



All Party Parliamentary Group on Motor Neurone Disease

Inquiry into Access to Specialist Palliative Care for People with Motor Neurone Disease in England



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1. Introduction

Motor neurone disease (MND) is a fatal, rapidly progressing disease of the brain and central nervous system. It leaves people locked into a failing body, unable to move, walk and talk. Degeneration of the motor neurones leads to weakness and wasting of muscles, causing increasing loss of mobility in the limbs, and difficulties with speech, swallowing and breathing. MND is not infectious or contagious and it can affect any adult at any age, but most people diagnosed with the disease are over the age of 40, with the highest incidence occurring between the ages of 50 and 70.

There is no cure and the average life expectancy is between two and five years from the onset of symptoms. In the UK in 2008, around 1,600 people died from MND – equivalent to five people each day. The number of people dying from MND is increasing year on year and urgent action is needed to ensure that they receive the best possible care in life and death.



The All-Party Parliamentary Group (APPG) on Motor Neurone Disease is a cross-party group of MPs and Peers with an interest in MND. In December 2009, the APPG set up an inquiry into access to specialist palliative care services for people with MND living in England. Since the publication of the summary report from the inquiry in March 2010, there has been a significant shift in health policy and these changes have been reflected in this report.

Specialist palliative care can help people with MND achieve quality of life and dignity and influence their end of life decisions. With half of those with the disease likely to die within 14 months of diagnosis, specialist palliative care is an essential service for people with MND.

2. Executive summary

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Appropriate and timely access to specialist palliative care is a lifeline to people with MND and their family and carers. Coping with the physical and emotional aspects of a terminal diagnosis requires access to high quality specialist palliative care.

Well-designed specialist palliative care services not only provide a positive experience for the patient, but also reduce the burden on the NHS. Good quality, co-ordinated care costs less by reducing inappropriate treatment, emergency hospital admissions and the duplication of effort by professionals.

However, many people with MND are poorly served by the existing infrastructure of specialist palliative care. Whilst there are pockets of excellence in which multi-disciplinary teams of health professionals provide high quality and coordinated specialist palliative care, they are the exception rather than the rule, and in many cases rely on the commitment of one or two individual clinicians. MND Care Centres provide the benchmark of specialist care for MND patients, but at best these only cover 60% of England. Many patients and their carers who do not have access to a Care Centre face a struggle to get the care they need from a patchwork of services. This is against a backdrop of a lack of understanding amongst some professionals as to what palliative care is appropriate and available and in which providers often have limited experience of treating people with MND.

The nature of MND means that serious patient episodes often occur outside of normal GP practice hours and there is a particular concern about the ability of the out of hours GP service to provide an acceptable level of care for people with MND. The inquiry heard harrowing experiences from past carers where the out of hours service simply failed, resulting in unnecessary and expensive emergency acute hospital admissions. In one instance, following the death of a patient in the middle of the night, the out of hours GP called the police, even though the patient was on the End of Life Register.

There is evidence that a significant proportion of the £286 million allocated to Primary Care Trusts (PCTs) for end of life care, following the End of Life Care Strategy in 2008, has not been spent on palliative care. However, there are encouraging signs that a number of the principal commissioners of specialist palliative care, PCTs, have begun to address the needs of patients facing end of life. Whilst only three PCTs made the provision of palliative care a management priority, nearly half have focused on reducing the numbers of patients who die in hospital.

The forthcoming changes to the NHS will bring about a fundamental change in the way services are commissioned. It is essential that the move towards increasing the availability and quality of specialist palliative care is not lost in the transition period to the new structures.

3. The changing health environment

The APPG on MND inquiry into specialist palliative care began in December 2009. Since that date the Coalition Government has published the NHS White Paper, *Equity and excellence: Liberating the NHS*ⁱ, and the Health and Social Care Billⁱⁱ representing significant change for the NHS. Here we identify some of the key reforms proposed, and how their introduction may impact on the provision of specialist palliative care.

Commissioning

Commissioning has often been identified as a barrier to progress in the provision of specialist palliative care services. Commissioning structures in the NHS are likely to change significantly. PCTs and Strategic Health Authorities (SHAs) will be abolished, and their commissioning responsibilities will largely be transferred to an NHS Commissioning Board and GP consortia. As GP consortia take on more responsibility for commissioning health services, it will be important that those people involved in the commissioning of specialist palliative care services fully understand the needs of people who will require it.

Outcomes and information

There is an increased focus on measuring outcomes rather than process targets in the emerging health environment. Commissioners will be performance managed based on the health outcomes that they achieve. So too, patient experience will increasingly be assessed to measure the quality of service provision. It is essential that outcomes related to specialist palliative care are included within the new performance management regime. Given the nature of MND, the experience of carers should be measured to provide a true assessment of the level of care. In order to achieve the ambition set out in the NHS White Paper, it will be essential that sufficient data is collected and reported to ensure that services are able to improve. Historically, there has been a relative lack of data on specialist palliative care provision. Data should be collected on the number of people able to die at home, those who achieve a 'good death' as well as on the investment in specialist palliative care.

The NHS and social care

People requiring specialist palliative care services will often experience services delivered by both the health and social care sectors. The Health and Social Care Bill recognises the importance of joint, integrated working to deliver services that meet peoples' health and care needs. Under the current proposals, health and well being boards are to be introduced to encourage joint working between health services and local authorities. This should encourage health and social care to work more closely together in the provision of specialist care services. However, we believe there should be a statutory duty for health and social care to work together.

The challenges outlined in this report, and brought to the fore by people with MND and experts who gave evidence to the inquiry, remain unchanged. The reform of the NHS must address the issues and difficulties that are experienced in the provision and experience of specialist palliative care by people with MND.

4. Key recommendations

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All providers of NHS services should have measures relevant to specialist palliative care in their quality accounts where appropriate.

End of life care registers should be standard practice, so that all providers of NHS care have information about the needs and wishes of people with MND.

Detailed patient information on the provision of specialist palliative care should be made available in a timely manner.

Data on the provision of specialist palliative care should be collected at a GP commissioning consortium level to allow scrutiny of the improvements being made in the services. Data should continue to be collected and published at a PCT level throughout the transition of commissioning structures.

Commissioners should use all resources available to them to ensure that they provide the highest possible quality of specialist palliative care services.

The quality standard on end of life care should include provision of 24/7 community nursing as a key indicator of the quality of a service being provided.

Given the unique, challenging nature of the condition, a quality standard should be developed for the provision of care to people with MND. The quality standard should consider diagnosis, care planning and the provision of specialist palliative care.

All commissioners should provide details of how they have spent the additional funding for palliative care.

All PCTs should be sure that funds allocated for end of life care are invested into palliative care services.

Further data should be collected on commissioner spend on end of life care and specialist palliative care services.

The review of funding for palliative care should consider a tariff for complex palliative care as well as one for general palliative care.

The review of funding for palliative care should consider what might constitute a best practice tariff to incentivise high quality care.

All providers of NHS services should include measures relevant to specialist palliative care in their CQUIN choices.

PCTs/GP consortia should publish on their own websites details of specialist palliative care services within their area and a full list of conditions for which they are appropriate.

The new GP commissioning consortia should actively communicate full details of end of life care services to their constituent practices and encourage them to promote this information to all patients on end of life care registers. GP consortia should include the provision of specialist palliative and end of life care in their annual plans to the NHS Commissioning Board.

