

## **Draft Portsmouth Hospitals End of Life Care Strategy for Adults – May 2011**

### **Introduction**

There are approximately two thousand deaths per year in Portsmouth Hospitals NHS Trust (PHT), six deaths a day on average, the majority of them occurring in over 65 year olds. Many of those dying in the hospital receive good care in an environment that is acceptable to them and their loved ones.

However, a significant proportion would rather not die in hospital for whom there is an onus upon us to try to support their choices wherever possible and safe.

Unfortunately, a significant minority still receive care that is not optimal at times causing distress for patients, families and staff and sometimes appropriately generating complaints.

Dame Cicely Saunders, the founder of the modern hospice movement, said that 'the way people die remains in the memories of those who live on.' To deliver the end of life care that we would want for our loved ones and ourselves is both our privilege and our daily challenge. It is not something that we should ever approach passively or routinely, but something that we must strive to improve upon as individuals and as teams throughout our careers. Where one of us fails in this duty we all fail, thus this is everyone's responsibility.

### **Aims**

The aims of our end of life care strategy are:

- to continuously improve the quality of end of life care delivered within our organisation
- to improve patient comfort and dignity
- to support patient choice wherever possible and safe to do so
- to ensure the highest standards of care and communication are extended to the dying individual's family or significant others
- to ensure that the education and support provided to our staff is commensurate with these goals
- to ensure that we carry our responsibility beyond death, to the respect and appropriate care of the deceased and those who have been bereaved

## Definitions

**General Palliative Care** - care given to ease symptoms and suffering in an individual with an incurable condition which it is believed will significantly shorten their life. In its many shapes this can be delivered by a broad range of people, some of whom may not be health care professionals, for example spiritual support by a minister of religion.

**Specialist palliative care (SPC)** - is delivered by health care professionals with specific training and qualifications relating to the care of terminally ill individuals providing physical, social, psychological and spiritual support as needed. We would know examples of SPC staff as Macmillan nurses and doctors and nurses working in hospices. Most hospitals also have a specialist palliative care team as does PHT. There are small numbers of specialist palliative care staff in our country, approximately 5000 compared to an NHS workforce of over 2 million. Due to their relatively small numbers, SPC staff cannot look after all terminally ill patients but provide specialist clinical support and education for patients, families and other health care professionals when requested to do so.

**End of Life Care** - relates to care of an individual within the last few days, weeks or months of their life. In addition to general palliative care, good end of life care requires communication, planning and regular review by a broad range of people, including informal carers (often family members), health and social care staff, the aim being to enhance the quality of life of an individual who is dying in their time remaining, identifying and supporting their preferences (for example as to where they would wish to die) and providing extra support in a timely manner as their condition deteriorates. Most end of life care is very practical and compassionate and day-to-day, hour-to-hour, the majority of it is delivered by informal carers (often family and friends) with the support of social care staff and community health care teams.

An excellent explanation of when end of life care begins is provided in the National End of Life Care Strategy July 2008, pgs 47-8:

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_086277](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_086277)

*'The definition of the beginning of end of life care is variable according to individual person and professional perspectives. In some cases it may be the person who first recognises its beginning. In other cases the principal actor may be the judgement of the health/social care professional/team responsible for the care of the person. In all cases, subject to the person's consent, the beginning is marked by a comprehensive assessment of supportive and palliative care needs.'*

*For some the start may be at the time of diagnosis of a condition which usually carries a poor prognosis, for example motor neurone disease or advanced liver disease. For others it will be at a point when there is a deterioration in a chronic illness and it becomes apparent that the likely prognosis is measured in months, or possibly a year or two, for example a patient experiencing an acute episode on the background of longstanding COPD. Some conditions, such as heart failure, have such a variable prognosis that whilst one patient may die within months of diagnosis another may survive for many years.*

*Alternatively, it could be an elderly person who is becoming increasingly frail and recognises that they need increased help to continue living at home, or makes the decision to become a resident of a care home or of sheltered or extra care accommodation.'*

### **Who Delivers End of Life Care?**

We all deliver end of life care with varying frequency and intensity according to our different roles. For example, some of the greatest day-to-day kindness in interpersonal care of the dying and their loved ones is delivered by our health care support workers and domestic staff. Working to deliver the best end of life care possible is the responsibility of all of us from the tea lady through to the Chief Executive.

In terms of staff training the National End of Life Care Strategy defines the following staff groups:

Group A – Staff working in SPC and Hospices who essentially spend the whole of their working lives dealing with end of life care. Within PHT this includes the Hospital Specialist Palliative Care (HSPC) team and the Medicine for Older People End of Life Support Team.

