended to NHS Trusts emphasises that each individual patient must be assessed personally for their wishes on resuscitation.<sup>15</sup> There can be no blanket policies and no discrimination on the grounds of age or perceived quality of life. Resuscitation decision-making processes have come under scrutiny from The Commission of Health Audit and Improvement (CHAI), and have to be

monitored and auditable.<sup>37</sup> The tangible result for the patient is that they are likely to be asked about their views on resuscitation by complete strangers within hours of being hospitalised, probably at a time of heightened stress, vulnerability and exacerbation of their MS.

Views on resuscitation are better initiated in advance of any hospital admission by carers, key workers or health professionals who are familiar with the patient. This information needs to be documented and shared with the wider caring team.

Symptom	MS <sup>(1)</sup>	Cancer <sup>(2)</sup>	Heart disease <sup>(2)</sup>	Respiratory disease
Pain	68%	35-96%	41-77%	34-77%
Fatigue	80%	32-90%	69-82%	68-80%
Nausea	26%	6-68%	17-48%	not known
Constipation	47%	23-65%	38-42%	27-44%
Breathlessness	26%	10-70%	60-88%	90-95%

<sup>(1)</sup> King's College London MS/Palliative Care Project  
<sup>(2)</sup> Solano, Gomes, Higginson, *Journal of Pain and Symptom Management* 2006, 31, pages 58-69

**Figure 7** Cause of death

## END OF LIFE CARE

*I want to find out if it [MS] can kill you [laughs]...I want to know if you're going to die from it. You know, that's the main thing that's been on my mind since I've been told.* Person with advanced MS King's College London MS/Palliative Care Project

### Die with or of MS?

Sadovnick, Eisen, Ebers and Paty found that in about 50% of patients with advanced MS, cause of death is related to complications of chronic disease, usually sepsis and fatigue caused by overwhelming infection.<sup>82</sup> Overall, causes of death are similar to the rest of the population: heart attacks (11%), tumours (16%) and stroke (5%). The increased risk of suicide has already been discussed.

Symptoms in the last few days of life are common to many disease areas, and derive from similar underlying physiology, namely breathlessness, nausea, confusion, insomnia, pain and overwhelming fatigue (see Figure 7). This means that robust expertise can be applied across the board to provide comfort in the last few days of life.

While discomfort and pain related to spasticity is a central feature throughout the course of MS, most people will be opioid-naïve compared with their cancer counterparts. Slow-release analgesic preparations may be useful, particularly delivered topically through patches or subcutaneously using a syringe driver.

Nausea is generally due to a catabolic state. Individuals may be uraemic and becoming septic. An appropriate anti-emetic should be given via an appropriate route. Fluid intake is likely to be poor and

subcutaneous fluids can also be given at home to minimise unwanted hospital admission.

Excessive saliva is a major challenge in caring for a person with MND but it can also be evident in advanced MS. Medication needs to be started early in order to gain control of symptoms. Unlike other treatments, glycopyrronium rarely causes sedation or delirium because it penetrates biological membranes slowly and erratically. It can be given orally or via a syringe driver or PEG. Dosages of 200 to 400 microgram tds given orally or via a gastrostomy tube can dry secretions effectively for up to eight hours.<sup>10</sup>

### Spirituality

Spirituality is difficult to define, precisely because it encompasses the immeasurable and often unspoken aspects of humanity. Spiritual needs are not necessarily the same as religious needs, and people who would not define themselves as religious may still have spiritual needs. Health professionals should not assume that spiritual care is the province of religious leaders. While this can be true for some, it might ignore the needs of others with no religious affiliation. Identifying and meeting all of an individual's needs are at the core of providing spiritual care. Including spiritual care in every aspect of care, providing opportunities for talking and listening, and identifying other routes such as music that are meaningful and helpful to the individual, are all potential aspects of good spiritual care.

There is some preliminary evidence that religious and spiritual belief can affect the way patients and their relatives cope with bereavement.

