



Triggers for palliative care

Improving access to care for people
with diseases other than cancer



Care and support
through terminal illness

June 2015

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Marie Curie offers expert care, guidance and support to people living with any terminal illness, and their families. We also campaign to ensure everyone can access high-quality care, regardless of their personal circumstances, where they live or the conditions that they experience.

Foreword

Each of our organisations, in different ways, has recognised the importance of providing the right care and support for people living with a terminal illness. We also recognise that much remains to be done to ensure that everyone who could benefit from palliative care gets it. Palliative care specialists, as well as general practitioners, nurses and specialists in other specialities all have a role to play in that care.

We also know that as we all live longer there will be greater complexity of need in the last days, months and years of life. This, together with the projected rise in numbers of people dying over the next couple of decades, reinforces the importance that providing care and support to people with terminal illness must have in our thinking and actions.

The members of our organisations have some of the solutions in their hands, but not all. We will need to work with others who are responsible for setting policies and strategies and for planning and commissioning services; we will need to work with clinical colleagues and people working in other public services as well as the voluntary sector; we will need to engage with patients and their families about how, where and when clinical care and support is provided, and above all else our work and leadership must be focused on the quality of life we can support right up to the point when someone dies.

It's for all these reasons that we welcome Marie Curie's wish to see the conversation about terminal illness change and support their desire to make it happen.



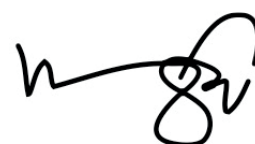
Professor Jane Dacre
President
Royal College
of Physicians




Dr Maureen Baker
Chair, Royal College
of General
Practitioners




Dr Peter Carter OBE
Chief Executive and
General Secretary
Royal College
of Nursing

Professor Rob George
MA MD FRCP
President
Association for
Palliative Medicine
of GB and Ireland



Introduction

“Many people with terminal illnesses miss out on palliative care because there’s limited understanding of how it can help improve quality of life for the individual and their family, at any point of their illness.”

Dr Jane Collins, Chief Executive

This report explores the evidence around access to palliative care for people with terminal illnesses other than cancer. It also uses existing evidence to identify factors which trigger palliative care referrals for people with these conditions.

What is palliative care?

Palliative care is the active, holistic care of people with advanced progressive illness, involving management of pain and other symptoms and the provision of psychological, social and spiritual support. Palliative care aims to help people with advanced illnesses or at the end of their lives have the best possible quality of life. This also includes support for their families.

Palliative care is traditionally associated with a range of principles of care including the view of dying as a natural process, while at the same time affirming life, and acting neither to hasten nor postpone death. It can begin early in the course of illness, in conjunction with other therapies that are intended to prolong life, as well as in terminal care. It includes investigations needed to better understand and manage distressing clinical complications.

Specialist palliative care is provided by multidisciplinary teams. These can include consultants in palliative medicine, nurse specialists, specialist social workers and experts in psychological care. These staff are specifically trained to provide, and advise on, symptom control and pain relief and other forms of psychosocial and spiritual support. Specialist palliative care services include in-patient units, run by both the voluntary sector and the NHS; hospital-based services including hospital support and outpatients; home care services; day care services and bereavement support.

General palliative care is provided by professional carers such as GPs, district nurses, hospital doctors, ward nurses, allied health professionals, staff in care homes, social care staff, social workers and chaplains. As these professionals have not received accredited levels of training in palliative care provision, they are not deemed specialists, but do routinely provide care for people with advanced illness, including those at the end of their lives.*

* Adapted from Dixon J, King D, Matosevic T et al. (2015) Equity in Provision of Palliative Care in the UK. LSE, PSSRU, Marie Curie.

What do we know about palliative and end of life care for people with different conditions?

There is significant evidence which suggests that those who have terminal conditions other than terminal cancer are less likely to be offered or to access palliative care services.¹ In this report, we explore in greater depth the evidence from recent research studies to see why this might be the case and how the issues could be addressed. The report brings together evidence on whether people with heart failure, chronic obstructive pulmonary disease, dementia, end stage liver disease, motor neurone disease, multiple sclerosis, Parkinson's disease and acute stroke are referred to or are able to access palliative care.

This report builds on an independent review the London School of Economics and Political Science (LSE) recently undertook on behalf of Marie Curie which explored inequalities in access to palliative and end of life care. It looks at research studies from the UK, Europe and around the world to determine patterns of referral and access to palliative care and other forms of care for people with different terminal

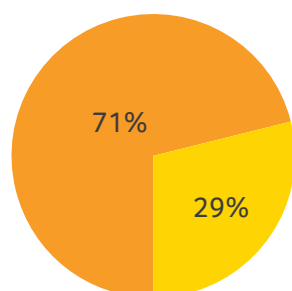
conditions. It is not an exhaustive review, but provides an overview of what we know about referrals to and outcomes of palliative care for people with different conditions.

Much of the literature on palliative and end of life care relates to research into different forms of cancer. We know that most people who access hospice and palliative care have a cancer diagnosis. In a review of nine general practices in Scotland, Zheng et al (2013) found that 75% of people with cancer had been identified as requiring palliative care, compared to just 20% of those with other conditions.²

There has been an overall increase in the number and percentage of people receiving specialist palliative care with a primary diagnosis other than cancer.³ However, the breakdown of diagnoses of patients seen in certain settings is still significantly unrepresentative. For example, 12% of people accessing specialist in-patient services in hospices or hospitals in England, Wales and Northern Ireland have a diagnosis other than cancer but more than two-thirds of deaths in England and Wales are due to illnesses other than cancer.⁴

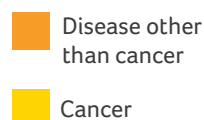
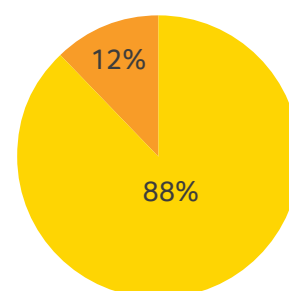
Disparity in access to palliative care

Total number of deaths in England and Wales 2012



Source: see notes 3 and 4

People receiving palliative care in specialist in-patient units in 2012-13



The first national survey of bereaved people (VOICES) in England in 2012 found that 92% of deaths in hospices were due to cancer. Relatives of people who had died of cancer were also more likely to rate their care outstanding than relatives of those who died of other conditions.⁵

In Wales in 2012, of the 8,892 people who died with cancer as the underlying cause, 4,108 (46.2%) had either a recorded palliative diagnosis or were recorded as having been treated within the specialism of palliative medicine. Of the 21,327 people who died from other causes (excluding accidents, suicides and murders) only 1,135 (5.3%) were similarly recorded.⁶

Research evidence also shows us that the picture regarding access and outcomes for people with cancer is far from perfect. Variations exist for people with different forms of cancer, with respiratory and digestive diagnoses being more prevalent across different palliative care settings than other types.⁷ As the recent report by the LSE found:

“Cancer patients who continue to receive aggressive care at end of life and those with haematological cancers are also less likely to access specialist palliative care services.”⁸

Numerous other studies have found people with different cancer diagnoses face specific barriers to accessing palliative care when they need it. Examples include people with brain tumours⁹ and with metastatic breast cancer.¹⁰

Even though referral rates for people with lung cancer are relatively high, there are still issues which prevent

people getting the support they need. A survey of European lung cancer specialists found that three-quarters typically referred their patients to palliative care when there were no other treatment options, or the patient was at the very end of their life, compared to less than a quarter who would refer patients at an earlier stage of the disease.¹¹ The survey identified numerous barriers, including negative attitudes of patients to palliative care and the belief that a referral to palliative care signified abandoning the patient.

It is clear there is still much work to be done to ensure that everyone who has cancer who wants and could benefit from palliative care is able to access it. Having said this, the available service level data and research reinforces the conclusion that the situation is very different for people with terminal illnesses other than cancer.

The following section of this report provides a brief overview of what we know about end of life and palliative care for people with some of the most prevalent terminal illnesses:

- It builds on the evidence base presented by the recent LSE report and further explores the barriers which prevent people with different conditions from getting the care they need.
- It identifies the factors that should trigger the involvement of palliative care services for people living with these terminal illnesses.
- It demonstrates the beneficial impact palliative care can have when good practice is implemented.

Part one: How accessible is palliative care for people with different conditions?

Throughout the UK, demographic changes mean that many more people are living with complex needs and multiple conditions.¹²

What are multimorbidities?

