Stockport Strategic Vision

for

Palliative Care and End of Life Care Services

Final Version

Ratified by the End of Life Care Programme Board

on

8th February 2012
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Executive Summary

This document articulates the clinical requirements of End of Life Care services within Stockport and outlines the level of services required from providers of End of Life Care services across the whole of the journey. The strategy therefore describes in detail the service model required including clinical and quality standards, clinical pathways and service and performance indicators, accommodation and facilities management and workforce standards. This document outlines the clinical requirements to deliver high quality integrated End of Life Care services for Stockport and will therefore also outline the public health needs of the local population to ensure that the services available to Stockport residents is commensurate with the needs of the population.

The strategy will form the basis of any contracts for palliative care and end of life care services in Stockport established between the commissioner and service providers. The detailed specification requirements within this document will be used alongside contracts for services. However more detailed individual specifications may also be required to sit alongside this strategy and contracts for individual services.

It is recognised that there are some elements of the services outlined in the document where additional resource and funding will be required to deliver first class services detailed in the Stockport Model. The strategy includes elements of services that are currently being delivered now, some that are developmental and some that are aspirational.

The vision for palliative and end of life care is that people with life-limiting illness will be enabled to live the best quality of life for that individual for the time left and have a peaceful death in the place of their choice. This will be achieved through co-ordinated and advance care planning and offering high quality, holistic care that is timely, integrated and seamless at the point of delivery and tailored to the individual’s needs and wishes. Families and carers will receive emotional and practical support through their caring role and into bereavement.

The Stockport End of Life Care Model sets of the stages out the end of life care pathway and illustrates the patient’s and carer’s journey and the range of services that need to be available. Importantly, it also highlights that assessment, planning and co-ordination are as essential as the actual services themselves; indeed they are essential to making the whole pathway work effectively.

The process of providing care for end of life care patients often involves multiple teams that work across health and social care services as well as voluntary sector organisations. It is not possible to create a detailed model pathway that will fit all patients; many patients on an end of life care pathway have multiple complex needs and having a coordinated approach to deliver end of life care and a focus on collaborative working will ensure that care is patient centred and tailored to the individual patient or carer.

This strategy aims to ensure that end of life care is coordinated and consistent and processes are in place to ensure that care is coordinated effectively across all providers delivered by competent, skilled practitioners who provide ongoing assessment and are aware of the patient’s current condition, preferences and needs.
There is also a recognition that the preferred place of care for some patients care will need more in depth discussion between clinicians, patients and their families and in some cases care in the preferred place can only be provided where it will be clinically and emotionally possible for support to be delivered and that for some patients and their families the preferred place of care may not be a feasible option.

1. Introduction

1.1 Background

In 2008, NHS Stockport undertook an extensive strategic review to ascertain the priorities for future development of End of Life Care services in Stockport. The review was led by local clinicians and managers who ensured that the opinions of service users were also taken into account. The review set out the strategic direction and made recommendations regarding the reforms, improvements and investment required in this area for the next five years. (NHS Stockport 2008) The strategy built upon the previous independent review in 2007 of Palliative Care Services in Stockport which evaluated palliative care provision made recommendations for commissioning changes or development.

The purpose of this strategy is to set out the requirements for the Stockport economy to deliver palliative and end of life care at the point of need to people with life-limiting illness and for people to be enabled to live the best quality of life for the time they have left and have a peaceful death in the place of their choice.

Service provision should be provided through delivery of co-ordinated and advance care planning by the generalist and specialist palliative care services offering high quality, holistic care that is timely, integrated and seamless at the point of delivery and tailored to the individual’s needs and wishes. Families and carers should receive emotional and practical support through their caring role and into bereavement.

1.2 Principles and Aims

The National Institute for Clinical Excellence (2004) defined palliative care as: ‘The active holistic care of patients with advanced, progressive illness”. Palliative care includes the management of pain and other symptoms, the provision of psychological support, social support and spiritual support. NICE (2004) highlighted the need to “offer a support system to help patients to live as actively as possible until death and to help the family to cope during the patient’s illness and in their own bereavement” Bereavement support for carers and families should therefore also be available.

The Department of Health defined end of life care as services that support

‘…all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.’

The aim of palliative and end of life care services is to achieve the best quality of life for patients and their families, to manage pain and other symptoms including psychological, social, spiritual and practical support throughout the end of life pathway. In the context of this strategy services...
will be provided for adults (16 years and over) with advanced, progressive life-limiting disease, malignant and non-malignant, who are registered with a Stockport General Practitioner.

The aim of the commissioning strategy for palliative and end of life care services is to describe the required features of high quality, consistent pathways for patients across a range of providers.

This will include:

- The identification of the end of life phase;
- Sensitive and timely discussions regarding end of life care needs;
- Assessment and care planning;
- Co-ordination of care;
- Ensuring that patients entering the end of life phase are added to appropriate registers;
- Integrated service provision across the range of commissioned services;
- Excellent communication and information provision between providers at relevant stages;
- Regular review to identify any changes in the stage end of life patients are at;
- Care in the last year of life;
- Care in the last 6 months of life;
- Care in the last days of life;
- Care in the first days after death;
- Bereavement support after death;
- Excellent, timely and sensitive information and communication with patients, families and carers.

Services should provide:

- High quality, safe care;
- Good access;
- Responsive, patient centred care;
- Equity and fairness;
- Efficient and effective use of resources;
- Dignity and respect.
Inequalities in health will be reflected in the local needs of the population. The priority will therefore be to achieve the same outcomes for all sections of the population. Palliative care and end of life care services must therefore be delivered in a manner that meets the needs of the population and addresses health inequalities. NHS Stockport is therefore committed to identifying and supporting all vulnerable groups to achieve positive outcomes. Patients and their families will receive the best personalised, locally accessible, safe, effective, evidenced based integrated care.