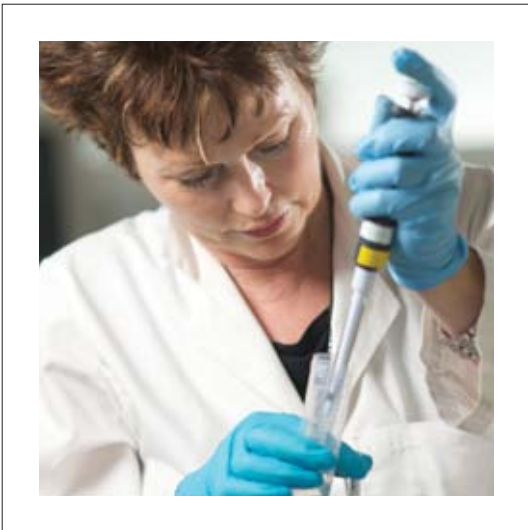
5. Overview of the evidence

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The inquiry took oral evidence from 20 witnesses who participated in four parliamentary hearings in January and February 2010. In addition, written evidence was submitted from 62 organisations and individuals, including people with MND and their carers. The following analysis reflects the main themes that emerged from the evidence, both oral and written.

a. Diagnosis

The absence of a diagnostic test for MND means diagnosis is often delayed and may present particular problems in elderly patients. Most GPs only see one or two people with MND in their careers and early diagnosis can be difficult.



In his oral evidence, Dr. Kevin Talbot, a consultant neurologist from Oxford, and the Director of the local MND Care Centre, stated that it was not a good idea for GPs to diagnose MND and whilst they may suspect that a patient was presenting symptoms, it was better for a neurologist to confirm the diagnosis. He also explained that many patients that are referred to him at the Oxford Care Centre have had the disease for between one and one and a half years. A good example of this delayed diagnosis was provided by another of the witnesses, Jane Campbell, whose husband died from MND. Despite the known presence of a neurological condition, it took 4 months before he was properly diagnosed.

Delays can be caused by a number of factors: first, by patients not realizing the seriousness of symptoms such as a weakened grip and muscle spasms; second, GPs may send patients away to return in a couple of months' time due to the lack of visible symptoms and a lack of awareness that the patient has a neurological condition; third, consultant referral waiting times; and then lastly, the neurologist wanting to be absolutely certain, before making the diagnosis with its associated serious consequences.

b. Access to palliative care

Early referral to specialist palliative care enables people with MND to better manage their symptoms, improve the quality of their life and plan for their death. This allows patients to be better cared for in the community and reduce the number of emergency hospital admissions. Specialist palliative care services are best placed to support and care for

terminally ill patients, both physically and, equally importantly, emotionally. The picture that emerges for people with MND is that access is patchy and there is quantitative evidence to suggest that although access to specialist palliative care is improving, it trails behind the levels experienced by people with other terminal conditions, such as cancer.

Historically, end of life and palliative care services have focused on the needs of people with cancer, and as a result, the needs of people with other conditions, including progressive neurological conditions, have often been overlooked. The presence of specialist MND centres and hospices is often a pre-requisite for good care and there is evidence to suggest that rural areas find it difficult to support people with MND.

In their evidence, Sue Ryder Care quoted from the Department of Health's 2008 End of Life Care Strategy to highlight the inequity in access to specialist care; in 2007, cancer was the underlying cause in 27% of deaths, yet the vast majority of specialist palliative care is accessed by cancer patients. This point was underlined by Sir Mike Richards, the National Clinical Director for Cancer and End of Life Care, who acknowledged that cancer patients ***'have had more access to specialist care than others'***.

Because of the speed of disease progression with MND, it is important that patients are referred for specialist palliative care at the time of diagnosis, or as shortly after as sensitively possible. The network of MND care centres established by the MND Association has been highly effective; the King's College MND Care and Research Centre, London, stated that they ***'had transformed care for people living with MND, not only by raising awareness and providing a direct route for access, but also by facilitating the training of professionals, allowing the establishment of key research environments, and encouraging a multidisciplinary approach to MND, which in turn leads to the education of other professionals.'***

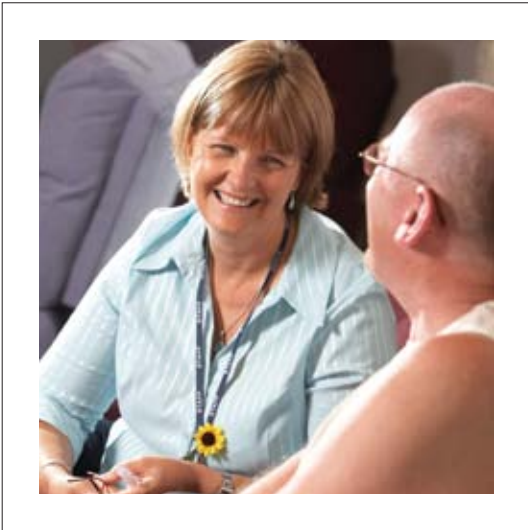


The Committee received evidence that acknowledged that advances have been made over the past five years, but also suggested that access to specialist palliative care was not the norm for all patients. One explanation cited by the National End of Life Care Programme was that many professionals working in neurology have a limited understanding of end of life care. Other reasons include lack of residential care services and staff who understand and are trained to care for people with neurological conditions including MND. Due to the time involved in providing respite care, the costs of providing inpatient care may not be fully recoverable by the provider.

Care often lasts substantially longer than the Full Consultant Episode basis on which services under contract to PCTs will be paid. Inpatient units therefore, can find themselves with MND patients in need of prolonged support for which they do not receive full remuneration.

Several other factors may prevent early referral to specialist palliative care for people with MND: late diagnosis limits the time in which a patient can benefit from palliative care;

many patients may refuse early referral, believing that it is a service solely for the 'dying'; anecdotal evidence at least, suggests that there are still some health professionals who do not fully appreciate the benefits of palliative care service to MND patients; and a lack of local neurology palliative care nurse specialists.



There is evidence that the introduction of the Gold Standards Framework (GSF) is only having a limited impact for people with MND. The GSF was set up to help GPs identify patients requiring end of life care to ensure access to high quality palliative care.

The John Taylor NHS hospice in Birmingham commented that not everyone with MND is registered with the GSF and questioned whether this was because health care

professionals view it as primarily for cancer patients, despite the efforts to highlight other conditions. It stated that, for someone with MND, not being on the GSF could result in a lack of urgency when responding to requests for equipment and support visits, and a lack of understanding about the rapid changes in the condition of those with MND. Similarly, the multidisciplinary MND team in West Suffolk reported that non-cancer patients are not routinely placed on the GSF.

c. Planning and co-ordination of care

Effective, patient-centred care for people with MND relies on a co-ordinated approach to ensure that professional involvement is both integrated and timely. The network of 18 specialist MND care centres provide a model of care in which the patient is helped at each stage of the condition and provided with timely access to a range of palliative treatments. In his oral evidence, Dr. Kevin Talbot, described the positive impact that the centre had made on the treatment of people with MND and contrasted the current situation with that previously:

'patients would be seen for diagnostic purposes by a neurologist who would then not take on the management. They would go back to their GP who knew nothing about MND. Whether they were referred then either to palliative care or to neuro-rehabilitation services was rather arbitrary kind of thing. Patients were either overwhelmed with people trying to help them, which was not co-ordinated and had a lot of duplication, or they had absolutely nothing. In fact, the latter was more common. By having a care centre, we have myself and another academic neurologist and we have funding for a Care Centre Co-ordinator and we see people very quickly...'

'...we have evolved what we think is a patient-centred kind of approach so that we are trying to understand what the disease means for this individual, what are their concerns, what are their needs and what is going to happen to them...we have access to people who can address the needs of individuals who have speech and swallowing problems, nutritional problems, breathing problems, very importantly, and also mobility problems, and we can do that very rapidly and in a very individual expert-led way.'

Similarly, the Birmingham MND Care Network group, based in Solihull, was set up to optimise the communication between services to benefit the patient and, importantly, to co-ordinate and ensure co-operation between service providers. The establishment of this group has led to strong links between the Marie Curie hospice in Solihull and specialist nursing staff, to encourage all newly diagnosed patients to be referred to the hospice. This opens the door for patients and family to a range of services that includes physiotherapy, social care, bereavement support, specialist palliative care nurses and pharmacy.

