

## **We need to talk about Palliative Care**

### **MND Scotland**

(Our response has been produced in consultation with MND specialist nurses and people affected by MND.)

#### **1. What has been your experience in terms of access to palliative and end of life care?**

Access to palliative and end of life care is very variable depending on where you live with some areas providing excellent service and others much less so.

Day care - Some areas have great access to day care. Other areas only have 10 week blocks at the beginning of the disease process, with nothing available later on, when it is just as valuable – this service needs expanded. In another area, accessing day care was limited and difficult because MND was seen as too complex for staff to deal with compared to other terminal illnesses.

Palliative Care beds - In some areas, accessing Palliative Care beds can be very difficult. This can present a real problem if a person wants to die in a hospice. For example, access to a hospice in Inverness isn't much good if you live in Oban, as your family will be too far away. In some areas it seems to be easier to get access to a palliative care bed if the patient is already known to the palliative care team through day care.

In one area, palliative care staff are so busy that they really only want to provide telephone support and want District Nurses and GPs to be the main providers.

#### **2. How could it be ensured that access to palliative care and end of life care is equitable and available in all areas and for all types of illnesses?**

All areas - All patients should be put on the Gold Standards Framework - GPs and consultants need more education on this. There needs to be more day care available, for longer than 10 week blocks, and much more of it available in each area. There needs to be more access to palliative care beds, as people can't travel for miles to die in a hospice – they need to be near their family. Clear and specific referral criteria, that all the team are aware of and agree to accept, are needed.

All types of illnesses - There is a view that access to palliative care is more difficult for those with illnesses like MND compared to terminal cancer but some people felt this is perhaps better than it used to be. Others said more neurology expertise is needed within palliative care which is currently too cancer focussed. As noted in response to Q1, accessing day care can be difficult because MND is seen as too complex for staff to deal with compared to other terminal illnesses.

**3. Can you identify any areas in terms of access to palliative and end of life care that should be focussed on as priorities?**

- More access to day care
- More palliative care beds for patients.
- *Mandatory* education, ideally as part of medical student and student nurse training with *ongoing* follow up. Big training days where health professionals can pick and choose subjects are not helpful. 'Time to learn' could be re-introduced, releasing health professionals from the wards.
- Symptom control. This would be in the community (GPs need back up on how to manage their patients) and in-patient, as well as end of life care.

**4. When is the right time to begin discussing options for Palliative Care, who should be party to that discussion, who should initiate it and where should it take place?**

When – as soon as possible after diagnosis.

Who should be party to it – patient and family; palliative care team; specialist (MND) team; primary care team. There needs to be an awareness that some patients will wish to protect some members of their family initially.

Who should initiate it – there is no one clear person who should initiate it. Some people feel it doesn't matter who, while others prefer a specific person, for example, specialist nurse, GP or district nurse. One person suggested whoever has the best rapport with the patient.

Where – ideally at home or a home setting. A hospital or GP surgery would be ok as long as the patient feels comfortable there.

**5. What works well in discussing palliative and end of life care and how is good practice communicated? Where do the challenges remain?**

What works well includes: involving the family in discussions; explaining palliative care, what it is, what it involves and all the options; accessing support for all the family; being informed about all the choices and ready to deal with any questions; ensuring GPs are updated and liaising with District Nurses.

Remaining challenges include: education, particularly of GPs and consultants; finding a palliative care bed when needed; communication of good practice - simple things like picking up a phone can make a big difference.

## **6. What is the role of anticipatory care plans in supporting Palliative Care discussions and how can their uptake be improved?**

Anticipatory care plans have a very important role to play in supporting Palliative Care discussions. They include important information on who is providing what care, when, why and how. They also document the patients' wishes, such as does the patient want to go into hospital for intravenous antibiotics, do they want ventilated 24/7, do they want a feeding tube? It is the patient's document and is left with them. All their health professionals must know they have one and it would ideally be shared electronically. Everyone who is on the Gold Standards Framework should have this highlighted on their anticipatory care plan (ACP). The ACP must be addressed and assessed regularly as it often needs to be changed as the disease progresses and the patient/their family learn what is possible and what they can live with, for example, they may initially want a feeding tube but cannot tolerate it physically.

Uptake of ACPs is varied. Some health boards use them, while others rely on letters. However, letters are more likely to be just filed away. A proper form like an ACP is much more likely to be used and, therefore, be more helpful. It is another form but new systems (such as Key Information Summaries) have bedded down and included a financial incentive for GPs.

## **7. How should information about Palliative Care be made available to patients and their family during any initial discussions and how easily available is this information?**

Information on Palliative Care should be made available to patients and their families verbally, in a face-to-face consultation. This would be followed up with written information (in print with

links to electronic information) for the patient and their family to refer to as and when they need it.

## **8. What training and support is provided to Health and Care staff on discussing Palliative Care with patients and families and are there any areas for improvement?**

There are a lot of courses available, held by, for example, hospices. However, uptake is a real problem. Courses are often not attended by the people who should be targeted, for example, doctors. The courses are also often cancelled due to lack of interest.

Palliative Care needs to be part of core training for medical students, student nurses and AHPs. It also needs to be included in mandatory ongoing training, rather than part of a 'training day' where health professionals can opt to pick another topic instead.

Care home staff would also benefit from training. In care homes there is often only one nurse to many professional carers. These carers could be expected to know about Palliative Care and asked questions by families.

**9. How do Health and Care organisations ensure that the discussions about palliative and end of life care are taking place at the right time?**

Ensuring discussions are happening at the right time needs monitoring. Currently, our specialist nurses are heavily relied upon to have these discussions. Training would be helpful as outlined above. 'Just in case' boxes (which can store medication such as morphine and midazolam, a sharps box, DNACPR, a note of where the patient wishes to die ) are used by some health boards and are thought highly of by some of our nurses. They are, perhaps, are a tangible way of ensuring conversations have taken place later in the illness.

**10. What are the challenges in recording and documenting Palliative Care priorities and how well are those priorities communicated between different health and care providers?**

Our specialist nurses each work across several health board areas. However, generally, they only have access to the records and software in the health boards they are *based* in. This means, for example, the specialist nurses may not be able to find out if a patient is on the Gold Standards Framework because they can't access that information. Staff who work across different health board areas need full access to all their patients records, no matter which health board that patient lives in. All the care teams - primary, palliative and specialist - need to have access. Patients are happy to share.

Each of the health board areas have different systems and different software. Some health boards have a system that flags up someone with MND, which is helpful for A&E.

Primary care probably now needs to be the linchpin in ensuring everyone has the information they need. Specialist nurse caseloads have doubled in recent years.

**MND Scotland**