## A 'GOOD DEATH'

According to the National Council of Palliative Care, 56% of the population would prefer to die at home but only 20% manage to achieve this. In contrast, only 11% of the population would choose to die in hospital, as opposed to 54% who actually do.<sup>67</sup> The Department of Health paper, *Building on the Best: Choice, Responsiveness and Equity in the NHS*, supports people's right to choose where they want to die.<sup>26</sup> There is evidence to suggest that palliative care for people with neurodegenerative conditions can be provided effectively in a home environment if a co-ordinated team approach is adopted (NSF 2005 page 52).<sup>32</sup> Current information suggests that the numbers of people able to die at home is low and decreasing. Communication difficulties can be a barrier to people being able to express their choice in this matter.

The concept of a 'good death' has developed as an important feature of modern palliative care, although what constitutes a good death and whether it is possible or desirable is still open to debate. There appears to be consensus related to pain control, dignity, privacy, choice of the location of death, and support for spiritual and emotional needs, but the extent to which people should be able to control their death and dying introduces wider ethical questions.

The House of Commons Health Committee enquiry into palliative care suggested that:

*'it is only by removing the taboo of the discussion of death, throughout all stages of life, that a better understanding of the realities of dying and death, better communication skills and ultimately better service provision will be delivered.'*<sup>48</sup>

## NHS end of life initiatives

It is important that people with MS benefit from the innovations being implemented as part of the Department of Health's NHS End of Life Care Initiative.<sup>27</sup> To improve care for people coming to the end of their lives regardless of diagnosis, £12 million has been committed over three years. The investment will specifically aim to support:

- the Macmillan Gold Standards Framework (GSF) developed for GPs, primary care teams and care homes
- the Liverpool Care Pathway for the Dying, for dealing with the last 72 hours of life in hospital, primary care settings and care homes
- the Preferred Place of Care tools, which empower people to choose where they would prefer to die

While initially developed for use with cancer patients, these tools are being adapted to meet the needs of all patients requiring end of life care.

## Teamwork

The NICE guidelines on palliative care emphasise the importance of co-ordinated planning and care between all agencies.<sup>71</sup> This is reiterated in Requirement 9 of the National Service Framework for Long-term Conditions, which states:

*Professionals working within neurology, rehabilitation and palliative care need to work closely with primary care staff and care providers, including non-NHS care staff (social care, domiciliary and home care staff), combining their expertise to support people in the advanced stages of long-term neurological conditions.*<sup>32</sup>

It is evident that the care of people with MS requires input from a range of professional disciplines in the community, hospital and, possibly, hospice settings. The overall objective is to ensure that people achieve and maintain an optimal level of symptom

control and functional status at all stages of their illness. Care will inevitably involve considerable explanation, reassurance and support.

### How can good teamwork be achieved?

The NSF will not be fully implemented until 2015, so access to specialist palliative care can be inconsistent in different areas of the UK. Despite this, government and specialist palliative care providers are committed to offering services to those who need them.

### Examples of good practice

The good examples of teamwork below illustrate innovation and burgeoning services that are being established nationwide.

- The NSF for Long-term Conditions suggests specialist palliative care teams working alongside specialist neurology and neuro-rehabilitation teams (eg. in joint clinics) could promote more consistent shared practice<sup>32</sup>
  - St Richards Hospice in Worcester has recently appointed a nurse specialist whose remit is to develop specialist palliative care services for people with non-malignant conditions. The hospice itself has received an increase in the number of referrals for day hospice care, especially from those with MS. The post-holder hopes to develop the service to provide homecare support in the community. There is strong commitment to developing collaborative working practices with local neurology teams and the MS nurse specialist. The post has been funded 50% by the hospice and 50% by the MS Society for the next three years.
  - The University Hospital North Staffordshire MS nurses, working in collaboration with their local palliative day-care team at the Douglas McMillan Hospice, offer a palliative day-care

service for people with advanced MS. Two groups of 18 people meet on alternate weeks. The aim of joint working was to improve identification, assessment and treatment of physical, social and psychosocial complex problems. The day-care programme includes various complementary therapies, art therapy, networking, support and socialisation as well as spiritual care and respite for carers. While the many benefits include improved symptom management, wellbeing, quality of life, self-esteem, confidence and empowerment, the project will be researched to assess ongoing benefits with the aim of promoting the work as best practice.