Multimorbidity, defined as the coexistence of two or more long-term conditions in a person,^{*} is rapidly becoming the norm and this is set to increase as the population ages.¹³ This means that people who are living with

a terminal illness will often have a number of conditions to manage at the same time, such as cancer, chronic heart disease and stroke, especially if they are older. Evidence suggests that 44% of adults in the last year of life have multiple long-term conditions.¹⁴

People have more complex needs

The number of people in England with at least three long-term conditions is expected to have risen from

1.9 million
2008

2.9 million
2018

Sources: see notes 15 and 16

44%
of adults

in the last year of life have multiple long-term conditions



* This report refers both to comorbidities, or comorbid conditions, and multimorbidity. Complex conditions which occur in addition to a primary condition are known as 'comorbid'. The term multimorbidity describes the state of having multiple long-term, complex conditions. See Newman AB (2012) *Comorbidity and Multimorbidity* in *The Epidemiology of Ageing*, eds. Newman AB, Cauley JA (Springer Netherlands) pp. 199-133.

People with multimorbidities often experience poorer health outcomes than those with single chronic conditions. They are more likely to die prematurely, be admitted to hospital and have longer hospital stays.¹⁷ They are also more likely to have a poorer quality of life, experience depression and have to negotiate fragmented services that focus on treatment and management of single conditions. People often have to cope with their conditions through complex self-management.¹⁸

This is further compounded by factors such as deprivation, with multimorbidity showing 10-15 years earlier in people living in the most deprived areas compared with those living in the least deprived areas.¹⁹

There is a clear need for integrated care across conditions, across primary and secondary care, between health and social care, and between medical care and self-management.

Heart failure

In recent years, the importance of providing good quality palliative and end of life care for people with chronic heart failure has been recognised across the four UK nations through a series of recommendations and guidelines.²⁰ The National Institute of Clinical Excellence (NICE) has also published guidance: Specifying supportive and palliative care for people with chronic heart failure.²¹

These documents build on the research evidence which shows people with

chronic heart failure have often lacked access to appropriate care as they reach the end of their life. It is clear their needs and symptoms could be better addressed through adopting a more holistic or palliative approach. Evidence from Scotland suggests that patients and their carers:

*“May complain that they are uninformed about their condition, are excluded from decision making and feel that control of their lives is taken away from them”.*²²

An American study found that less than a fifth of people who would be suitable for hospice care* were able to access it.²³ The study identified the lack of prognostic indicators and the relatively high cost of providing care as barriers to access. It also cites evidence from other studies to argue that the traditional focus within hospice care on supporting people with cancer “may discourage practitioners who care for cardiac patients from referral to hospice programs.”²⁴ This is a recurring theme in the literature for conditions other than cancer.

Green et al (2012) looked at the perceptions of healthcare professionals regarding the transition of people with heart failure to palliative care.²⁵ They highlighted that the issue of ‘unpredictable trajectories’ was paramount and that this led to ‘diagnostic ambiguity’. The authors identified:

“A need for both established prognostic guidelines and further education to

* Note: The American meaning of hospice care is broader than that used in the UK. It refers to the philosophy of the holistic approach to care available to people who are approaching the end of life and for whom curative treatments are no longer an option. It therefore includes palliative care. It is often provided at home, rather than within a hospice. See <http://palliatiivedoctors.org/faq> for more information.

develop the communication skills to facilitate end of life discussions with [heart failure] patients.”²⁶

One key related issue seems to be a lack of recognition of condition-specific triggers which can help to signal that a palliative care approach would be appropriate, or that the person with heart failure is reaching the end of life stage. These may well be different to symptoms one would expect in a person with advanced cancer. Johnson et al (2010) argue that:

“Complex or persistent problems (eg intractable pain, difficult breathlessness) should trigger referral to specialist palliative care services – these are not only for the dying patient... Breathlessness is a neglected and ‘invisible’ symptom which is a risk factor for emergency hospital admission and caregiver distress.”²⁷

Their solution is ongoing but episodic involvement of palliative care teams, working alongside cardiology and respiratory teams to ensure patients have the best access to care when they need it.

D’elia et al (2013) conclude that high levels of hospital use should trigger access to palliative care, both for people with heart failure and those with chronic obstructive pulmonary disease (COPD):

“The length of hospitalization [sic] during the previous year represents the main mortality predictor for both populations and it is a key sentinel event in the late clinical course of HF (heart failure) or COPD, thus it might be used as a screening tool for appropriate referral to palliative care.”²⁸

Another barrier to people with heart failure getting the care they need is patients’ and professionals’ perceptions of palliative care. In another US study, Kavalieratos et al (2013) explore providers’ perceptions of the barriers to palliative care facing people with heart failure.²⁹ These include ignorance about what palliative care is and what it can do among both patients and care providers, perceptions of palliative care as giving up, the role of religion and culture in individual preferences and the preference for ‘aggressive treatment’.³⁰

It is important to underline that these barriers are the perceptions of providers rather than of people with heart failure. However, the authors conclude that it is imperative to educate both the public and professionals to increase palliative care awareness and disassociate it from “the notion of ‘comfort only’ or terminal care”.³¹ The Scottish Partnership for Palliative Care has also suggested that:

“Wider recognition of heart failure as a terminal condition which adversely affects the quality of life of patients and carers would facilitate better service provision.”³²

It is clear that healthcare professionals need specialist training and support on this issue. Naib et al (2015) argue for increased palliative care education and training among clinicians involved in cardiac critical care in intensive care units.³³ Clinicians could also be better supported to talk to their patients about their wishes and options for treatment as they approach the end of life. In a review of studies reporting on heart failure patients’ experiences, Barclay et al (2011) found:

“End of life care is rarely discussed with conversations focusing largely on disease management although some people would welcome such conversations – many patients do not realise the seriousness of their condition.”³⁴

Although some people with heart failure may not want to discuss the end of life with their clinicians,³⁵ the evidence suggests that many perceive they have not been given the opportunity to do so. A recurring issue in the literature is the willingness and confidence of doctors and nurses working in specialist services to deal with communication about palliative care, death and dying. Some clinicians may avoid these discussions because of the uncertainty of a person’s prognosis or the high risk of sudden death from the condition.³⁶ A recent US based study found that some clinicians lack confidence in dealing with decisions and communication regarding end of life care:

“Only 12% of clinicians reported having annual end of life discussions as advocated by the American Heart Association. In total, 52% of clinicians hesitated to discuss end of life care citing provider discomfort (11%), perception of patient (21%) or family (12%) unreadiness, fear of destroying hope (9%), or lack of time (8%).”³⁷

The study also found confusion between clinicians about whose role it is to communicate with people about their end of life care preferences and needs.

Better education about when palliative care is appropriate and who it is appropriate for could also help to tackle the problem of late referral, another recurring theme in the literature.

Following a five year review of case notes for people with heart failure, Bakitas et al (2013) found that the average time from referral to palliative care to death was just 21 days.³⁸ The authors conclude that earlier palliative care consultations could allow for broader integration across palliative care services. This would enable people with heart failure to benefit from this care and support before they reach the final month of their life. Charnock (2014) argues that earlier access to palliative care could help support advance care planning, support patients and families and promote better symptom management.³⁹

The benefits of having a palliative care consultation and accessing palliative care for people with heart failure are widely reported. Schwarz et al (2012) found that using the American College of Cardiology/ American Heart Association (ACC/AHA) palliative care guidelines led to more appropriate interventions with people with advanced heart failure who were awaiting transplantation. The study found that:

“[Palliative care] consultation resulted in a decrease in the use of opioids and increased patient satisfaction. Patients and their family members generally reported improved holistic care, continuity of care, more focused goals of care, and improved planning of treatment courses.”⁴⁰

The study concluded that:

“Palliative care consultation appears to be beneficial in the treatment and quality of life of advanced HF (heart failure) patients, independent of their prognosis.”⁴¹

These findings are echoed by Evangelista et al (2012), who found that improvements in symptom burden, quality of life and depression were more pronounced for patients who received a palliative care consultation.⁴² Ensuring that Heart Failure Nurse Specialists have a clear understanding of the role of palliative care, and know when and why to refer people, can also have a significant impact on timely referrals.⁴³

Chronic obstructive pulmonary disease (COPD)

Many of the issues for people with heart failure also apply to people with COPD. D'elia et al (2013) carried out a study which looked at the palliative care needs and experiences of people with COPD and/or advanced heart failure. They found that clinical experiences relating to symptom burden, function and quality of life impairment and six-month mortality rates were broadly comparable.⁴⁴ The study also found that prognostic uncertainty was a barrier to accessing palliative care for people with either (or both) conditions and suggested high hospital use as a potential trigger for palliative care. However, far fewer palliative care intervention studies focusing on COPD are available.