However, there is a concern that these examples of good planning and the attendant access to specialist palliative care are not replicated across large parts of the country; and that many patients and carers struggle to access the services they need. The specialist MND centres cover no more than 60% of the population of England and the Inquiry heard evidence from carers of people with MND with a very different experience from that described above. Several examples were provided of problems with the out of hours GP service, including instances where MND patients' records were not checked, leading to unnecessary, distressing and ineffective admissions to acute hospitals.

An example of the difficulties carers can have in accessing out of hours care when they need it was given by Glynis Sinclair from Suffolk, who is the main carer for her husband:

'Sadly, MND does not have a 9 - 5 shelf life, it is on-going, and we have recently had a problem where we have called for a doctor on a Saturday lunchtime, the doctor finally arrived ten hours later, and he left 15 minutes later saying: "Ring your GP on Monday".'

case study:

How the introduction of a multi-disciplinary team increases access and co-ordination of care

Background

People with MND were rarely accessing specialist palliative care in West Hertfordshire; access to specialist interventions was poor; hospital deaths were high; and neuro-rehabilitation staff were concerned at the poor care provided to patients.

Objectives

- Improve access to specialist palliative care
- Increase home deaths through advanced care planning and co-ordination of community care

Methods

- Introduction of a monthly multi-disciplinary team (MDT) meeting with representatives from community occupational therapy, physiotherapy, dietician, speech and language therapy, specialist palliative care clinicians, trained volunteer visitors and social services. The meetings were led by a consultant in palliative medicine
- Education for neuro-rehabilitation and social services staff about palliative care
- Education for specialist palliative care staff regarding MND
- Education to patients and carers
- Change of referral pathway for non-invasive ventilation (NIV)

Outcomes

- Access to specialist palliative care increased 15 fold in the first year (2007)
- Increased home deaths and hospital admission is now rare
- Improved access to NIV - wait reduced from 8 months to 3 weeks

Conclusions

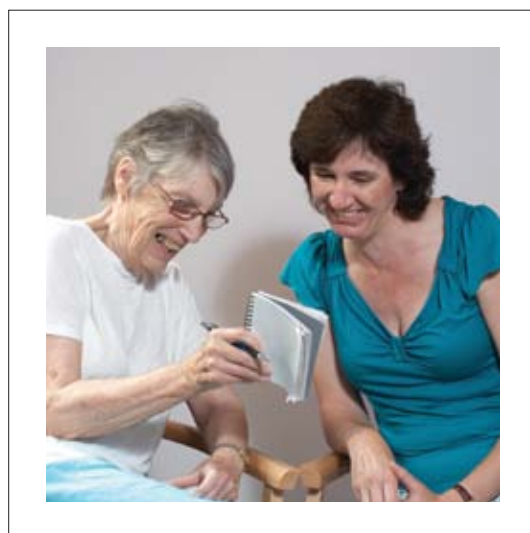
Clinical leadership, education and monthly MDT meetings delivered a sustained improvement in care for people with MND. Access to specialist palliative care increased, allowing most patients to die at home.

d. The management of symptoms and interventions

Interventions such as percutaneous endoscopic gastrostomy (PEG), radiologically inserted gastrostomy (RIG), and non-invasive ventilation (NIV) require specialist medical and nursing personnel. There appears to be a consensus that there are too many unplanned acute admissions for these procedures, many of which can be anticipated and thus conducted in a more appropriate setting. According to the Palliative Care Research Consortium at University College Hospital, specialist palliative care teams can manage PEG/RIG after insertion working closely with dietetic colleagues. Whilst many hospices accept and look after patients requiring these treatments, for others it is problematic, as not all palliative care teams have expertise in MND care.

e. Psychological and spiritual support

Given the stark nature of the MND prognosis, access to emotional support for patients and families is an important element of specialist palliative care. Ideally, a psychological, social and spiritual assessment for each newly diagnosed patient will be followed by referral to the appropriate resource within the multi-professional palliative care team. In its evidence, Sue Ryder Care cited research that indicates that where the psychological needs of a person with MND are met, they are less likely to suffer from depression and will have better quality of life scores. However, where these needs are not met, experiences of suffering, fear, hopelessness and desire for a hastened death are more common .



One of the people (R, aged 48 from London) with MND who gave oral evidence to the inquiry underlined the benefit that psychological support had given him:

'I found that it was a very beneficial referral for me because I had people there that were prepared to talk to me about my death and prepared to talk to me about it very courageously. It was a very, very difficult time for me but I have got used to that now and it is something that I can do, not without difficulty, but with a hell of a lot less difficulty than in the past. I found that I began to discuss end of life issues with them at this very early stage and that has been of enormous benefit to me in my head, so I am very grateful to them for that'.

Whilst it is difficult to make a valid assessment of the prevalence of psychological support, Sue Ryder Care opined that it ***'it is not currently practised in all settings and areas'.***

f. Support for carers

Caring for someone with MND can be a huge strain both emotionally and physically, due to the unrelenting nature and physical hard work involved in looking after someone who becomes rapidly physically disabled, as well as the associated sadness and profound distress such an experience is associated with. Specialist palliative care teams work

with carers to support them pre-and post-death into bereavement. Carole Thomas, a past carer, underlined the importance of having the support of a key worker and stated that they are:



'Essential to taking the stress off the family so that you are not constantly having to telephone x number of persons; there is one person you can call who understands what services the person you are caring for is in contact with and also understands what else is available that you could be put into contact with'.

More effective carers assessments are essential to avoiding situations in which carers are not given information about even the most basic services. Carole Thomas described the situation of a young woman in London who had been told

nothing about getting continuing care funding for her husband: ***'she had to seek all that out herself. She had not been offered a carer's assessment; she had not even been given simple information or directed to places where she could get that information. Everything that she had had to put into place for her husband she had had to find out about herself'.***

6. Reforming for palliative care: an agenda for change

To ensure that everyone with MND has access to the appropriate palliative care services when they need them, the government must take a number of steps to ensure that local providers are equipped to deliver high quality care, based on need. These are as follows:

a. Improving quality

There are currently three good practice guidelines for the provision of palliative and end of life care – the Gold Standards Frameworkⁱⁱⁱ (for the last 12 months of life); the Liverpool Care Pathway for the Dying^{iv} (for the last 72 hours of life) and the Preferred Priorities of Care^v. If the geographical variations in quality of care for people with MND are to be reduced, it will be essential that all health commissioners and providers are taking note of these guidelines in developing their palliative care services.

The Gold Standards Framework

The Gold Standards Framework (GSF) is a systematic evidence based approach to optimising the care for patients in their last 12 months of life, delivered by generalist providers. It is concerned with helping people to live well until the end of life and includes care in the final year of life for people with any end stage illness in any setting. The GSF provides resources for primary care, care homes and acute settings.

The Liverpool Care Pathway

The Liverpool Care Pathway (LCP) is an integrated care pathway that is used at the bedside to drive up sustained quality of the dying in the last 72 hours of life. It was introduced as a means to transfer the best quality for care of the dying from the hospice movement into other clinical areas. The LCP has been implemented into hospitals, care homes, patients' own homes and hospices.

Preferred Priorities of Care

The Preferred Priorities for Care (also known as PPC) helps patients prepare for the future by giving them an opportunity to think about, talk about and write down their preferences and priorities for care at the end of their lives. If a time comes when a patient is unable to make a decision for themselves, anyone who has to make decisions about their care on their behalf will have to take into account what is written in the PPC.

Recommendation: Commissioners and providers should pay due attention to key guidelines in designing and delivering specialist palliative care services.