Group B – Staff who frequently deal with end of life care as part of their role. This would include the vast majority of adult health care staff in acute hospitals, more so those involved in acute care, medical specialties including renal, oncology and haematology and critical care.

Group C – Staff working as specialists or generalists within other services who infrequently have to deal with end of life care.

## **End of Life Care Away Day**

In February 2008 an end of life care away day took place within PHT which involved 108 staff and lay representatives. Key recommendations from that day were published widely and presented to our Executive and Board and are as follows:

1. Respect and provide for patient and carer privacy and dignity, ensuring provision of side rooms and quiet rooms on all wards.
2. Staff training and education.
3. Cross sector (secondary-to-primary health care, health and social care, voluntary sector) planning and communication to support patient choice and best care, placing the patient and not organisations at the centre of our efforts.
4. Investment in hospital SPC staff and resources.
5. Review and invest properly in Trust bereavement services.
6. Enable senior nursing staff with a special interest in this field to broaden their roles to support excellent communication around end of life issues, including resuscitation discussions and care after death.

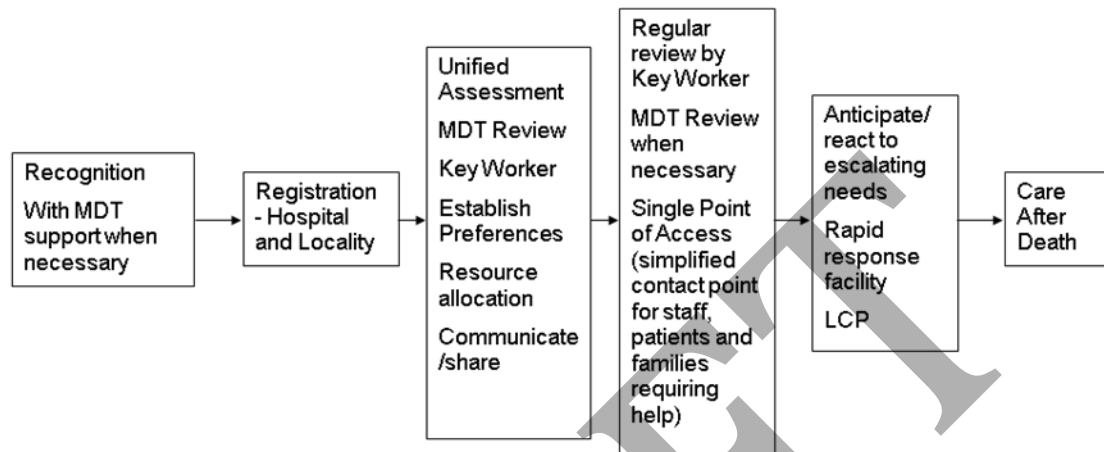
## **End of Life Care Pathway**

Existing end of life care pathways have been developed with community care and the Gold Standard Framework (GSF) in particular in mind (see section on Recognition below for more information about the GSF). One of the aims of these pathways is to improve patient choice, not least about place of care. This includes a goal to reduce the proportion of people dying in acute hospitals, currently approximately 60% with a goal for this to reduce to 30-40% over the next 5-10 years. This will be a gradual change and even if the National End of Life Care Strategy achieves all it has set out to do 30-40% of patients will still die each year in hospital (1000-1400 deaths per year in PHT). Thus, there is always going to be a need for us to ensure that the highest standards of end of life care possible are constantly striven for and maintained within our acute hospital Trust.

We also have a huge role to play in contributing to the broader end of life care strategy and pathway by supporting the whole system in identifying individuals who we believe are approaching the end of their lives and communicating that to our community colleagues in health and social care.

We also need to continuously improve our ability to support the wishes of individuals to be supported in transfers out of hospital to die elsewhere, such as home, care home or hospice.

The following is an adapted version of existing end of life care pathways to be applied to acute hospital practice, this will be the basis for the component parts of our end of life care strategy. It is very much intended that this pathway will not function in a stand-alone manner, but will fully promote and facilitate seamless cross-sector interaction with equivalent community pathways and services.



**1. Recognition** – Probably the hardest and most controversial part of any end of life care pathway, how do we recognise when an individual may be entering the last few weeks, months or on occasions years of their life (for example in the case of someone with Motor Neurone Disease or Alzheimer’s dementia)?

This is prognostication and has been described as an art and a rather inexact science. The key is flexible and sensitive interpretation, understanding that even the most experienced practitioners will get it wrong sometimes. Entering an end of life care pathway is about optimising the care of an individual in the time they have remaining, about living whilst planning, it is not about setting a date.