A key issue again is that people with COPD aren't accessing the care that they need, particularly when compared with people with cancer, despite having similar symptoms. Chou et al's (2013) retrospective study, comparing hospital based end of life care for people with COPD and end stage lung cancer in Taiwan, showed greater levels of multimorbidity and more days spent in intensive care for those with end

stage COPD.⁴⁵ Those with COPD were also more likely to die in intensive care and less likely to die in a hospice despite similar symptom burdens for the two conditions. Again, prognostic uncertainty is a contributing factor. They found:

*"Differences in treatment management suggest that COPD patients receive more care aimed at prolonging life than care aimed at relieving symptoms and providing end of life support. It may be more difficult to determine when COPD patients are at the end of life stage than it is to identify when lung cancer patients are at that stage."*⁴⁶

Further research has found this disparity in available care persists despite hospitalised patients with COPD having similar preferences for comfort-based care.⁴⁷

Colman et al (2013) argue that, given palliative care's focus on symptom control and psychosocial support, it should have a greater and earlier role in supporting people awaiting lung transplants.⁴⁸ They conclude:

*"In patients awaiting lung transplantation, [palliative care] need not be delayed until the final hours but can be provided earlier without compromising eligibility for transplant or exercise tolerance. The effect of [palliative care] interventions on patient quality of life requires further study."*⁴⁹

As with heart failure, a lack of routine communication with health professionals acts as a barrier to people with COPD getting the most appropriate care. In a survey of 214 UK general practitioners, Elkington et al (2001) found that only 41% reported

‘often’ or ‘always’ discussing prognosis with patients who had severe COPD, even though 82% felt that GPs should discuss prognosis with this group.⁵⁰ Two thirds of the physicians who reported infrequently discussing end of life care also reported feeling inadequately prepared to have such discussions.

Consequently, other studies have found that people with severe COPD are more likely to feel concerned about the lack of information they’ve been given about approaching the end of life when compared to people with conditions such as metastatic cancer or advanced AIDS.⁵¹ Curtis et al (2002) found that patients with severe COPD wanted more information from their physicians regarding diagnosis and disease process, treatment and prognosis, what dying might be like and advance care planning (ACP). The authors conclude:

“Physicians and educators should target patients with COPD for efforts to improve patient education about their disease and about end of life care.”⁵²

As noted by Weber et al (2014), there is a paucity of palliative care intervention studies for people with severe COPD. More research is needed in this area to determine how and whether early palliative interventions affect outcomes, such as the amount of emergency hospital admissions and intensive care use.⁵³

However, evidence does show that palliative care can have a positive

effect on physical and psychological symptoms. Schroedl et al (2014) carried out a retrospective case analysis of people with COPD who were referred to an outpatient palliative medicine programme in the US.⁵⁴ Many of the patients were found to have comorbid conditions (in addition to their primary diagnosis) such as heart disease and undertreated symptoms such as fatigue and breathlessness. None of the patients had advance directives* in place at their initial appointment. However, after follow-up appointments, they reported better outcomes on self-management of their illness, legal preparation for the end of life, lower symptom distress, better physical functioning and higher self-rated health when compared to a control group.

Researchers at the Marie Curie Palliative Care Research Centre in Cardiff have looked at the care needs of people with idiopathic pulmonary fibrosis (IPF), a chronic lung disease with an average survival time of three years. They found that patients and carers often understood the poor prognosis and would value a structured approach to the management of the condition. This approach should account for their differing needs in ongoing care and support and better communication of key points along the disease trajectory. The authors conclude that:

“Implications for service provision includes multidisciplinary team involvement, keyworker assignment and provision of increased information resources.”⁵⁵

* In the US an advance directive is a legal document which sets out a person's wishes for their treatment should illness or accident render them incapable actively participating in these decisions. They may be very basic, simply naming a proxy to make decisions for that person's care, or very detailed.

Dementia

A major research programme at University College London (UCL), funded by Marie Curie, has extensively explored the end of life care and experiences of people with advanced dementia.⁵⁶ Outputs have already shone a light on the previously neglected area of end of life care for people with dementia. However, as recent reports from Marie Curie have shown, the increased research focus on end of life care needs of people with dementia has not necessarily translated yet into national strategic approaches to dementia care across the UK.⁵⁷

The starting point again is that people with dementia have much less access to palliative and hospice care. De Vries et al (2011) undertook a retrospective case note audit of people using a hospice in England which found that only 9% of people had either dementia as a primary diagnosis or a comorbidity.⁵⁸

This is echoed by the World Alzheimer Report 2013.⁵⁹ This found that fewer than one in 10 people with dementia at the end of life on acute medical wards were referred to a palliative care specialist, compared to one in four people who did not have cognitive problems.

The report concludes that professionals' perceptions of dementia may partially explain these relatively low rates:

*"Dementia is not often thought of as a terminal illness that requires specialist care. The lack of specific dementia training for staff working in end of life facilities could play a role in this."*⁶⁰

Sampson et al (2012) aimed to identify barriers for people with dementia to access good quality end of life care.⁶¹ In a case note review of nine people who had died with dementia, they found two-thirds had a care plan documented in the six months prior to their death but in only one case had any advance care planning (ACP) occurred. None had any formal ACP documentation in place. No records were found of palliative care team involvement in any of the cases and only one had been put onto an end of life care pathway.

The study also found that health and social care professionals reported feeling inexperienced in supporting ACP and they lacked confidence in adhering to advanced directives, especially 'do not resuscitate' orders.⁶² These findings are echoed in Denning et al (2012), which again assessed barriers to end of life care for people with dementia through interviews with carers and health and social care professionals.⁶³ It was found that underpinning many of the barriers were:

"Feelings of uncertainty, the perceived futility of caring for someone with dementia and the need for education and training."

Research has however shown that palliative care interventions can be very appropriate for people with advanced dementia, for whom symptoms associated with multimorbidity and pain may be common. In an observational study of 230 people with dementia, Sampson et al (2015) found that nearly two-thirds were observed to experience pain, however fewer than 40% were able to report it due to the nature

of their condition.⁶⁴ The authors conclude that:

“Improved pain management may reduce distressing behaviours and improve the quality of hospital care for people with dementia.”

A US study by Lubow et al (2013) sought to establish the proportion of people with advanced dementia referred to palliative care following in-patient psychiatric care.⁶⁵ They concluded that fewer than one in every 10 of those with advanced dementia who died within 90 days were referred to a palliative care setting. They advocate taking advantage of opportunities to discuss advance care planning and palliative care during psychiatric admissions for this group of people.⁶⁶

Other studies have drawn attention to the challenges of engaging in ACP for people with dementia.⁶⁷ As mentioned above, staff may feel confused about which parts of a plan are legally binding. They may also be afraid of possible consequences if they follow an advance plan which requests that active treatment is *not* given. From the person with dementia’s perspective, they may not wish to engage in ACP and instead focus on the ‘here and now’. (This is not a wish unique to people with dementia and may be the case for anyone with a terminal condition.) In their review of advanced directives for people with dementia, Sampson and Burns (2013) conclude that:

“Embedding ACP in practice would require effort at a number of levels throughout the health and social care system: wider changes in the system (eg standardisation

of documentation), changes at the team level (training and supporting staff) and at the level of the individual, for example, encouraging staff in feeling confident that ACP is their responsibility and giving them and the person with dementia the ‘ownership’ they need to complete this process.”⁶⁸

Another issue in the literature relates to identifying appropriate triggers for when a person with dementia may benefit from palliative care. The prognosis for people with dementia is often uncertain. Sampson et al (2012) conclude that emergency hospital admissions may be a useful indicator of mortality risk for a person with advanced dementia.⁶⁹ The authors recommend:

“This may be a useful ‘transition’ point at which to consider advance care planning and discussion of prognosis with the patient (if possible) or with their family to consider which interventions are in their best interests both now and in the future.”⁷⁰

Brown et al (2012) identify indicators relating to nourishment and eating habits, increased risk on dementia severity scales and multimorbidity as the most common prognostic indicators. More research is needed in this area.⁷¹

End stage liver disease (ESLD)

The palliative care needs and experiences of people with end stage liver disease has, until recently, received much less research attention than for people with conditions such as heart failure. As Iredale (2008) notes:

“With a few key exceptions, there is little in the literature on the appropriate palliative

approach for patients with end-stage liver disease.”⁷²

Marie Curie is currently funding research led by Dr Joe Low at the Marie Curie Palliative Care Research Unit, University College London which is helping to provide insight into the experiences and barriers to palliative care for people with end stage liver disease in their final year of life. In a case note review of 30 patients with ESLD, the team found that planning for end of life care was often limited with intensive treatments pursued instead.⁷³ When referrals were made to palliative care they were in the last few days of life and all patients died in hospital. Further research found links between liver health professionals and palliative care services are tenuous.⁷⁴

Boyd et al (2012) argue that people with ESLD stand to benefit from palliative care delivered in parallel with disease-focused treatment because many will have comorbidities and organ donor supplies are limited.⁷⁵ The authors do note that the trajectory of ESLD is very different than would be predicted for a typical progressive cancer and

there is no clear terminal phase, meaning decisions about when to introduce palliative or end of life care can be complicated. However, they suggest multimorbidity and recurrent unplanned admissions to hospital could be suitable triggers. They note that:

“When asked directly about their care preferences, many patients with end-stage organ failure, including those with liver disease, expressed a clear wish for a palliative care approach that focuses on reduction of morbidity.”⁷⁶

Gardiner et al (2011) emphasise that waiting until the palliative care need is certain “may result in missed opportunities for symptom control and advance care planning.”⁷⁷

The NHS National End of Life Care Programme published *Getting it Right: Improving End of Life Care for People with Liver Disease in England in 2013*. The document sets out a strategic approach to improving end of life care for those with advanced liver disease⁷⁸ and explains why this may be particularly challenging:

- For patients: a lack of public awareness that liver disease is commonly fatal and late presentation in the disease process, possibly due to unawareness or perceived stigma.
- For healthcare professionals: the fact that gastroenterology and hepatology training programmes do not currently teach end of life care and the need for a culture change which encourages the adoption of end of life care planning in parallel to active treatment.

“Because there was hope of a transplant he didn’t think of himself as terminal...If we had had a care plan, then that would have made it more real. It would have been something to have had that option – to say: ‘If you get to this stage then what do you want? Do you want to die at home?’ But it was never discussed with us.”

Woman whose husband died of end stage liver disease

- For healthcare organisations: a lack of access to specialist experience both for liver and palliative care advice (particularly during out-of-hours times) and an increase in the number of people with ESLD which may put a strain on resources.⁷⁹

Marie Curie and the homelessness charity St Mungo's have previously worked with colleagues from the Marie Curie Palliative Care Research Unit at UCL on a project which explored the experiences of homeless people with ESLD.⁸⁰ They looked at the role of a palliative care coordinator in ensuring that people with ESLD were able to access palliative care. The coordinator identified staff training needs, assisted staff with recognising residents who may need palliative care and engaged residents in advance care planning. Previously there had been very little evidence of these activities.

Motor neurone disease (MND)

Guidelines are available which outline when palliative care is appropriate for people with MND.^{81,82} However, it is acknowledged that:

*"The palliative care of a patient with motor neurone disease (MND) starts even at the time of diagnosis, and this care throughout the disease process is crucial to management in the later stages."*⁸³

Unlike many of the other conditions covered in this report, MND often has a predictable course which means palliative care can be planned in a similar way as for those with a terminal cancer diagnosis. However, about 10% of people with MND will have

a more slowly progressive form, which they may live with for 10 to 20 years.⁸⁴

The All Party Parliamentary Group on Motor Neurone Disease published their Inquiry into Access to Specialist Palliative Care for People with Motor Neurone Disease in England in 2011. The inquiry took oral evidence from 20 witnesses and written evidence from 62, including 23 people with MND and their carers. It concluded that the rate at which the condition progresses means that palliative care should begin as soon as possible:

*"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."*⁸⁵

However, it found that while 'pockets of excellence' in specialist palliative care for people with MND do exist in England, these are the exception rather than the rule. MND Care Centres were found to provide the benchmark of specialist care but these only covered 60% of England and there are particular difficulties of access for people with MND who live in English rural areas.

The importance of the psychological and spiritual support palliative care could provide was underlined in oral evidence from a person with MND:

"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...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...”⁸⁶

Multiple sclerosis, Parkinson’s disease and acute stroke

The research evidence about some conditions which are not generally considered terminal illnesses shows that many of the same issues around access to palliative and end of life care apply. Even though they are typically not thought of as being terminal, for many people the condition will eventually lead to their death. A palliative care approach can improve the quality of life for people with these conditions, perhaps alongside other active treatments.

Multiple sclerosis (MS) and Parkinson’s disease are both long-term neurological conditions. Both conditions progress slowly and are not fatal. However, a large scale retrospective analysis of people with MS in Denmark found that MS was the underlying cause of death in over half of people living with the condition.⁸⁷ Another study found that 62% of people who died with MS in Scotland had died from complications of the disease.⁸⁸

An analysis of trends in mortality for people with Parkinson’s disease in England and Wales found that the disease has been listed as the underlying cause of death for about half of those who died with the condition since changes to coding practices were introduced in 2001.⁸⁹

Statistics from Stroke Association show that one in eight strokes are fatal within

the first 30 days, and one in four are fatal within a year.⁹⁰

Multiple sclerosis (MS)

Issues of limited access to timely palliative care are again evident for people with MS. This is despite evidence which suggests the symptom burden for those who are severely affected is similar to that for people with advanced cancer.⁹¹

People with MS may also have emotional and psychological problems that palliative care could help with, such as how to cope with change and loss.⁹² Higginson et al (2011) assessed the impact ‘fast-track’ palliative care referral for people severely affected by MS had on five key symptoms (pain, nausea, vomiting, mouth problems and difficulty sleeping) which could be considered triggers to palliative care. They also looked at how this affected the staff involved in the person’s care.⁹³ They found that receiving palliative care earlier had a similar effect on reducing symptoms as standard best practice. Earlier referral did, however, have greater effects on reducing the burden on care givers.

The need for, and challenges to, providing appropriate palliative care for people with MS are considered in the National Council for Palliative Care’s (2011) document End of life care in long term neurological conditions: A framework for implementation.⁹⁴ The document also considers how best to provide palliative and end of life care for people with other neurological conditions such as MND and Parkinson’s disease. It notes that, unlike MND or

cancer, the long duration and fluctuating nature of MS may require a more dynamic involvement of palliative care which responds to appropriate triggers:

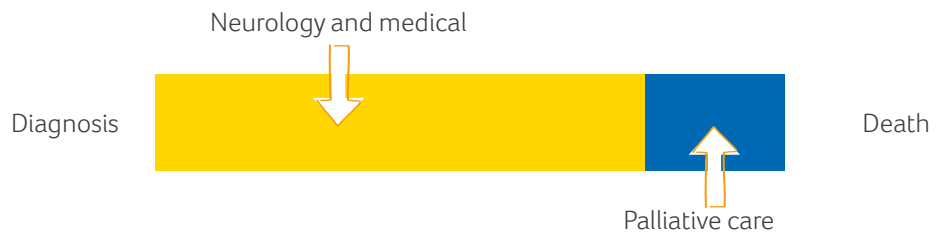
“As individual needs vary over time there may be a role for episodic involvement of palliative care services, especially at times of particular symptoms or psychosocial issues – such as the start of new interventions (like gastrostomy feeding or ventilatory support) or at the very end of life.”⁹⁵

This dynamic approach is illustrated in Figure 1:

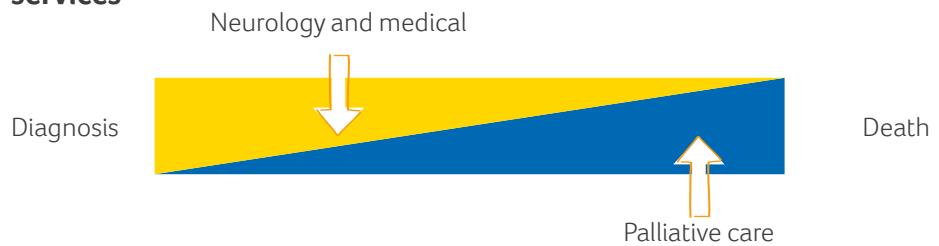
The perceptions of people with MS and of healthcare professionals may, however, act as a barrier to access. Golla et al (2014) carried out a qualitative study which assessed the attitudes towards palliative care of people severely affected by MS and their health professionals in Germany.⁹⁷ The study highlights that people’s awareness of palliative care is often associated with imminent death and therefore it is approached with (or rejected out of) fear. Many patients were either unfamiliar with the term or associated it with cancer and dying. Physicians