- Training in palliative care skills for staff providing care in people's own homes, hospitals and care homes
  - Brambles, an MS Society respite care centre, works closely with the local hospice, St Catherine's, to meet the needs of people with complex needs. An exchange programme between 11 staff from the hospice and 11 staff from Brambles was recently completed. The two-day experience offered one day for training and one for practical application. The programme was extremely well received by staff, raising awareness of the skills implicit in each other's jobs. The exchange also enhanced communication and two-way advice. Brambles staff were particularly interested in the lymphoedema, respiratory and counselling services offered through the hospice. Since then, advice and assessment of lymphoedema from the hospice has been a direct benefit to Brambles guests.
- Forums for information exchange
  - The North West Regional Link Group was established in 2003 with the aim of influencing care and knowledge of MS among health care professionals who see people with MS on a regular basis.

The group is informal and acts as an opportunity for multidisciplinary networking. Membership consists of nurses, rehabilitation therapists, palliative care specialists and primary care teams. Among other topics discussed by the group, a session was run on palliative care management.

- The Greenwich and Bexley Cottage Hospice runs a group called the Cakewalk Café from 10am to 3pm twice a month. The group is open to anyone living with a life-threatening illness, carers and those who have been bereaved. Membership includes people living with cancer, MND, MS and HIV. The hospice counselling team offers practical help and support, lunch is provided, and alternative therapies such as massage and reflexology are offered. The Cakewalk Café has an attendance of about 65 people and has been a springboard from which other support groups have developed.
- The Community MS Team (CMST) Regional Neurological Rehabilitation Centre, Newcastle, was set up in 1995 as a joint venture between health, social services and the local branch of the MS Society. Based in the community, it provides physiotherapy, occupational therapy, counselling and psychology, and is linked to MS specialist nurses and neurologists at the acute trusts to ensure joined-up services for people with MS.

The team is also a member of the Regional Partnership Forum for the North of England, an MS Society initiative to improve services for people with MS, which brings together health and social care providers. Members of the CMST interface with palliative care on an increasingly regular basis as more clients with advanced MS live at home. They and their colleagues in specialist palliative

care felt they needed to increase their skills and knowledge to meet the needs of this client group. In 2005 a small working party was set up with representatives from neuro-rehabilitation, specialist palliative care and a person with MS. Their starting point has been a well-attended joint study day, with further sessions planned for the future. The working party plans to look at issues around continuing care as well as practical matters such as the provision of, and training for, specialist equipment like a suction machine.

- Other examples of joined-up working in Newcastle include the CMST 'sister' service, the Regional Disability Team, which has a long association with the local Leonard Cheshire Home and has been working on an education programme for staff covering the later stages of MS.

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Written by Sally Plumb  
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**MS National  
Centre**

372 Edgware Road  
London NW2 6ND  
Tel 020 8438 0700

**Scotland**

Ratho Park  
88 Glasgow Road  
Ratho Station  
Newbridge EH28 8PP  
Tel 0131 335 4050

**Northern Ireland**

The Resource Centre  
34 Annadale Avenue  
Belfast BT7 3JJ  
Tel 028 9080 2802

**Wales/Cymru**

Temple Court  
Cathedral Road  
Cardiff CF11 9HA  
Tel 029 2078 6676

**Multiple sclerosis (MS) is the most common disabling neurological disorder affecting young adults, and around 85,000 people in the UK have MS.**

The MS Society is the UK's largest charity dedicated to supporting everyone whose life is affected by MS – personally or professionally. The MS Society works with health and social care professionals to improve services by:

- promoting good practice in MS treatment and care
- publishing newsletters, reports and educational materials
- organising networking opportunities and events
- funding health and social care posts in community, rehabilitation, primary and acute care settings, and in palliative care
- funding research into the cause, cure, and management of MS, as well as development of services, with an overall research commitment of £12m

The **MS Professional Network** is a group of health and social care professionals with a common interest in improving services for people affected by MS. Membership is free and includes regular newsletters, conferences and learning events. To join, go to [www.mssociety.org.uk/profs](http://www.mssociety.org.uk/profs) or call 020 8438 0810



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