As of July 2010, all providers of NHS care have been required to produce quality accounts^{vi}. Quality accounts are a mechanism for ensuring that providers have a board-level focus on quality issues, and they have the potential to be an important lever in improving the quality of services provided to patients. Among priorities focused on improving clinical effectiveness, 14 (5%) healthcare providers chose to include measures on the end of life care pathway in their first quality account. It is concerning that more providers have not chosen to prioritise the issue. Figure 1 identifies the lead

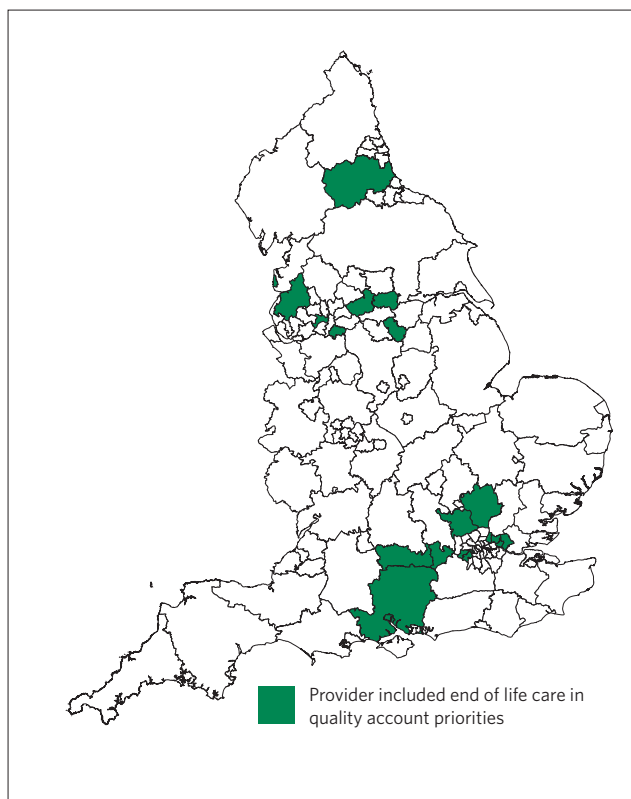


Figure 1: Prioritisation of the end of life care pathway through quality accounts^{vii}

commissioners for those NHS providers that have prioritised the issue through their quality accounts^{vii}.

The end of life care pathway was, reassuringly, a key indicator of quality selected by many ambulance trusts in their quality accounts. Figure 2 shows the most popular priorities selected by ambulance trusts. The end of life care pathway accounted for 20% of selections among the group. People with MND will come into regular contact with a wide range of NHS providers and professionals, including ambulance services.

To ensure that patients are receiving joined up care, end of life care registers, detailing the needs and wishes of people with MND, should be standard practice, and should be accessible by all professionals providing care to a patient. This will help to coordinate care and ensure that patients are always treated in the most appropriate environment, reducing unnecessary and distressing admissions to acute care.

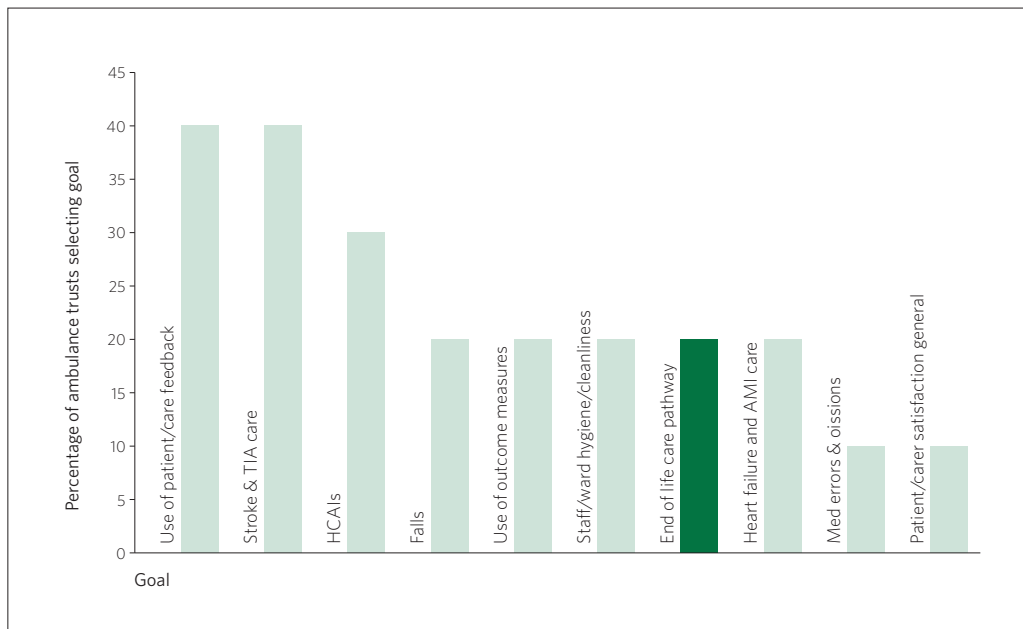


Figure 2: Most popular priorities selected by ambulance trusts

Recommendation: All providers of NHS services should have measures relevant to specialist palliative care in their quality accounts where appropriate

Recommendation: End of life care registers should be standard practice, so that all providers of NHS care have information about the needs and wishes of people with MND

b. Commissioning

The world class commissioning assurance process, which ran from 2008 to 2010, required all primary care trusts to select outcome areas for prioritisation^{ix}. All commissioners were required to select at least five nationally defined outcome indicators, with the option to select a number of locally defined indicators. Included in the nationally defined outcome indicator set were two areas that impact on the provision of specialist palliative care:

- Palliative care prevalence
- Percentage of all deaths that occur at home

Figures 3 and 4 below highlight the commissioners who chose to prioritise these two areas. Palliative care prevalence was selected as an outcome indicator by only three PCTs: Berkshire West; Gloucestershire; and Sunderland. Percentage of all deaths that occur at home was a much more popular indicator, being selected by 69 (45%) commissioners in total. It is promising that 72 (47%) PCTs chose to focus on an indicator relevant to the provision of specialist palliative care. This no doubt reflects the focus that was placed on palliative care through the Department of Health End of Life Care Strategy in 2008^x.