The Gold Standard Framework (GSF) provides a section on prognostication on its website (<http://www.goldstandardsframework.nhs.uk/TheGSFToolkit/Identify/TheThreeTriggers>) in which it includes a number of suggested triggers for us to consider in determining whether an individual may be appropriate for an end of life care pathway:

- i. *The surprise question ‘Would you be surprised if this patient were to die in the next 6-12months’ - an intuitive question integrating co-morbidity, social and other factors.*
- ii. *Choice / Need - The patient with advanced disease makes a choice for comfort care only, not ‘curative’ treatment, or is in special need of supportive / palliative care e.g. refusing renal transplant*
- iii. *Clinical indicators – general and specific indicators of advanced disease for each of the three main end of life patient groups - cancer, organ failure, elderly frail/ dementia*

Importantly the GSF also provides us with a traffic light prognostication system (figure below), emphasising that an end of life care pathway is not a one way journey and that individuals (e.g. those with respiratory or heart failure) will have periods of acute deterioration in their condition in which their life may be in immediate danger but may recover to obtain a prognosis measured in months again. For individuals with continued good prognosis (blue) it may well be appropriate for them to come off the end of life pathway (and register) altogether.

**A - Blue 'All'**  
from diagnosis Stable  
Year plus prognosis

**B - Green 'Benefits' - DS1500**  
Unstable / Advanced disease  
Months prognosis

**C - Yellow 'Continuing Care'**  
Deteriorating  
Weeks prognosis

**D - Red 'Days'**  
Final days / Terminal care  
Days prognosis

Navy  
'After Care'

[http://www.goldstandardsframework.nhs.uk/About\\_GSF/TheEssentialsofGSF](http://www.goldstandardsframework.nhs.uk/About_GSF/TheEssentialsofGSF)

**2. Multidisciplinary Team (MDT) Meetings** – many Trusts have *Palliative/End of Life Care MDT's*, similar to those held for respective cancer sites already. Given the sometimes complex nature of decision making relating to end of life care this forum would provide an opportunity for weekly review, advice and support for clinicians when required.

Given the predominance of adult deaths that occur within the Medicine for Older People, rehabilitation and Stroke (MOPRS) service it is proposed that a weekly two-hour meeting should be hosted by MOPRS. Either a consultant geriatrician, a specialist palliative care consultant or the clinical lead for end of life care will act as the chair in the first instance, providing cover for each other in periods of absence.

The meeting would be open to all services and would have the full support of the HSPC team. Given that some decisions may relate to supporting complex discharges for an individual to die at home, representation by the discharge planning team and relevant community services (e.g. community matrons, Jubilee House) would also be beneficial.

Given that some decisions relating to end of life care must be made on a much shorter timescale than a weekly meeting would allow, there will be a facility for virtual electronic decision support to take place between core members of the MDT on each weekday.

An *End of Life Care MDT* will need the support of an administrative *EOLC MDT Coordinator* equivalent to the model for the cancer MDT's. A Band 4 0.5 wte post is suggested in the first instance.

**3. Registration** – in the community registration means inclusion on an end of life care register held within GP surgeries. Registration is not an end in itself,

but a trigger for multidisciplinary assessment, capture of preferences, resource allocation, (e.g. DS1500, care package, equipment) and also importantly, communication with other services such as Out of Hours and the ambulance service to share information about diagnosis, prognosis and preferences (e.g. resuscitation status, place of care).

*Locality registers* are being piloted nationally with an IPSOS MORI report on the initial pilots published in February 2011.

<http://www.endoflifecareforadults.nhs.uk/publications/end-of-life-locality-registers-evaluation>

This report supports the efficacy of sharing of information across sectors with the establishment of such *locality registers*, and is now a part of the Portsmouth City PCT QIPP plans for 2011-12.

The advantage of having a register of end of life care patients within PHT is that it will give our services a memory of patients who have previously been identified as having end of life care needs. The ultimate goal would be a register/registers that will share information across sectors so that patients included on an end of life care register in PHT will populate the lists of registered end of life care patients in primary care and vice versa. If a patient were taken off an end of life care register in any sector, or their registration details were changed in any way, that data would similarly be updated for all service users.

The locality register evaluation highlights the need for patients to give formal consent to opt in to inclusion in such a register.

*'An opt-in model of consent is universally felt to be necessary. Patients should be consented onto the register. Patients and carers information needs have to be taken into account and details shared with them where possible. The register also needs to incorporate a mechanism to highlight patients who refuse to be consented onto the register as this will prevent these patients being repeatedly asked whether they want to be registered.'*

Establishing and maintaining the PHT component of a locality end of life care register will require a data coordinator, a role that should be incorporated with that of the EOLC MDT coordinator.