Figure 1. Models of involvement of palliative care services

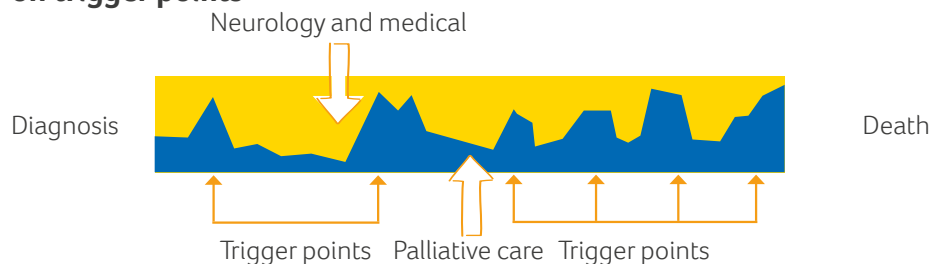
A. The traditional model of late involvement of palliative services



B. The model of early and increasing involvement of palliative services



C. The model of dynamic involvement of palliative services based on trigger points



Source: NCP, NEoLCP.⁹⁶

were likely to dismiss its relevance for a long term neurological condition such as MS. Interestingly, most also reported that they felt they already offered their patients sufficient palliative care. Recognition of the potential benefits palliative care offers MS patients was much better with nurses and social workers.⁹⁸

Parkinson's disease

The National End of Life Care Programme framework for implementing end of life care in long term neurological conditions recommends that palliative care should be involved at an early stage for people with Parkinson's disease to assist with symptom management.⁹⁹ However, research suggests that this is not currently happening.¹⁰⁰ Lack of awareness and understanding of palliative care services are once again key barriers.

Tuck et al (2015) found a clear preference from people with Parkinson's disease to receive information regarding their prognosis, treatment and ACP earlier.¹⁰¹ The authors argue

that a failure to identify the disease as terminal by healthcare professionals may complicate decisions about when to begin communicating about ACP. The high prevalence of dementia and cognitive impairment in people with Parkinson's disease makes the early introduction of these discussions all the more important.

Richfield et al (2013) identify that a 'palliative phase' is conventionally recognised in practice.¹⁰² This is associated with a lessened response to drug treatments aimed at increasing levels of dopamine in the brain and cognitive decline. They find this phase typically lasts just over two years. However, they find that qualitative research suggests palliative care is appropriate from the point of diagnosis. The authors emphasise that:

*"There is a compelling argument to move away from the traditional prognosis-based model towards fully integrated, needs-based provision."*¹⁰³

They also stress the need for research to look at 'red flags' for unmet palliative care need and 'trigger' events to identify when it is necessary to refer someone to specialist palliative care.¹⁰⁴ The Palliative care Outcome Scale (POS) has been designed to improve outcome measurement in palliative care for people with advanced diseases. Making use of this tool, adapted for use with Parkinson's disease, has been shown to help identify the large amount of unmet need for specialist palliative care for those in an advanced stage of the disease.¹⁰⁵

"I think Mum was very fortunate in that when she moved into the palliative stage, in the nursing home, it was a really good experience. She had an end of life care plan, which covered things like having her favourite music on and that she would like to be treated with dignity and respect."

Woman whose mother had Parkinson's disease

Acute stroke

An acute stroke is not necessarily a terminal condition. However, some people who have severe strokes, or who develop chronic cerebrovascular disease following an acute stroke, may have needs which would benefit from palliative care or end of life care.

Burton et al (2010) acknowledge that despite high mortality rates (30%) for those who have acute strokes “little is known about the palliative care needs of this group”.¹⁰⁶ Their study of people admitted to hospital after an acute stroke using the Sheffield Profile for Assessment and Referral to Care (SPARC) – a screening tool for referral to specialist palliative care – found that they had high levels of palliative care needs. These included fatigue, pain, symptom management, psychological distress, concerns about disability and dependence, and about death and dying. Burton et al advocate the use of SPARC to assess the palliative care needs of people who have had an acute stroke.¹⁰⁷

NHS Quality Improvement Scotland produced a best practice statement on end of life care following acute stroke which provides guidance to support professionals to ensure that people who have had acute strokes can access palliative care.¹⁰⁸ It includes a focus on the relationship between stroke specialists and palliative care teams and the requirements on multidisciplinary teams.

Cowey et al (2015) highlight the additional challenges clinicians face in trying to recognise whether people will

die from stroke such as sudden onset, uncertain outcomes, aphasia (language disorders) and cognitive impairment.¹⁰⁹ This can make decisions about whether to support the patient through end of life care more complicated. Through interviewing healthcare professionals, the authors found that:

*“Physiological signs such as altered breathing patterns, blood results or vital signs were the most commonly reported indicators that patients were dying. Clinical trajectory was also relevant. Thus, persistent coma with lack of meaningful improvement, absence of response to sustained treatments or serious clinical deterioration were all used as markers of impending death.”*¹¹⁰

Other indicators included the severity of the stroke or the clinical picture, gained through discussions with the wider multidisciplinary team about the person’s clinical history. Professionals also described two distinct trajectories following acute stroke: sudden death or prolonged dying. The study found that both healthcare professionals and relatives were uncomfortable with prolonged dying, and relatives were unprepared for this outcome. However, relatives expressed most discomfort when excluded from decision making or when they felt overly responsible for decisions. The authors conclude that greater communication between clinicians and relatives about the end of life is important:

“It may be impossible to prepare families fully for the distress of a relative’s prolonged death. However, healthcare professionals are required to communicate the

“Although my husband was quite poorly, we were not offered any palliative care support. The only day that we had any dealings with the palliative care team was on the day before he died...I wish there was more communication, and earlier in time, to help us prepare for the end and to discuss his last wishes.”

Woman whose husband died of end stage liver disease

uncertainties of end of life care to families. It may be helpful for clinicians caring for dying stroke patients to communicate uncertainty more clearly to families from early in the hospital admission.”¹¹¹

Barriers and triggers

Although there is not scope within this report to provide a fully comprehensive coverage of all the research, the evidence discussed brings to light a number of key issues which could be preventing people with conditions other than cancer accessing the care they need. These include:

- Prognostic uncertainty and hard to predict disease trajectories.
- A failure or reluctance to identify certain conditions (eg dementia) as terminal by professionals.
- A lack of understanding of what palliative care is, and what it can achieve for people with conditions other than cancer, by both professionals and people with a terminal illness and their families.
- For some conditions, such as COPD, a paucity of research which demonstrates potential benefits of palliative care on patient’s health outcomes (compared to the amount of research on lung cancer, for example).
- A lack of confidence from professionals in delivering care appropriate for people approaching the end of their life, for example, thinking that initiating end of life care discussions is someone else’s role or concerns about the legal standing of advance decisions.
- Under-developed links between condition specialists and palliative care specialists.

It is also possible to identify a number of ‘triggers’ which could provide effective indicators that someone with a terminal illness would benefit from palliative care services. These triggers include:

- Complex or persistent problems with symptoms such as:
 - intractable pain
 - difficult breathlessness
 - nausea
 - vomiting
 - mouth problems
 - difficulty sleeping and fatigue
 - psychological issues, such as depression and anxiety.
- High levels of hospital use, especially unplanned admissions.
- Having more than one condition (multimorbidity).

- Factors relating to nourishment and eating habits in people with cognitive impairment (eg dementia).
- The introduction of new interventions (eg gastrostomy feeding or ventilator support).
- For some conditions, such as MND, at the point of diagnosis.
- When a screening tool indicates that it would be appropriate (eg the Sheffield Profile for Assessment and Referral to Care (SPARC) or the Supportive and Palliative Care Indicators Tool (SPICT) – see page 24).

The research discussed in this section has also highlighted examples of good practice which evidence the benefits of timely access to appropriate palliative care for people with different conditions. The following section considers what needs to change to ensure good practice becomes the norm and all people with a terminal illness are able to access the care they need.

Part two: Redressing the balance

We need everyone to play a part in breaking down the barriers identified in the research.

This section explores what needs to change to make timely access to appropriate care a reality for people regardless of their condition, based on the available research. Governments, service commissioners, health and social care professionals, voluntary sector organisations, people living with terminal conditions and their carers all need to work together to bring about change.

How understanding the triggers can ensure timely referral

Owing to significant variations in disease trajectories for different terminal illnesses, a number of authors argue that we need to avoid adopting traditional prognosis-based approaches to palliative care referrals. Instead, we should focus on the person, their experiences of a particular terminal illness and their present needs.