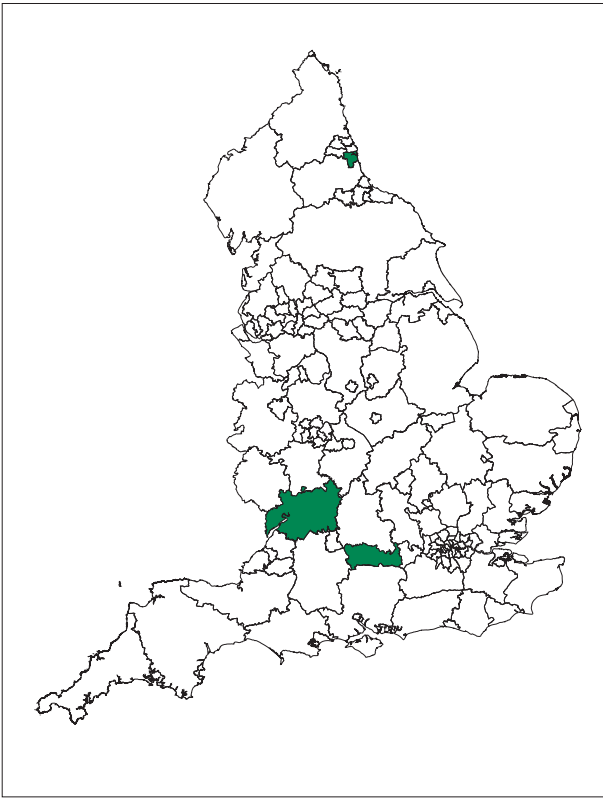


Figure 3: PCTs who prioritised palliative care prevalence

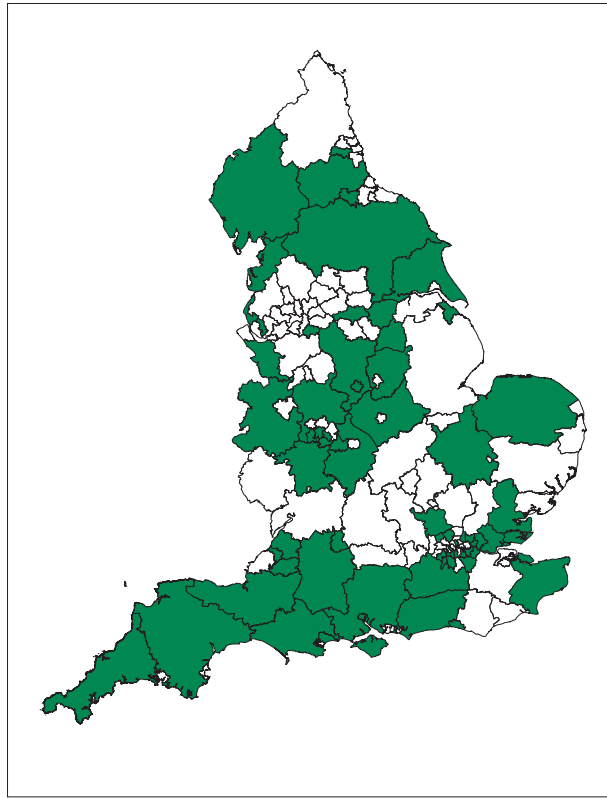


Figure 4: PCTs who prioritised percentage of all deaths that occur at home

Given the relative lack of timely data on the provision of end of life care it is difficult to determine the impact that this prioritisation has had. For example, data is not available for the number of deaths that occurred at home in 2008/09. However, analysis by MHP Health Mandate has demonstrated a link between commissioning prioritisation and improved outcomes^{xi}. The NHS must give the same priority to access to palliative care as it does to the delivery of care to patients in active treatment. If commissioning of specialist palliative care is to be improved, it will be necessary to ensure that commissioners are prioritising this important area of the patient pathway.

Recommendation: Data on the provision of specialist palliative care should be made available in a timely manner.

Recommendation: In future, data on the provision of specialist palliative care should be collected at a GP commissioning consortium level to allow scrutiny of the improvements being made in the services. Data should continue to be collected and published at a PCT level throughout the transition of commissioning structures.

Access to specialist palliative care has improved the experience for some patients, ensuring that people are supported in death, but there remain significant variations in the service that is being provided. Good commissioning will be vital to ensure that specialist palliative care is available to all patients who would benefit from it.

As responsibility for commissioning is shifted to GP consortia and the NHS Commissioning Board, it will be essential that all commissioners are engaged in the provision of palliative care services in their area, and are supported in commissioning services of the highest quality. In future, those organisations with responsibility for commissioning specialist palliative care services for people with MND, including GP consortia, should be given clear information about the markers for high quality care. People with MND will need specialist care, and as such a quality standard specifically for MND should be developed, incorporating markers of quality for specialist palliative care.

There are a number of resources available that could also support commissioners in the development and provision of specialist palliative care services, including the MND Association Year of Care Pathway for MND^{xii}, the NeuroNavigator^{xiii} and the Leicestershire end of life care pathway.

The MND Association has produced an MND Year of Care Pathway to help the NHS and Social Services improve the provision of services for people with MND^{xiv}. The MND Year of Care pathway lists all the possible care and equipment needs that a person with MND may have over a 12 month period. By attaching a cost to each element, commissioners of services in the NHS will be able to plan and deliver services more effectively for the benefit of people with MND.



The NeuroNavigator^{xv} has also been developed to help commissioners understand the complexity of support and services that need to be provided for people affected by a long term neurological condition. The NeuroNavigator maps out the services, care and support that should be available to a person living with MND throughout the course of their condition, shows the associated costs of those services and uses existing data to give approximate numbers of how many people will need access to these services.

Recommendation: Given the unique nature of the condition, a quality standard should be developed for the provision of care to people with MND. The quality standard should consider diagnosis, care planning and the provision of specialist palliative care.

Recommendation: Commissioners should use all resources available to them to ensure that they provide the highest possible quality of specialist palliative care services.

One of the key areas of care that should be commissioned for people with palliative care needs is the provision of out of hours community care. The importance of out of hours care was recognised in the Department of Health End of Life Care Strategy for England, published in 2008^{xvi}. A Freedom of Information audit carried out by Macmillan Cancer Support highlighted that progress in commissioning this area of care has been slow. The data collected showed that 24/7 community nursing was available for all end of life patients in only 56% of the responding PCTs^{xxii}.

It will be essential that a focus on out of hours care is included in any and all commissioning support provided to GP consortia.

Recommendation: The quality standard on end of life care should include provision of 24/7 community nursing as a key indicator of the quality of a service being provided.

c. Funding

The End of Life Care Strategy, published in 2008, was accompanied by funding of £286 million to improve palliative care services to be spent in 2009/10 and 2010/11^{xviii}. Much

of this funding was distributed to PCTs, and there is evidence that the funding has not reached the palliative services it was designed for in all cases. In its written submission, Sue Ryder Care expressed concern about how the money had been spent, given that the money went straight into PCT baselines, rather than being ring fenced, making it difficult to analyse whether the programmes it has been spent on all directly relate to end of life and palliative care. Similarly, Tom Hughes-Hallett, Chief Executive of Marie Curie Cancer Care, told the inquiry that he could **'see no evidence of additional funding having been spent on end of life care since the allocation'** of the funding, adding that it was ironic that 2010 was the first year in the organisation's history when its nursing service did not grow, given that it was the first year of additional funding.

Two examples of PCTs not spending their additional funding were identified in the oral evidence given to the inquiry: Dr Kirstine Knox, Chief Executive of the MND Association cited Southampton City PCT as going back on previous commitments to allocate funding to palliative care; and quoted Dr David Oliver, Consultant in Palliative Medicine at the Wisdom Hospice in Kent, who had calculated that the local PCT had not spent its indicative budget of £420,000.

The End of Life Care Strategy Second Annual Report provided details of the additional funds spent by PCTs in 2009/10^{xix}. They demonstrated a high degree of variation in the level of new investment between PCTs. This varied from £5.4 million additional spend in Hampshire, to no reported additional investment in Blackburn with Darwen. Figure 5 highlights the variation in additional spend in 2009/10 across all PCTs (with outliers removed).

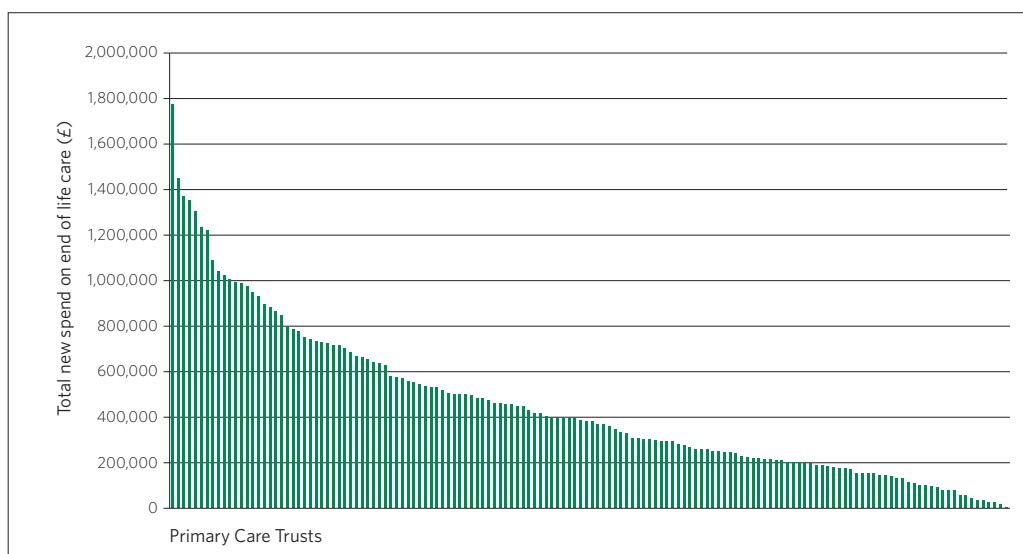


Figure 5: Total new spend on end of life care by PCT

This data reflects additional rather than total spend on end of life care. If GP consortia are to be held accountable on their commissioning decisions, it will be important to know in what they are investing.