Beyond the establishment of the *locality register* in itself, this work stream will also embed the fundamental need for demonstrable cross sector collaboration and communication to improve choice and quality of care for this vulnerable patient group.

**4. Unified Assessment** – in the community, the process of end of life registration should be accompanied by an assessment of the health and social care needs of the individual, with resource allocation to follow accordingly from its findings.

It is proposed that a similar model of assessment should be used for inpatients in particular that are recognised as potentially appropriate for end of life registration. In those for whom this decision is complex or in any way controversial, the assessment itself may help to inform the MDT about the appropriateness or otherwise of such registration.

This should be a multidisciplinary assessment process involving medical, nursing and allied health care professionals where appropriate. A social component to such an assessment is also critical and should be completed by hospital social workers or the discharge planning team according to the normal practices of any given area of care within the Trust.

It is proposed that a *Standardised Assessment Document* should be produced to support this process to allow for consistency, clear reference and to form the basis of information to be communicated to community services on the patients discharge. The assessment would be repeated during subsequent admissions for individuals who have remained on the end of life care register.

Clearly the assessment must make recommendations that will then need to be acted upon by the team caring for that individual with the help of others such as the discharge planning team, for example, the provision of a home care package on discharge.

**5. Key Worker** – a hallmark of both cancer care and community end of life care pathways is the provision of a Key Worker for an individual patient and their informal carer. The Key Worker is someone who will provide a point of contact for the patient and carer within the MDT, acting as their advocate and forming a supportive and, at times, therapeutic relationship with them.

Examples of Key Workers already present within PHT would include our site specific cancer clinical nurse specialists in particular. Experience from both cancer care and end of life care within the community is that different individuals and even teams (to cover for leave etc.) will take on this role fluidly at different points in a patient's journey. Thus, a community matron may well be a Key Worker for many terminally ill individuals in the community, with their role supported by their immediate team. At times this responsibility may be taken on by social care staff, specialist palliative care staff, or therapists. Some General Practitioners in particular pride themselves on being able to fulfil that role for vulnerable individuals under their care.

It is important that we include this responsibility within our hospital pathway but understand that the role may already be fulfilled by clinical nurse specialists, social workers and therapists and that this is just a reframing of their roles rather than something very new and unfamiliar. Within that generalisation though we mustn't lose sight of the principal that we will allocate a named Key Worker, with clear contact details, to every individual we place on the end of life care register within our organisation. The HSPC team and the Medicine for Older People End of Life Support teams will take on a share of this responsibility proportionate to their available resources.



As patients move back into the community the Key Worker role may well pass on to a member of the community team with links remaining with hospital based Key Workers where required as they do at present. With time as service boundaries themselves become more fluid it would be encouraging to see community matrons (for example) continuing in their roles as a patient's main Key Worker even if they move back into the hospital at some point in their journey.

**6. Establishing Preferences** – one of the most vital roles of the Key Worker is to establish, document and communicate the preferences of the individual patient in particular, encompassing as far as possible those of their most immediate informal carers or family members. This latter component is important because we know that although 60% of us would prefer to die at home if given a choice, 60% of admissions to die occur because of difficulties the carer is struggling to contend with, rather than specifically due to symptomatic deterioration and/or a direct request by the dying individual themselves.

This information may in part have been encompassed within the unified assessment (section 4). However, it is important to give it its own place in the pathway so that we are specifically mandated to try to capture and embed the hopes and wishes of the individual rather than simply tailoring the package we provide for them on the basis of our own objective health and social care assessments.

An individual's preferences will often include choice of place of death, but might include, for example, the making of a will, funeral plans, a desire to donate tissue or organs after death, planning for the future care of a dependent person or even pet after they have gone.

Vital and very practical information for the Key Worker to at least introduce to the individual and their family are those pertaining to Advanced Care Planning, legally active Advanced Decisions to Refuse Treatment and a more specific instruction not to attempt cardiopulmonary resuscitation in the event of a cardiac arrest. Ideally these subjects should be raised, with standard literature provided identical to those already used by our local community teams (produced by the National End of Life Care Programme <http://www.endoflifecareforadults.nhs.uk/publications/planningforyourfuturecare>) to enable the individual and their carer to have time to consider and discuss the issues raised before coming to an informed decision at a later meeting with the Key Worker.

For terminally ill patients who do not have the mental capacity to be involved in such decisions about their future care the guidelines within the Mental Capacity Act should be adhered to, seeking the views of their representatives where available or in cases where there is no one to represent the individual, the input if an Independent Mental Capacity Adviser (IMCA) may be required.