For people with conditions such as MND, where the trajectory of the illness is often quite similar to that of terminal cancer, there is a strong case for offering palliative care from the point of diagnosis.¹¹²

For other conditions, in which progression is slower or more unpredictable, deciding when to introduce palliative care may be more difficult. In a letter to the editor of the journal *PallMed*, Small et al (2010) focus on the issue of palliative care referrals for people with heart failure and/or COPD. They argue that the ‘surprise question’ – “Would I be surprised if the person in front of me died within the next six months or one year?” – should not be used as a trigger for a referral to palliative care as it “will inhibit the initiation of palliative care for these patients.”¹¹³

They argue that using the ‘surprise question’ reinforces too narrow a definition of when palliative care is appropriate. They conclude it should not become a ‘shorthand referral tool’ for people with advanced heart failure and COPD and end of life care strategies should reflect this. Similar arguments have been made about the inadequacy of a conventionally recognised ‘palliative phase’ of about two years prior to death for people with Parkinson’s disease.¹¹⁴

Research evidence identifies (see pages 21–22) a number of potential triggers which could signal that a person may benefit from a palliative approach. These include breathlessness, complex and persistent pain, high levels of hospital use, multimorbidity, problems with maintaining psychological and social wellbeing and the introduction of new interventions. These triggers are aligned with a more person-centred approach, focusing on holistic need rather than life expectancy. They also support the adoption of a more dynamic and flexible approach to palliative care interventions which can be more episodic and multidisciplinary. This sort of approach has been recommended for people living with MS and Parkinson's disease and is likely to be beneficial for other conditions which are characterised by a cycle of crises and remissions.¹¹⁵

Palliative care screening tools have been shown to support a more holistic, person-centred approach to referral. In a study of people admitted to hospital after an acute stroke, Burton et al (2010) found that using the Sheffield Profile for Assessment and Referral to Care (SPARC) – a holistic screening tool for referral to specialist palliative care – helped to identify people with high levels of palliative care needs. Items on the assessment tool include fatigue, pain, symptom management, psychological distress, concerns about disability and dependence and fears about death and dying. This means it can be relevant regardless of diagnosis or stage of disease. Burton et al advocate the use of SPARC to assess the palliative care needs of people who have had an acute stroke.¹¹⁶

Other research has found that the tool would be widely acceptable to other potential users.¹¹⁷

The Supportive and Palliative Care Indicators Tool (SPICT) is a clinical tool that NHS Lothian and The University of Edinburgh Primary Palliative Care Research Group have been developing since 2010. The tool is designed to support improved care by those providing general supportive and palliative care for their patients rather than to identify patients for specialist palliative care referral. It includes readily identifiable general indicators of deteriorating health commonly present in advanced conditions. It also features evidence-based clinical indicators of major advanced, life-limiting conditions and multimorbidity. An evaluation by Highet et al (2013) found that:

*“It helped identify patients with multiple unmet needs who would benefit from earlier, holistic needs assessment, a review of care goals, and anticipatory care planning”.*¹¹⁸

Health bodies across the UK and globally have adopted or adapted SPICT to identify patients who would benefit from holistic support and care planning.¹¹⁹

Changing perceptions of palliative and hospice care

A recurrent theme in the literature addressing barriers to accessing appropriate care for people living with terminal illness is the lack of understanding of palliative care, what it is and how it can support people. This is true both for the person and for health and social care professionals. This

is not simply the case for those with conditions such as dementia,¹²⁰ heart failure¹²¹ and MS,¹²² but includes some forms of cancer.¹²³

Zheng et al (2013) assessed how well the World Health Organization (WHO) recommendation that palliative care is gradually phased in from the point of diagnosis of a progressive life-threatening illness is being put into practice. They found:

“... a reluctance to discuss issues around death and dying hindered open end of life conversations. Both patients and some professionals struggled with palliative care concepts and the negative connotations associated with words such as ‘palliative’, ‘hospice’, ‘resuscitation statuses’ [...] This in turn led to reluctance to initiate conversations, which impeded formal inclusion on the [Palliative Care Register].”¹²⁴

They conclude:

“Any campaign to encourage early recognition of the dying phase must emphasise that the purpose of a palliative care approach is to provide more clinical,

emotional and practical support to patients and their families, rather than to withdraw treatment. Adequate staff training is also vital.”¹²⁶

Inappropriate perceptions about what palliative care is and when it is suitable can prevent or delay referrals. As Table 1 shows, people with dementia in particular are likely to be referred to palliative services only when they are very near the end of their life.

Bakitas et al (2013) reviewed palliative care notes of people who had heart failure and found that the median time from palliative care consultation to death was just 21 days.¹²⁷ They conclude palliative care consultations are ‘not being initiated until the last month of life’, which mean people with heart failure are missing out on the broader benefits of palliative care.

As became evident in the previous section of this report, uncertainty around disease trajectories and the association of palliative care with death and dying is a key barrier to access. In their work on referral to children’s

Table 1. Number and percentage of patients identified for palliative care and referred to specialist palliative care, and median time before death

	Cancer (n=200)	Organ failure (n=170)	Frailty and/or dementia (n=160)	All trajectories (n=530)
No. identified on the palliative care register (PCR)	149	32	32	213
% of all patients identified for palliative care	75%	19%	20%	40%
Median time identified on the PCR before death (weeks)	7.3	13.4	2.4	6.6
No. referred for specialist palliative care (SPC)	137	18	8	163
% of all patients referred for SPC	69%	11%	5%	31%
% of patients on the PCR referred for SPC	92%	56%	25%	77%
Median time referred for SPC prior to death (weeks)	5.3	5.2	2.0	4.9

Source: Zheng et al (2013)¹²⁵

palliative care services, Twamley et al (2014) suggest that:

“The association of palliative care with end of life may be a modifiable factor relevant to late and non-referral and deserving of further investigation and attention in education and training.”

It would appear these factors are worth similar consideration in the world of adult palliative care.¹²⁸

Poor understanding of hospice care which overlooks the diversity of services available – for example, clinical services, chaplaincy, social work, therapy, counselling and support from dieticians¹²⁹ – can also contribute to people missing out on care and support. A more holistic approach to referral to specialist palliative day care, which helps to evidence the breadth of support available, has been shown to be valuable.¹³⁰ One positive impact was that those who were referred to hospice day care were introduced to the hospice environment. This may have helped breakdown some preconceptions of what hospices are like.

Achieving appropriate referral practices

The process of securing a referral has been shown to be complex and may be dependent upon personal and interpersonal factors relating to the professional which extends beyond their understanding of palliative care. Walshe et al (2008) identify two key influences on how healthcare professionals decide to make palliative care referrals beyond their assessment of the patient’s clinical need:

“First, their perception of their own role in providing palliative care; autonomous professionals make independent judgements about referrals, influenced by their expertise, workload, the special nature of palliative care and the relationship they develop with patients. Second, their perception about those to whom they may refer; professionals report needing to know about services to refer to, and then make a complex judgement about the professionals involved and what they could offer the referrer as well as the patient.”¹³¹

Achieving change in referral practices is therefore revealed to be a more complex issue than it may first appear. Better communication between professionals and improved knowledge about what others in a multidisciplinary palliative care team can offer may be useful here.

Cummings et al (2010) help to sum up the issues around the timeliness of referral in an extensive literature review on discharge, admission and referral practices in Australia:

“The literature provides evidence of the risks associated with the timing of referrals within the palliative care environment and the impact delayed or late referrals may have on the quality of care. The literature also points to reducing patient risk through the development of referral criteria within palliative care, and ensuring the timing of the referral is not dependant on the age of the patients or type of diseases present.”¹³²

Training, education and the use of appropriate referral criteria could all potentially help to ensure people get access to palliative care as soon as they need it.

Making palliative care everyone's business

A recurring theme in this report has been a lack of awareness about what palliative care can achieve and when it is suitable among both healthcare professionals and the general public. Training, support and education for all professionals involved in the care of people with a terminal illness would play a significant role in breaking down the barriers to accessing palliative care.

Palliative care can be, and is, delivered by a wide range of professionals across a range of settings. This includes geriatricians, cardiologists and GPs, not just palliative care specialists. In their study of palliative and end of life care for patients with chronic heart failure and chronic lung disease, Johnson et al (2010) concluded:

*“Most palliative care problems suffered by these patients should be within the abilities of the usual medical team. All clinicians involved should have good palliative and communication skills.”*¹³³

Shipman et al (2008) surveyed 210 healthcare practitioners, commissioners, academics and representatives of user and voluntary groups about their major concerns regarding the provision, commissioning, research, and use of generalist end of life care.¹³⁴ They found a lack of uniform understanding about what ‘end of life care’ referred to and a need for greater knowledge regarding how it fits in with a generalist’s other competing

priorities and incentives.¹³⁵ They also found that typically the number of patients approaching the end of life on a generalist’s caseload at any one time is quite low.