Recommendation: All commissioners should provide details of how they have spent the additional funding for palliative care

Recommendation: All PCTs should be sure that funds allocated for end of life care are invested in palliative care services

Recommendation: Further data should be collected on commissioner spend on end of life care and specialist palliative care services

Too often in specialist palliative care money does not follow the patient. Good quality co-ordinated specialist palliative care costs less than poor quality care as it keeps people away from hospital by reducing crises, inappropriate treatment, emergency hospital admissions and duplication of effort by professionals. Care for someone with MND,

well-delivered, costs around £200,000 in the final year of life, or £16,500 per month. Case studies compiled by the MND Association show costs soaring above these levels when care goes wrong, for instance to £28,000 per month in a bad, but not uncommon example^{xx}.



NHS providers should be incentivised to improve the quality and efficiency of specialist palliative care services in their area. The second annual report of the End of Life Care Strategy has proposed the introduction of a tariff for palliative care^{xxi}. The proposed introduction of a tariff for end of life care is welcome, but there will have to be significant work done if potential issues in its implementation are to be avoided. There is some concern, for example, that a tariff covering all palliative care would fail to take into account the complexities involved for some

conditions. The review of funding for palliative care, being chaired by Tom Hughes-Hallett of Marie Curie Cancer Care, should consider the introduction of a tariff specifically for complex palliative care to ensure that the needs of all patients are being met.

Recommendation: The review of funding for palliative care should consider a tariff for complex palliative care as well as one for general palliative care

Recommendation: The review of funding for palliative care should consider what might constitute a best practice tariff to incentivise high quality care.

The payment by results framework has traditionally connected funding to volume of activity rather than the quality of care provided. Increasingly there has been a move away from this approach, and funding is becoming more closely linked to the quality of care provided. One key example of this shift in thinking was the introduction of the Commissioning for Quality and Innovation (CQUIN) payment framework^{xxii}, which makes a proportion of a provider's income conditional on quality and innovation.

A number of NHS providers selected CQUINs directly related to the provision of end of life care^{xxiii}. These were:

- Derby Hospitals NHS Foundation Trust
- East of England Ambulance Service NHS Trust
- East Midlands Ambulance Service NHS Trust
- Hull and East Yorkshire Hospitals NHS Trust
- Leeds Teaching Hospitals
- Mid Staffordshire NHS Foundation Trust
- Northampton General Hospital NHS Trust
- South East Coast Ambulance Service NHS Trust
- Scarborough and North East Yorkshire Healthcare NHS Trust
- United Lincolnshire Hospitals NHS Trust
- Worcestershire Acute Hospitals NHS Trust



Recommendation: All providers of NHS services should have measures relevant to specialist palliative care in their CQUIN choices

d. Information for patients

Patients and carers require easy to understand information on palliative care together with details of local services and how to access them. The public NHS website www.nhs.uk contains good information on what palliative care is and links to external organisations

such as Help the Hospices, where patients and carers can look up details of their nearest hospice through a postcode search <http://www.helpthehospices.org.uk/about-hospice-care/find-a-hospice/>.

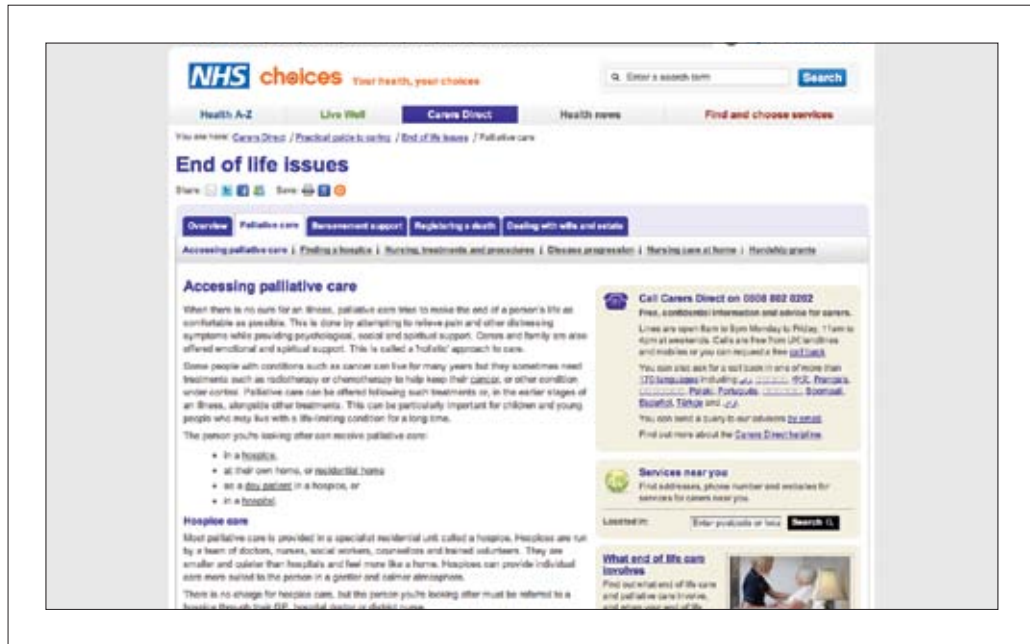


Figure 6: The NHS Choices website (www.nhs.uk)

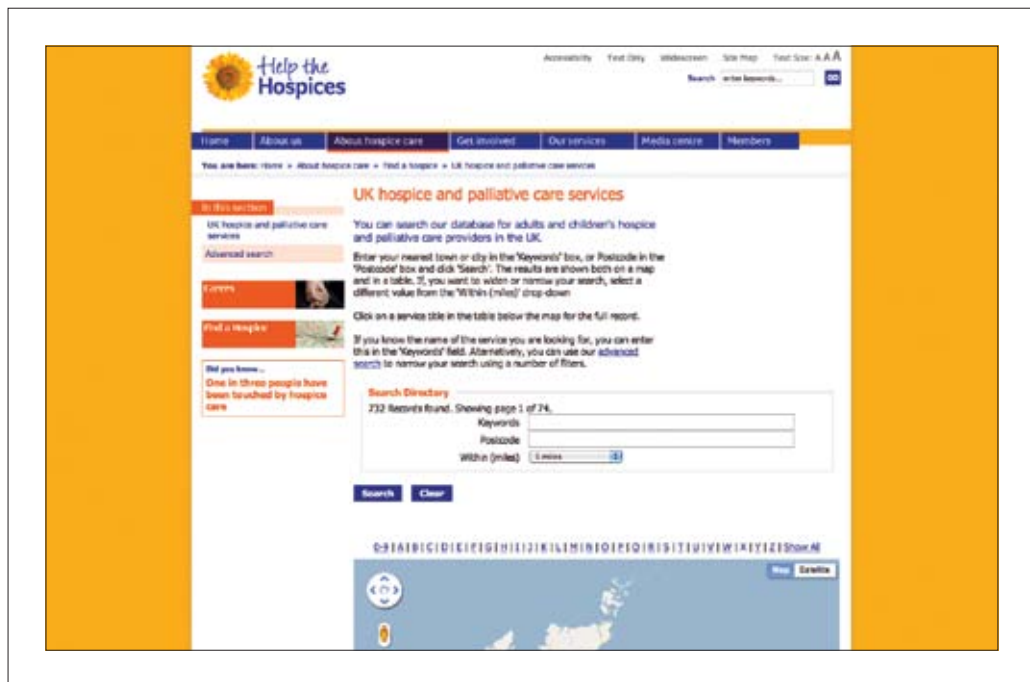


Figure 7: The Help the Hospices website (www.helpthehospices.org.uk)

However, by only referencing cancer on its 'Accessing palliative care' page^{xxiv} NHS Choices inadvertently re-enforces the stereotype that specialist palliative care is only for cancer patients.