<http://www.legislation.gov.uk/ukpga/2005/9/contents>

It is important to emphasise here however that medical professionals are not required to provide treatments that they regard as futile. The key to approaching this situation sensitively and successfully is to provide honest and open communication about what can and cannot be achieved medically from the outset of such conversations. It is best practice to readily seek a second opinion in the event of a disagreement with a terminally ill individual or their representatives, for example, when they are adamant that they wish cardiopulmonary resuscitation to be performed even in the face of a non-remediable and rapidly deteriorating terminal illness.

Once preferences have been established they should be documented, ideally within the *Standardised Assessment Document* described in section 4. Following which they should be communicated to other carers and agencies, in particular the primary care team, but also at times to care home staff and domiciliary care providers, out of hours and ambulance services. Studies from around the country show that sharing information in this way can bring high levels of success (up to 85%) in supporting people's choices to die well in a particular place.

**7. Communication** – a significant proportion of complaints related to end of life care stem from poor communication with the individual and their family, or between health and social care staff in different sectors at some point and sometimes even throughout the journey. Delivering high quality end of life care and supporting individual's choices requires excellent communication at every point of the pathway. This can be challenging at times, for many reasons, not least the high pressure roles we frequently find ourselves in. Also at times the fear of raising prognostic issues with our patients and their families. This creates barriers to our ability as health and social care professionals to deliver choice and thereby support more people to die in the community if that is their wish than currently seems possible.

All of the steps of the pathway require good communication to be negotiated successfully and all of them ultimately facilitate optimal ongoing communication through to an individual's death and beyond. For example, we cannot communicate prognostic information to an individual and their family without first recognising that their life expectancy is limited. We cannot begin to support individual's preferences without being able to capture them and communicate them with other key groups such as the ambulance service.

The key people we need to communicate with therefore are:

- the individual themselves wherever possible
- their family/informal carers/next of kin
- other health and social care professionals, *seamlessly* between sectors

The key challenges to successful communication in this setting are:

- *Staff time*: hence the need to define our pathway and Key Workers.
- *Staff ability, confidence and knowledge*: demanding clear information about what we're trying to achieve and what we expect of our staff; requiring a robust and dynamic supporting educational package; requiring enhanced communication skills training for our Key Workers in particular; requiring local champions.
- *The ability of patients and families to understand and accept these difficult issues*: helped by early recognition, tailored communication and care, again supported by Key Workers. There are societal barriers and taboos to the subject of end of life care in the twenty-first century which the National Council for Palliative Care in collaboration with the Department of Health are trying to address with their high profile Dying Matters coalition [www.dyingmatters.org](http://www.dyingmatters.org); for us locally however, the best advert for good end of life care is good end of life care itself.

**8. Single Point of Access** – from their outset work to develop local and national end of life care, long term condition and unscheduled care strategies in the UK have emphasised the importance of a Single Point of Access for patients, relatives and health care professionals within a given area. The idea is that instead of a multitude of different numbers for potential contacts who may or may not be the right person to help you at any given time, there is one number for that area manned by staff who will then signpost you to the appropriate individual or service. There are now Single Points of Access (SPA) for both Portsmouth and South East Hampshire which although primarily intended for use by patients, carers, and community health and social care staff are also frequently used by our hospital staff to make contact with or refer patients to specific services in the community.

Extending the idea of an SPA to a hospital based end of life care pathway brings the challenge of creating a single phone number, fax number and intranet site for all enquiries, referrals and resource needs.

For patients and family members this number, which would be provided by their Key Worker, would give them a point of contact for extended hours on 7-days a week initially (eventually proceeding to 24-hours a day), where they can be rapidly signposted to appropriate help or input, whether that be for poor symptom control, a need for help to get home to die, a need for emotional or spiritual support, or just to find places to rest and eat in the Trust or enquire about car parking costs.

For staff this would provide a similar single point for enquiry and referrals relating to end of life care. For example, in the situation of a junior doctor struggling to achieve symptom control for a dying patient out of hours; for a staff member struggling to achieve optimal communication with a distressed relative or with another member of the multidisciplinary team during a busy

shift; when trying to mobilise the complex support sometimes required to allow an individual to go home to die if that is their request.

The end of life care intranet site will also provide a range of both practical and educational resources for staff such as HSPC referral forms, Liverpool Care of the Dying Pathway (LCDP) teaching modules and electronic guidance on symptom management (through a digital version of the Wessex Palliative Care Handbook).

**9. Rapid Response** – this is another key component of the community pathways that we're adapting to the needs of the hospital service in this strategy. There's no point having a SPA if you can't respond in a timely manner to unmet need. A Rapid Response for community nursing teams from example must occur within 2-hours of the referral being received.