Training ‘non-specialists’ so they feel confident to talk to their patients about the end of life and deliver palliative care could help ensure more people get the care they need without placing a huge, and perhaps unnecessary, demand on specialist palliative care professionals. The Gold Standards Framework* approach, when implemented well, has achieved improvements in quality of care, proactive planning and coordination across various settings, including GP practices, care homes and acute hospitals.

A variety of condition-specific implementation frameworks and guidelines exist across the UK nations which could assist with this. A number of these have already been referenced in this document.¹³⁶ Others are available, including for people with dementia¹³⁷ and the frail elderly.¹³⁸

In 2012 in England, the National End of Life Care Programme published an evaluation of the Route to Success series of resources, related tools and implementation frameworks. The evaluation looked at how these resources had affected clinical care pathways for people with heart failure, advanced kidney disease, dementia and long term neurological conditions at the end of life. It concluded that such tools had improved quality and

* The National Gold Standards Framework (GSF) Centre is a not-for-profit social enterprise Community Interest Company. It provides training and support to enable generalist frontline staff to provide a gold standard of care for people nearing the end of life. GSF aims to improve the quality, coordination and organisation of care leading to better patient outcomes in line with their needs and preferences and greater cost efficiency through reducing admission to hospital.

were useful across a range of different terminal illnesses.¹³⁹

The National Council for Palliative Care has published commissioning guidance to help commissioners ensure specialist palliative care is available to all those who need it, regardless of the conditions they have.¹⁴⁰

Better coordination and team working

Coordination is identified as a key reason why people with cancer get better access to palliative care. Epiphaniou et al (2014) compare levels of coordination of care for people with lung cancer and advanced COPD. For those with cancer, the role of a key worker ensured access to services and care based on their needs, in particular in coordinating hospital services and transitions to community based palliative care. The key worker also provided wider support and advice. By comparison, those with advanced COPD did not routinely have a key worker to help them access palliative care services and wider support.¹⁴¹ This

underlines the importance of good communication between people with a terminal illness and health and social care professionals in order to ensure care packages are based on their needs.

An Australian study demonstrated the importance not only of the timing of referrals to palliative care services, but also the need for greater dialogue and communication between different medical specialisms about individual cases. It concluded:

“Significant barriers exist to the timely referral to palliative care and, in order to improve patient care and quality of life and lessen clinical difficulties, further work is needed to develop streamlined practices that are sensitive to specialty needs and patient desires.”¹⁴²

This conclusion is echoed in the National End of Life Care Programme’s framework for delivering end of life care for people with long term neurological conditions, which considers the benefits and drawbacks of multidisciplinary care. It ultimately concludes that:

“The evidence supports a multi-professional approach to neurological conditions as summarised in guidelines around the interface between neurology, rehabilitation and palliative care... In order to achieve the best quality of care it is important that professionals recognise the limits of their own experience and know when to contact other specialists for support.”¹⁴³

In line with guidance from the Royal College of Physicians on long-term neurological conditions,¹⁴⁴ the framework recommends that neurology, rehabilitation and palliative care develop

“It was a difficult illness to nurse. I felt almost abandoned until Marie Curie came along and I saw what real care was all about...Marie Curie asked for two case conferences to be held. No one had done that before. They wanted a plan of action for my wife. They got everyone involved in her care together.”

Man whose wife died of motor neurone disease

close working links to provide people with support from diagnosis to death.

Northern Ireland's Palliative and End of Life Care strategy addresses palliative and end of life care across different care settings. It states:

*“The seamless delivery of appropriate palliative and end of life care at all stages, and in all settings, during the patient’s illness requires an integrated and coordinated approach to care.”*¹⁴⁵

The strategy advocates the role of palliative care nurse liaison and the use of patient passports to provide health and social care professionals with real time information about the person. This should facilitate streamlined delivery of care and support. It also makes clear the need for timely and integrated services within individual teams (eg primary care), between teams within a single environment (eg heart failure teams and specialist palliative care teams within hospitals), and across organisational boundaries (eg between hospitals and care homes).

The Welsh Government's End of Life Care delivery plan also sets out plans and aspirations for an integrated end of life care service, with closer working between local authorities, the voluntary sector, social services and health services.¹⁴⁶ It tasks Local Health Boards to “provide information so generalist teams know how to access support from specialist palliative care services, including paediatricians” and to prioritise effective information sharing.

Living and Dying Well: A National Action Plan for Palliative and End of

Life Care in Scotland was published in 2008 to provide focus and momentum to improve palliative and end of life care for everyone in Scotland.¹⁴⁷ It also encouraged efficient collaborative practice across health care, social care and voluntary sectors. The Scottish Government has committed to producing a new strategic framework for action on palliative and end of life care by the end of 2015.

The NICE Clinical Knowledge Summary on dementia underlines the importance of integrated approaches to care, arguing that “primary care should be coordinated with secondary care and social care”.¹⁴⁸ They also stress the involvement of people with dementia in decisions about their care and argue professionals should work on the assumption that someone has capacity “until proven otherwise”.¹⁴⁹

It is also important to consider the role palliative care can play in the care of particular groups, such as older people with terminal illnesses, and how this links to existing services. Hall et al (eds) (2011) argue we need to develop strategies to focus on the palliative care needs of older people with all terminal conditions. They recommend that policymakers and decisions makers should:

*“Develop, invest in and implement a palliative care strategy that includes specifically the needs of older people in relation to all diseases and the insights and practice of modern care of older people (geriatric medicine, geriatric nursing and mental health services for older people) and dementia care.”*¹⁵⁰

A number of research papers have focused on the issues which people with dementia face in accessing palliative care. Coordination and team working are recurrent themes.¹⁵¹ For example, Ryan et al (2012) found:

“Data would support the notion that transition to good quality palliative care continues to be the exception and that collaborative working relationships between acute and primary care, as well as among mental health specialists and others, are not always apparent.”¹⁵²

For people with non-malignant conditions other than dementia, the literature does hold numerous examples of good practice in coordination and working across specialisms, especially involving voluntary sector partners. For example, collaboration between British Heart Foundation Heart Failure Specialist Nurses, Marie Curie Nurses, Health Care Assistants and primary care teams showed that joint training and working benefited the professionals and allowed for a more comprehensive delivery of end of life care in the community.¹⁵³

For people with MND, the introduction of a multidisciplinary team (MDT) improved coordination of care and increased access to specialist palliative care 15 fold in a year.¹⁵⁴ The MDT meetings were led by a palliative care consultant and included representatives from community occupational therapy, physiotherapy, speech and language therapy and social services, as well as dieticians, specialist palliative care clinicians and trained volunteer visitors. Improvements also included more people dying at home, fewer hospital

admissions and improved access to non-invasive ventilation. These were attributed to better clinical leadership, education and monthly meetings of the MDT.

If good practice is to become normal practice, it is essential that the results achieved through such initiatives are amplified and replicated wherever possible.

The important role of nurse specialists

Clinical nurse specialists can provide a crucial support and they are an effective means of ensuring patients are able to access the best package of care for them. The valuable role played by Heart Failure Nurse Specialists (HFNS) in particular is highlighted in the literature. Johnson (2012) concluded:

“It is possible to recognise advanced disease in HF [heart failure] and to talk with most patients about end of life care. Awareness of, and support for, their preferences can reduce the number of hospital deaths. The HFNS is a crucial healthcare professional and can coordinate assessment of need, sensitive discussion and access to appropriate care. They require the committed support of SPC [specialist palliative care] teams.”¹⁵⁵

A national audit by the British Society for Heart Failure (2013) found that nurse specialists can and do routinely provide much of the palliative care a person needs. Therefore, it is necessary to exercise caution when interpreting the very low number (4% in this audit) of formal referrals to specialist palliative care and what it means for patients.¹⁵⁶ The authors conclude:

“Palliative care referrals remain low, which is surprising, given the high age of the heart failure patient population, and the high mortality rates within a year of discharge. However it should be noted that palliative care training is part of the role of a heart failure nurse specialist, and thus most patients treated by the heart failure MDT, or by a specialist nurse, will receive palliative care input if necessary.”¹⁵⁷

There is little research into how nurses who specialise in other conditions are helping their patients with palliative needs. However, it is clear that nurse specialists can play a vital role and should be given enough support to do so. The British Heart Foundation and Marie Curie investigated the challenges and barriers nurses in the innovative role of heart failure palliative care nurse specialist face and found that the attitudes of other professionals constituted a significant obstacle to arranging care:

“Possibly, the most significant challenge in terms of establishing a palliative care service for heart failure patients was the lack of support from local cardiologists and senior members of local [primary care trusts]. Nurses felt that without this support, their service was unlikely or indeed unable to achieve its aims. One nurse reported that as one local cardiologist ‘did not acknowledge palliative care’, it had proved impossible to work with them and they had to work with other colleagues.”¹⁵⁸

Improving palliative care across all settings

Clark et al (2014) found that nearly three in every 10 hospital in-patients in Scotland are in their final year of life.¹⁵⁹ In England, people who die from

a condition other than cancer account for 80% of deaths in hospital,¹⁶⁰ while people in the last year of their life account for over a quarter of all hospital bed days in Wales each year.¹⁶¹ Even with efforts to deliver more care in the community, which is often in line with people’s wishes, many people with a terminal illness who have palliative care needs will spend a considerable amount of time in hospital. Yet systematic reviews of hospitals in England found that the identification of appropriate patients and management of their transition to a palliative care approach within hospitals was often not aligned with the prognostic indicators set out in the Gold Standards Framework:

“Patients with palliative care needs represent a significant proportion of the hospital in-patient population. There is a significant gap between NHS policy regarding palliative and end of life care management in acute hospitals in England and current practice.”¹⁶²

The Hospice Friendly Hospitals programme in Ireland offers one model for improving the situation of the many people with a terminal illness who still face death in hospital.¹⁶³ It aims to promote a culture of care for people who are dying in hospital, based on the principles of hospice care. Initiatives introduced as part of the programme include communication courses for doctors and staff in acute hospitals and residential homes, employing end of life care coordinators and setting up end of life care committees in 34 hospitals. These committees involve a mix of clinical, support and administrative managers and front-line staff. Design and dignity guidelines have also been

introduced to improve the physical environment of hospitals.¹⁶⁴

Care homes are another place where effective delivery of palliative care would be appropriate and valuable for many residents. Around 80% of people living in care homes have a form of dementia or severe memory problems.¹⁶⁵ In England in 2013, nearly 60% of deaths in care homes were from conditions other than cancer or cardiovascular disease,¹⁶⁶ while in Wales a quarter (25.3%) of deaths in care homes have mental and behavioural disorders (including dementia) as their underlying cause.¹⁶⁷ A 2011 national census of 751 care homes in Scotland found that over half (54%) of residents had care needs relating to dementia, stroke or Parkinson's disease.¹⁶⁸ The palliative and end of life care available to residents must reflect these facts. Hall et al (2011) explored the "effectiveness of multi-component palliative care service delivery interventions for residents of care homes for older people".¹⁶⁹ The review highlighted the absence of UK based studies focusing on this group and underlined the need for high quality studies focused on measuring outcomes, cost effectiveness and reducing bias.¹⁷⁰

The Scottish Partnership Agency for Palliative Care and Cancer Care has previously published practice guidance about palliative care in care homes in Scotland.¹⁷¹ These were then built into the Care Commission's inspection frameworks. In Northern Ireland, guidelines for palliative and end of life care in nursing homes and residential care homes, which promote best

practice based on a person-centred approach to care, have also been introduced.¹⁷²

Expanding the research and knowledge base

While the research base for conditions such as heart failure and dementia has grown significantly, there is still a paucity of research evidence around palliative approaches and the outcomes of palliative care interventions for others such as COPD¹⁷³ and acute stroke.¹⁷⁴ More research evidence is needed in these areas to ensure that the care and support provided to people towards the end of their life is based on robust evidence.

As the recent report by the LSE shows, there are population based studies which have estimated unmet palliative care need. Murtagh et al (2014) use data in England to reach an estimate of unmet need for high income populations.¹⁷⁵ There are no country specific estimates using data from Wales, Scotland or Northern Ireland.¹⁷⁶ The LSE's report also finds that there is no way of assessing whether current estimates of receipt of specialist and generalist palliative care services reflect the appropriate balance between these services for meeting need. As the need for palliative care is likely to increase in the future across the UK, it is important that robust methods for carrying out population-level needs assessments are developed which reflect the changing reality. It will also be important that this work distinguishes between specialist palliative care and palliative care which can, and probably should, be delivered by generalists (such as GPs) or disease specialists (such as nurse specialists).

Quality and outcome indicators are important to demonstrate the benefits adopting a palliative approach can have for people with different conditions, or earlier in a person's illness. Sashara et al (2014) argue that in order to ensure a better understanding of what palliative care can offer, we require standardised methods for reporting palliative care team activities.¹⁷⁷ They suggest using the Standard Format for Reporting Hospital Palliative Care Team (PCT) Activity. This comprises a cover sheet with the patient's basic information, a section for reasons for referral and problems identified by the PCT, and a section on activity. This section contains 13 major components ranging from care for physical symptoms to staff support. The authors conclude:

*"...the format for reporting hospital PCT activity could be effective for improving hospital PCT practice and for the education of new hospital PCT members."*¹⁷⁸

Work is underway across Europe to develop a set of 'structure and process' quality indicators for palliative care (Europall) which are being tested and evaluated. At the local level, in south London, the Outcome Assessment and Complexity Collaborative (OACC) initiative aims to embed outcome measurement into routine palliative care in five south London hospitals and a local hospice.¹⁷⁹ Ultimately, we hope that such an approach adopted at a national (England) level would enable comparisons between services and outcomes in different parts of the country. There is no reason why this sort of approach could not be applied in the other nations of the United Kingdom.

Part three: What needs to change?

Each of the four nations of the UK has come a long way in setting out end of life care strategies over the past decade.

Each nation has introduced, in the past, an end of life care plan or strategy – although in England and Scotland these are not current.¹⁸⁰ There are many examples of where the palliative and end of life care needs of people with specific conditions have been recognised in broader condition-specific strategies and delivery plans.

As this report demonstrates, there is a significant amount of work to do to ensure referral to and experiences of palliative care are equitable for people with different conditions. Each of the UK nations' end of life care delivery plans should be regularly reviewed and revaluated in this context. Actions that explicitly target these inequities in referral practices and access should be a priority.

The research and associated literature addressing issues around access to palliative care is not as comprehensive as it should be in many respects. We also lack outcome based data on which to base decisions and prioritisation, though this is being addressed in England.

However, we can draw some conclusions from the literature which is

available. Based on these conclusions we have identified a number of recommendations which would make access to palliative care significantly more equitable and which would benefit people with all diseases.

Recommendations for governments

- Commit to providing the resources required to ensure all those with a palliative care need can access palliative services, regardless of their condition. This commitment should recognise the growing need for palliative care services into the future.
- A mandatory requirement for everyone involved in the healthcare of people with a terminal illness to undertake practice based palliative care training as part of their continuing professional development.

Recommendations for health and social care professionals

- Carry out regular holistic needs assessments for all people living with terminal conditions and, where it is in the best interests of the patient, introduce a palliative care approach or make referrals to specialist palliative care based on this assessment.

- Facilitate well-coordinated care by developing stronger relationships between condition-specific health professionals and palliative care specialists in both acute and community care settings.

Recommendations for health and social care bodies

- All health bodies should recognise in their planning (service, financial and workforce) the importance of ensuring that everyone understands what palliative care is, what it can offer patients across all disease conditions and how it can be accessed.
- Develop clear care pathways and guidance which can be used in service planning and commissioning, depending on the healthcare system. This guidance should recognise the triggers identified by the research reviewed in this report. Where this already exists it should be reviewed against best practice and greater efforts should be made to encourage awareness and implementation.
- Health bodies should ensure their palliative care strategies and service delivery plans recognise the important role that can be played by disease specific nurse specialists. These should include what steps will be taken to ensure nurse specialists receive training and support to enable them to deliver palliative care.

Recommended research priorities

The conclusions and recommendations above are only possible due to research that has been undertaken.

More research focusing on need and outcomes is essential.

- Develop a robust population-level assessment of need (including unmet need) for specialist and generalist palliative care in all UK nations.
- Develop quality and outcome indicators which focus on palliative care for people for whom it would be beneficial across all disease conditions.

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This report explores the evidence around access to palliative care for people with terminal illnesses other than cancer. It also uses existing evidence to identify factors which trigger palliative care referrals for people with these conditions.

There is a significant amount of work to do to ensure referral to and experiences of palliative care are equitable for people with different conditions. Each of the UK nations' end of life care delivery plans should be regularly reviewed and revaluated in this context. Actions that explicitly target these inequities in referral practices and access should be a priority.

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Simon Jones, Head of Policy and Public Affairs, Marie Curie
029 2042 6038
simon.jones@mariecurie.org.uk

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