We share the view of organisations that told the inquiry that information on the specific services available for those with palliative care needs who do not have a cancer diagnosis is poor and often those with MND do not realise that they can access hospice services. Until 2013, the primary responsibility for providing information on local specialist palliative care services lies with PCTs, and these should reinforce that palliative care is available for patients whatever their terminal condition.

Recommendation: PCTs/GP consortia should publish on their own websites details of specialist palliative care services within their area and a full list of conditions for which they are appropriate

Recommendation: The new GP commissioning consortia should actively communicate full details of end of life care services to their constituent practices and encourage them to promote this information to all patients on end of life care registers

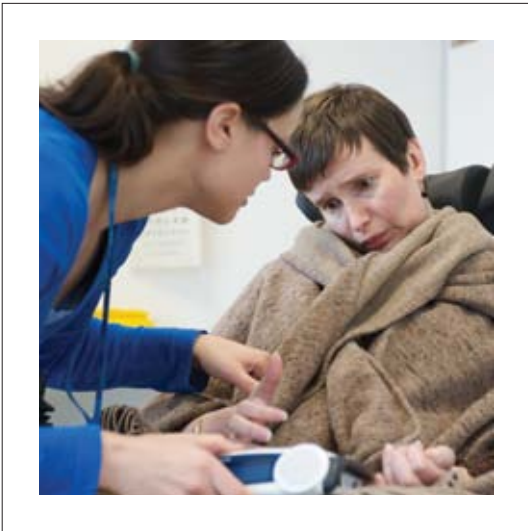
7. Conclusion

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The inquiry that led to this report, the first undertaken by the APPG, has been immensely helpful to the parliamentarians involved and the group would like to thank again all the witnesses and organisations who gave up their time to give evidence and prepare written submissions.

During the inquiry we heard distressing experiences from carers and others who testified to the fact that palliative care for people with MND is patchy at best and completely

disfunctional at worst. However, we take encouragement from the expert witnesses who during their evidence often articulated a genuine passion and a sense of purpose in their work to provide high quality palliative care for people with MND. Their work is to be applauded and, together with the care provided across the MND Care Network, should be held up as an example to others as what can be achieved through co-operation, communication and commitment. The End of Life Care Strategy, together with the Gold Standards Framework and Liverpool Care Pathway, provide a strategy to ensure that these examples of excellence can and should be replicated across the country.



The current squeeze on NHS budgets and considerable upheaval in the NHS as the organisational changes are implemented and take time to bed down should not be allowed to set back the progress that has been made. Our proposals set out in this report are intended to ensure that the very best in specialist palliative care is available to everyone with MND, wherever they live and whatever their circumstances.

Annex 1: Inquiry terms of reference

1. The Inquiry will focus on the following areas. Please describe from your perspective the current situation, issues and any concerns regarding the following:
 - a. The identification of people with MND within the community (and hence who can benefit from specialist palliative care)
 - b. The planning and co-ordination of specialist palliative care for people with MND
 - c. Fast-track access to specialist palliative care as needs arise, including 24hour access
 - d. Access to specialist palliative care in all locations - a person's home, a hospice, a care home, hospital
 - e. The management of all symptoms of MND by specialist palliative care providers
 - f. The specific management of interventions such as percutaneous endoscopic gastrostomy (PEG)/ radiologically inserted gastrostomy (RIG) and non-invasive ventilation by specialist palliative care providers
 - g. The specific management of communication difficulties in the provision of specialist palliative care
 - h. The specific management of people with MND with cognitive impairment in the provision of specialist palliative care
 - i. The role of rehabilitation within palliative care, for example access to physiotherapy and occupational therapy
 - j. The provision of psychological, social and spiritual support for people with MND
 - k. Support for family carers of people accessing specialist palliative care, including bereavement support
 - l. The provision of information on the full range of specialist palliative care provision available locally and how to access it
 - m. The roles, and co-ordination, of different health and social care professionals in the provision of palliative care - GPs, neurologists, district nurses, palliative care consultant, hospice staff, care home staff, hospital staff
 - n. The role of MND Care Centres, commissioners and third sector organisations in the provision of specialist palliative care to people with MND
2. What do you think are the barriers to provision of high quality specialist palliative care services to people with MND?
3. There are currently three good practice guidelines for the provision of palliative and end of life care - the Gold Standards Framework (for the last 12 months of life); the Liverpool Care Pathway for the Dying (for the last 72 hours of life) and the Preferred Priorities of Care. Do you agree that these are being used effectively for people with MND?
4. In your experience is access to specialist palliative care determined by need and not diagnosis? Or do some conditions have priority access to palliative care?
5. The MND Association recommends that everyone with MND is referred to specialist palliative care services soon after diagnosis due to the often rapid progression of the disease and the expertise of specialist palliative care services in managing a condition that is incurable. In your experience, does this happen?
6. Do you think the End of Life Care Strategy has improved access to specialist palliative care for people with MND? Has the funding attached to the Strategy reached the services it was designed for?
7. Is it your experience that funding for specialist palliative care services for people with MND is determined equitably?

Annex 2: Submissions to the APPG on MND inquiry into specialist palliative care

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Oral evidence (20)

Jane Campbell, past carer, Norfolk
 Simon Chapman, National Council for Palliative Care
 Dr Chris Clough, consultant neurologist and NSF Adviser to the DH
 Baroness Finlay of Llandaff, consultant in palliative medicine, Cardiff
 Julia Franklin, Association Visitor, Sussex
 Claire Henry, National End of Life Care Programme
 Barbara Howe, London Specialised Commissioning Group
 Tom Hughes-Hallett, Chief Executive, Marie Curie Cancer Care
 Dr Kirstine Knox, Chief Executive, MND Association
 Roch Maher, person with MND, London
 Greg Mulholland MP, Liberal Democrat Shadow Health Minister
 Dr David Oliver, consultant in palliative medicine, Kent
 Professor Sir Mike Richards, National Clinical Director for Cancer and End of Life Care
 Benny Rossi, LOROS (Leicestershire and Rutland Hospice)
 Glynis Sinclair – current carer, Suffolk
 Dr Kevin Talbot, consultant neurologist and Director of the MND Care Centre, Oxford
 Carole Thomas, past carer, Cambridgeshire
 Professor Keri Thomas, Director, Gold Standards Framework
 Sue Thomas, Neurology Commissioning Support
 Emma Wiley, MND Care Centre Coordinator, King's College Hospital

Written evidence (62)

23 people with MND and carers, plus:

Aintree Specialist Palliative Care Service, Liverpool
 Anniemieke Fox, RCDA South Central, MND Association
 Camden OCT and UCLH Palliative Care Team
 Chris Lynch, Regional Care Development Advisor, MND Association
 Community Assessment and Support Team, Huddersfield
 Dorothy House Hospice, Wilshire
 Hospiscare Specialist Palliative Care Team, Exeter
 John Taylor Hospice, Birmingham
 The King's Fund
 Kings MND Care Centre, London
 Leeds MND Care Centre
 Leicestershire and Rutland Hospice (LOROS)
 Manchester MND Care Centre
 Margaret McIntosh, RCDA West Midlands South, MND Association
 Marie Curie Hospice, Solihull
 Marie Curie Palliative Care Research Unit, London
 National Council for Palliative Care
 National End of Life Care Programme
 Neurological Commissioning Support (NCS)
 Newcastle MND Care Centre
 NHS Hertfordshire Community Health Services
 NHS Mid Essex
 NHS Norfolk
 NHS South East Essex
 MND Care Centre, National Hospital London
 Nottingham MND Care Centre
 Peninsula MND Network, Truro
 Royal Cornwall Hospitals Trust, Truro and Cornwall Hospice Care
 Rowcroft Hospice and South Devon Healthcare Foundation Trust
 Dr Jenny Smith, Specialist Registrar, mid-Yorkshire
 South Warwickshire MND Network
 Southampton MND Care Centre
 Sue Ryder Care Hospice, Leeds
 Sue Ryder Care (National)
 Sue Smith, RCDA West Yorkshire, MND Association
 The Walton Centre NHS Foundation Trust
 West Suffolk MDT
 Wisdom Hospice, Kent
 Woking and Sam Beare Hospice

Annex 3: Summit statement on end of life care* for people with MND

Motor neurone disease (MND) is devastating. A fatal, rapidly progressing disease of the central nervous system, it leaves people trapped inside failing bodies, unable to walk, talk or eat and struggling to breathe. There is no cure and limited treatments. Few doctors recognise the disease immediately and diagnosis is often delayed, meaning that many people die within fourteen months of diagnosis. The death rate from this uniquely cruel disease is rising. Action is needed now to make sure that those affected get the best possible care.

Pockets of high quality care exist, but they too often rely on individual clinical champions rather than coherent systems. Co-ordinated care is better for the patient and the public purse.

On 9 November 2010, the MND Association hosted a major summit on end of life care attended by its Royal Patron HRH the Princess Royal. The participants at the summit agreed the following statement.

To achieve quality and value in end of life care for people with MND, we call on the Government and commissioners to implement the following recommendations:

Recommendation 1 - Outcome measures

The Government should include access to end of life care in the NHS Outcomes Framework.

Recommendation 2 - Commissioning

The Government should give specific consideration to the future commissioning arrangements for low prevalence, high cost, high need diseases like MND. Commissioning must take place against outcomes, accountability must be clear and patients and carers should be at the heart of decision-making

Recommendation 3 - Standards

The National Institute for Health and Clinical Excellence (NICE) should develop a clinical guideline and a quality standard for the treatment of people with MND, which includes access to end of life care.

Recommendation 4 - Universal access

The Government should guarantee universal access to end of life care services, and promote publically funded third sector provision of these services.

Recommendation 5 - Funding

The Government should explicitly include the needs of patients with complex conditions when developing the new funding mechanism for palliative care.

Recommendation 6 - Education

GP consortia should develop a workforce education and development strategy for the recruitment and training of professionals in palliative care, including the specific care associated with MND.

Recommendation 7 - Out of hours services

GP consortia should ensure access to out of hours specialist care for everyone with MND.

Recommendation 8 - Co-ordination and continuity of care

Co-ordination of care must be embedded in the system. GP consortia should ensure multi-disciplinary teams are in place for people with MND in their locality. Each team should appoint a key worker and include a specialist in palliative care.

Recommendation 9 - Information for patients and carers

GP consortia should provide good quality information on the availability and benefits of end of life care services locally for people with MND and their family

Conclusion

These steps need to be taken now so that people currently living with MND achieve quality in life and dignity in death, and the NHS delivers value for the public purse. We call on the Government to implement these recommendations during the course of this Parliament.

Signatories:

The Baroness Finlay of Llandaff, *Professor of Palliative Care at Cardiff University and Patron of the MND Association*

Dr Iona Heath, *President of the Royal College of General Practitioners*

Barbara Howe, *Trustee of the MND Association*

Dr Kirstine Knox, *Chief Executive of the MND Association*

Professor Nigel Leigh, *Professor Emeritus, Department of Clinical Neuroscience, King's College, London*

Professor Tim Luckhurst, *Professor of Journalism and the News, Kent University*

Greg Mulholland, *MP for Leeds North West and Vice-Chair of the All-Party Parliamentary Group on MND*

Eve Richardson, *Chief Executive, National Council of Palliative Care*

Mr Craig Stockton, *Chief Executive of MND Scotland*

Dr Nigel Sykes, *Medical Director and consultant in palliative medicine, St Christopher's Hospice, London*

Mark Todd, *Chairman of the MND Association*

Dr Jean Waters, *Trustee of the MND Association*

Gavin Williamson, *MP for South Staffordshire and Chairman of the All-Party Parliamentary Group on MND*

Chris Woodhead, *Former Chief Inspector of Schools in England and Patron of the MND Association*

December 2010

*In this context end of life care includes both palliative and end of life care

References

- i Department of Health, Equity and Excellence: Liberating the NHS, July 2010
- ii Health and Social Care Bill 2011
- iii National Gold Standards Framework Centre, webpage: <http://www.goldstandardsframework.nhs.uk/>
- iv The Marie Curie Palliative Care Institute Liverpool, Liverpool Care Pathway for the Dying Patient, webpage: <http://www.liv.ac.uk/mcpcil/liverpool-care-pathway/>
- v National End of Life Care Pathway, Preferred Priorities for Care
- vi Department of Health, Quality Accounts, webpage: <http://www.dh.gov.uk/Qualityaccounts/index.htm>
- vii MHP Health Mandate, Provit, data on file
- viii MHP Health Mandate, Accounting for quality: an analysis of the impact of quality accounts in the NHS
- ix Department of Health, World Class Commissioning: Vision, December 2007
- x Department of Health, End of Life Care Strategy, July 2008
- xi MHP Health Mandate, Commissioning in the new world: an analysis of the impact of prioritisation on quality, expenditure and outcomes in the health service
- xii Motor Neurone Disease Association, MND Year of Care Pathway, webpage: http://www.mndassociation.org/for_professionals/sharing_good_practice/mnd_year_of_care.html
- xiii Neurological commissioning support, NeuroNavigator, webpage: <http://www.csupport.org.uk/about-us/our-toolkit/neuronavigator.html>
- xiv Motor Neurone Disease Association, MND Year of Care Pathway, webpage: http://www.mndassociation.org/for_professionals/sharing_good_practice/mnd_year_of_care.html
- xv Neurological Commissioning Support, NeuroNavigator, webpage: <http://www.csupport.org.uk/about-us/our-toolkit/neuronavigator.html>
- xvi Department of Health, End of Life Care Strategy, July 2008
- xvii Macmillan Cancer Support, Always There, June 2010
- xviii Department of Health, End of Life Care Strategy, July 2008
- xix Department of Health, End of Life Care Strategy: Second Annual Report, August 2010
- xx Motor Neurone Disease Association, Getting it right for people with motor neurone disease, 2010
- xxi Department of Health, End of Life Care Strategy: Second Annual Report, August 2010
- xxii Department of Health, Commissioning for Quality and Innovation (CQUIN) payment framework, webpage: http://www.institute.nhs.uk/world_class_commissioning/pct_portal/cquin.html
- xxiii MHP Health Mandate, Provit, data on file
- xxiv NHS Choices, Accessing palliative care, webpage: <http://www.nhs.uk/carersdirect/guide/bereavement/pages/accessingpalliativecare.aspx>



All Party Parliamentary Group on Motor Neurone Disease

**Inquiry into Access to Specialist Palliative Care
for People with Motor Neurone Disease in England**

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