The speed of any such responses must clearly be tailored to the particular situation. In hospital practice, unrelieved, distressing symptoms such as pain should be met with immediate advice through the SPA with a facility for rapid review (within an hour) by a member of an *extended end of life care support team*\* within the Trust should the initial advice not bring a timely significant improvement.

In the situation of supporting an individual to go home to die if that is their expressed wish, then there must be an appropriate review (most likely by the discharge planning team in the first instance) with initial preparations put in place within one working day of the request being placed if it is felt following the review that the request can be fulfilled in a safe and appropriate manner. This facility must be available 7-days a week. The goal should be to support discharge to die in appropriate cases within 24-72 hours of the request being made (to put this in context the average time from placement on LCDP to death in our Trust is currently approximately 36 hours).

Achieving these ambitious goals will not be straight forward and will require us both to use existing resources differently and to make a real financial investment in end of life care within the organisation.

\*An *extended end of life care support team* does not exist within PHT at this time. However to meet even a 7-day a week extended day commitment to SPA and rapid response in end of life care as described above we will need to create an extended team of this sort and our ambition must be to extend this to a 24-hour model in due course.

Existing resources include:

- the HSPC nursing team at 3.6 wte working 9-5 Monday-Friday
- 6 PA's SPC consultant
- the MOPRS EOL support team at 3.6 wte working 8am-11pm 7-days per week but only ever having one staff member on duty at one time

Potential additional resources (initial thoughts):

- extend SPC consultant time to 10 PA's
- potential to involve other consultants with an interest in end of life care in 7/7 provision, e.g. current EOLC clinical lead
- potential to involve some cancer CNS's with appropriate additional training and support in the extended team

**10. Liverpool Care of the Dying Pathway** - believing that an individual is going to die within the next few hours-to-days, the Liverpool Care of the Dying Pathway (LCDP) challenges us to review our priorities and establish a new, tailored management plan for them. Our aim, supported by the LCDP, is to provide excellent communication to support the delivery of high quality care, comfort and dignity for that individual and their loved ones.

How do we recognise when someone is dying and likely to succumb in the next few hours-to-days? In the context of an individual with a severe life threatening illness in whom all remedial causes have been managed appropriately with failure to obtain any meaningful improvement, or in an individual who is terminally ill and we recognise as having deteriorated significantly, the LCDP gives us the following prompts to trigger a multidisciplinary discussion about whether we believe the individual is dying, suggesting that at least 2 of the 4 should be present:

- *the patient is bed bound*
- *the patient is semi-comatose*
- *the patient is only able to take sips of fluid*
- *the patient is no longer able to take tablets*

<http://www.liv.ac.uk/mcpil/liverpool-care-pathway/>

It is important to remember that one-in-twenty patients placed on the LCDP will recover to some extent and come off it. The LCDP is not a one-way path and by frequently reviewing the condition of individuals on the LCDP as a MDT we are able to ensure that symptom control is optimal, dignity is maintained and that it remains appropriate for them to remain on the pathway. If they are improving we must review their needs again, communicate their situation carefully and take them off the LCDP if indicated.

It is also important to remember that the LCDP is not an end in itself. The LCDP doesn't provide outstanding care of the dying, we do. We can do that even without the LCDP and we sometimes do, but what it brings for us is a welcome challenge to engage with our dying patients and their families, to do our best for them and not to step away.

Our work relating to the LCDP will include ensuring a smooth transition from LCDP version 11 which we are using at present, to a Hampshire wide adaptation of version 12 for which we have a PHT working group at this time.

**11. Symptom Management** – patients with advanced progressive disease frequently experience multiple complex symptoms. Although pain is often reported as the most prevalent and most feared symptom, others such as nausea, constipation and shortness of breath can also be present. It is not uncommon for patients to experience all of the above.

Many if not all patients will at sometime during their disease trajectory be admitted to an acute hospital and will have an expectation that their symptoms will be adequately managed. Unfortunately this is not always the case and as an acute trust we have a duty to these patients to provide them with the best assessment and treatment that is available to them.

Different priorities in patient management, as well as lack of knowledge and skills, individual opinions and the culture of the workplace, can create barriers to the provision of good symptom management. Our aim is to provide education and support to the generic workforce to enable them to recognise, assess and treat appropriately the symptoms that our patients experience. The clinical and nursing staff on the wards have a responsibility to these patients to provide good generic palliative care (National End of Life Strategy group B staff) with the support of the Hospital Specialist Palliative Care Team (HPCT) and End of Life Support team.

Supporting resources include the Wessex Palliative Care Handbook for advice on clinical management (the little green book), now available by kind permission through the Trust's EOLC intranet page. The Liverpool Care of Dying Pathway itself (available on all wards and through Trust's EOLC Intranet page) contains locally adapted treatment algorithms for pain, nausea and vomiting, terminal restlessness and agitation, respiratory tract secretions and breathlessness

**12. Dignity and Privacy** – our strategy is entirely in keeping with the NHS document **Essence of Care 2010 - Benchmarks for Respect and Dignity** which is available through the PHT Intranet home page. This document provides the following definitions:

- **Respect** - *is regard for the feelings and rights of others*
- **Dignity** – *is the quality of being worthy of respect*
- **Privacy** – *is freedom from unauthorised intrusion*

In the specific context of EOLC in PHT it's important to clearly state that people dying under our care are at their most frail and vulnerable and are often unable to express their wishes clearly and independently. In this situation the family will sometimes be able to act as their advocate, but often that duty will fall upon us as health care professionals, not infrequently extending to the support of the family members themselves. In this privileged role we must strive to deliver the care and support that we would expect for ourselves or our own family members.

When an individual is dying or dead their right to dignified care is as great as when they are well and fully able to express themselves. Thus physical care in this setting should be delivered with kindness and sensitivity, anticipating discomfort wherever possible and respecting the individual's privacy.

The need for privacy itself is clearly paramount and there are sufficient side rooms within the Trust to ensure that at most times such a room will be available for a dying individual and their family to use. A minority of dying individuals will feel isolated in a side room however and may prefer the company that a bay affords. In such circumstances the sensitivities of other patients sharing that bay must be recognised and supported.

The need for privacy extends to the need for quiet spaces on all wards where discussions with families can take place, or they can seek some privacy when distressed or obtaining spiritual support for example. The practical and humane support of families who wish to stay with a loved one who is dying should extend to us offering them drinks and even food in some circumstances; providing accommodation for those who are travelling some distance to be with a dying relative; providing exemption documentation to minimise parking costs at such a distressing time.

**13. Care After Death** – our responsibility for the care of an individual and their family does not cease at the time of their death. We are fortunate to have new Guidance for Staff Responsible for Care After Death to act as our benchmark in this area. This document, published in April 2011, was produced by the National End of Life Care Programme and the National Nurse Consultant Group (Palliative Care) with a link provided below.

<http://www.endoflifecareforadults.nhs.uk/publications/guidance-for-staff-responsible-for-care-after-death>

The national guidance states that care after death includes:

- *honouring the spiritual or cultural wishes of the deceased person and their family/carers while ensuring legal obligations are met*
- *preparing the body for transfer to the mortuary or the funeral director's premises*
- *offering family and carers present the opportunity to participate in the process and supporting them to do so*
- *ensuring the privacy and dignity of the deceased person is maintained*
- *ensuring that the health and safety of everyone who comes into contact with the body is protected*
- *honouring people's wishes for organ and tissue donation*
- *returning the deceased person's personal possessions to their relatives*



Examples of good practice highlighted in the guidelines include a responsibility for us to document the time of death wherever possible, not solely the time of verification of death; that a doctor or appropriately qualified nurse should aim to verify a death occurring in an acute hospital within one hour of death; that when the death need not be referred to the coroner, the Medical Certificate of Cause of Death (MCCD) should be issued within one working day of the death.

**14. Education** – the National EOLC strategy uses the different staff types, A-C (see page 3) to describe the differential learning requirements of staff who are more or less involved in the day-to-day care of the dying. In practice, type B staff who make up the largest proportion of staff caring for dying patients on a daily basis in PHT are generally very busy, have limited time and resource to support protected learning and have multiple competing demands on such time when it is available. Strategies such as e-learning have not as yet delivered the return they promised in terms of giving these staff more accessible educational resources in end of life care.

The NHS South Central education strategy for EOLC describes blended learning approaches as the optimal mode of training for busy clinical staff of this sort. This emphasises the importance of providing protected learning opportunities in addition to experiential hands on training of staff performing their normal duties. This *point of care* training is one of the key roles of our HSPC and MOP EOL support teams within the limits of their own availability.

How best to provide the extra teaching is challenging and requires a variety of traditional and more novel approaches including face-to-face teaching, not necessarily in a classroom, but in short aliquots as a supplement to ward hand-overs for example. E-learning, phone apps and other IT based learning tools will suit some whilst the use of spoken word podcasts might work more flexibly for others. To this end, we are currently developing a short educational podcast on the LCDP for trial which if well received we hope to follow with other modules such as symptom control and prognostication.

The Sage and Thyme communication training module is now available to all staff in South Central and is taught in a 3-hour level 1 course, ideal as an introduction for staff groups B and C. The model is designed to enable health and social care professionals to listen to concerned or distressed people and to respond in a way that empowers the distressed person.

<http://www.uhsm.nhs.uk/academy/sageandthyme/Pages/home.aspx>

We continue regular classroom based end of life care training of final year medical students, Foundation and Specialist training grade junior medical staff. We will be presenting on end of life care in the medical Grand Round this June for the second time in 12-months. We are also providing end of life care teaching at some surgical M & M meetings.



**15. Monitoring** – we have made great progress with monitoring end of life care delivery in the Trust in the past 12-months and continuing this work will clearly be vital to assess the delivery of our end of life care strategy.

Current monitoring, by the PHT EOLC steering group and also by commissioners for certain specified indices includes:

- monthly quantitative data on number of adult deaths including proportion dying on the LCDP (quarterly report to commissioners) – 40% currently identified as dying on LCDP
- monthly qualitative audit of 4 deaths on LCDP versus 4 deaths off LCDP which we report on a quarterly bases (report to commissioners twice a year)
- the end of life care clinical lead reviews all complaints relating to EOLC in the organisation, commenting on them and contributing to responses including meeting bereaved relatives when necessary. The EOLC steering group meets quarterly and receives a verbal and printed update on EOLC complaints at each meeting
- an End of Life Care questionnaire is now offered to all relatives attending to collect a death certificate from the bereavement office. Relatives are asked to contact PALS if they have any concerns and are referred from there to the relevant Clinical Service Centre if required. The output of this questionnaire is now required to be provided to our commissioners in the 2011/12 contract. By the close of quarter 2 we must have identified themes and be able to demonstrate that we are implementing improvements. By the end of quarter 4 we must be able to show evidence of improvement in outcomes reported by bereaved relatives through the year.
- monitoring of number of staff in different staff groups who have received training in EOLC
- MOPRS completed a survey of staff experience and confidence relating to end of life care in 2010 which will be repeated later in 2011. A similar survey is to be used in other clinical areas within the Trust to provide a baseline assessment for the educational component of our strategy in particular
- participation in National Care of the Dying Audit for Hospitals (occurs every 2-3 years, we are currently submitting data for the 3<sup>rd</sup> round with 26 auditors entering data for the Trust over the 3-month audit period
- we are about to launch a new coding and communication form to be used in place of the District Spell for deceased patients to improve the quality of information we provide to GP's on the death of their patients

and improve the quality and depth of coding information we routinely provide as a Trust on our deceased patients

In 2011 we also plan to complete an audit of adult deaths in the Emergency Department (20-30 per month) with a particular intention to look in more detail at cases where we think people have come into hospital to die when with better planning and support they might have been able to die more comfortably in the community. We are also planning a more extensive survey of the attitudes of our medical staff of all grades towards the care of the dying.

## Recommendations

- Develop a Portsmouth Hospitals adapted *end of life care pathway*
- Promote early *recognition* and cross-sector communication regarding patients with a poor prognosis bringing a life expectancy estimated as weeks-to-months
- Establish a weekly PHT *End of Life Care Multidisciplinary Team meeting* with a dedicated coordinator and chair
- Participate actively in the establishment of a *locality register* for EOLC
- Develop a *unified assessment* tool for patients recognised as having end of life care needs under the care of PHT, incorporating the use of a *standardised assessment document*
- Develop the role of *Key Worker* for patients having end of life care needs under the care of PHT
- Formalise mechanisms for capturing, recording and communicating *patient preferences* with respect to their end of life care
- Ensure our staff have the required training and support to enable them to maintain *optimal communication* relating to end of life care at all times
- Develop a *Single Point of Access* within the Trust for patients, carers and staff members to obtain timely support and information relating to end of life care
- Develop a PHT *Rapid Response* mechanism to support unmet need relating to end of life care, ideally incorporating an *extended EOLC support team*
- Continue to promote the appropriate use of the *Liverpool Care of the Dying Pathway*, supporting a smooth transition from Version 11 to Version 12 by January 2012

- Ensure that *optimal symptom management* is at the very heart of all we strive to achieve through this strategy
- Clearly define and adhere to the highest standards of dignity and privacy for dying patients within our care
- Define high standards for care after death, incorporating the new national guidelines on Care After Death
- To continue to develop and vigorously pursue a programme of blended learning in end of life care for our staff, incorporating traditional and more novel protected teaching opportunities and point of care experiential training
- To continue to actively monitor and publish all relevant outcomes relating to end of life care within our organisation, developing new methods as necessary, to underpin our efforts to continuously improve the standards of care we deliver to those at the end of their lives. This must include a commitment to successfully deliver contractually defined monitoring and improvement including the CQUIN measures for 2011/12 (*to be concluded by 20/05/11 and included in strategy then*)

Dr Mark Roland, PHT End of Life Care Clinical Lead, May 2011

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