In 2008, the National Audit Office reported variable standards of end of life care provision. The national Quality, Innovation, Productivity and Prevention (QIPP) agenda sets the challenge to maximise quality and the impact resources assigned to end of life services. Improving co-ordination of care between providers should lead to greater efficiency, shorter length of stay in hospital, a reduction in emergency hospital admission and most importantly an improvement in care for patients, enabling people to die in the place of their choice.

The vision for NHS Stockport is to achieve first class care across the whole pathway through the development and delivery of patient focused and family-centred services that meet the national quality markers for end of life care. NHS Stockport is committed to the proactive development of palliative services and end of life care to meet future needs and as such will ensure that this strategy is subject to regular review.

1.3 Purpose and scope

A review of national and international best practice highlights a raft of guidance for palliative and end of life care services including:

- Implementing the end of life care strategy: lessons for good practice (Addicott and Ross, 2010)
- Information for commissioning end of life care (DH, 2009)
- End of Life Care Strategy (DH 2008a, 2008b)
- Operating Framework 2007/08: PCT baseline review of services for end of life care (DH 2007)
- Palliative Care Bill (2007)
- Our health, our care, our say: a new direction for community services (DH, 2006)
- Building on the best: end of life care initiative (DH, 2004a)
- NHS End of Life Care Programme (www.endoflifecare.nhs.uk/cole/acp)
- End of Life Care Strategy, 3rd Annual Report End of life care strategy third annual report
- Route to Success: National End of Life Care programme (2010) www.endoflifecareforadults.nhs.uk/publications
The continued availability of evidence and best practice guidelines both nationally and locally means that service providers must be committed to the ongoing development of services to ensure that Stockport residents receive the best care possible. Whilst this document refers to current best practice, it is expected that providers will adopt the most advanced evidenced based practice as it becomes available.

The purpose of this strategy is to establish the clinical basis and the minimum standards required from such a service. The strategy refers to the national and international standards of care required and identifies the health inequalities existing in Stockport and any additional services required to ensure that vulnerable groups are targeted. The scope of the strategy ranges from psychological support to bereavement but also refers to in patient care, out patient care and telephone support to ensure that the entire care pathway is included and services are not fragmented. The strategy has been written collaboratively between commissioners at NHS Stockport, provider staff within Community Health Stockport, GPs, Stockport NHS Foundation Trust, St Ann’s Hospice and Stockport Metropolitan Borough Council.

1.4 Health Needs of the Stockport population

1.4.1 Summary

As life expectancy increases overall numbers of death in Stockport continue to fall. In 2009, there were 2,700 deaths in total for local residents (see figure 1.4.1). It is anticipated that, despite the ageing population, death rates will continue to fall as the average age of death increases. However the mortality projections from the Office of National Statistics (ONS) indicate that there will be a dramatic rise in the total number of deaths from 2012 to 2016. Locally analysis of data has suggested that it is reasonable to plan for similar volumes of death to occur over the next few years.

End of life care within local areas is assessed by an outcome measure evaluating the proportion of deaths which occur in a resident's own home. Whilst there is evidence that many people would prefer to die in their own home rather than in a hospital deaths in Stockport follow the national pattern with most happening in hospital whether they are expected or unexpected.
Until 2011 the outcome measure has measured only deaths in own private home, and it is this indicator that has been used in forming this needs assessment. A new indicator has just been released in 2011 which alters the definition to also include deaths in nursing and residential homes. Data for both indicators is outlined below, as we are in the transition period.

According to national benchmarks on the existing indicator Stockport has a particularly low rate for this outcome measure with just 19.1% of deaths in Stockport in 2009\(^1\) taking place at home.

Benchmarking data is only available for earlier years and for the period 2006 to 2008 Stockport’s average rate was 17.0%; the 15\(^{th}\) lowest rate out of 152 PCTs. At this time the England average was 19.5% and the best performing PCT achieved 26.0%. This has therefore been identified as an area for improvement in Stockport and in the 2010/11 Corporate Strategic Plan NHS Stockport set a target of achieving 24% of all deaths in 2014 occurring at home (see figure 1.4.2).

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\(^1\) 2009 data is the most recent complete year available at the time of writing

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According to national benchmarks on the new indicator Stockport benchmarks at similar levels to the national and regional average for this outcome measure with 36% of deaths in Stockport in 2009\(^2\) taking place at usual residence. Trends have been generally increasing since 2004 (see figure 1.4.2.1). It is also important to recognise the local preferences of where patients want to die at home or hospital and how the gaps between preferences and reality can be addressed. With regard to expected deaths that do not occur in hospital, young people are the most likely to die at home; middle aged adults are most likely to die in their home or a hospice and the elderly are most likely to die in a care home. Almost all expected deaths outside of a hospital setting are for cancer (71%) which may indicate that patients with cancer are more likely to plan for the end of their life.

### 1.4.2 Stockport demographics

Stockport has an ageing population (see figure 1.4.3). In 2001, 16.6% of the population (47,120 people) were aged 65 and over; 7.7% (21,980) were aged 75 and over and 2.0% (5,670) were aged 85 and over. By 2009, the 65 and over population had increased by 6.3% to 17.7% of the population (50,090 people). The 75 and over population had increased by 9.8% to 8.5% of the population (24,130 people) and the 85 and over population had increased by 18.1% to 2.4% of the population (6,690 people).

It is expected that this trend will continue and on the next five years it is projected that there will be an additional 4,050 people aged 65 and over, an additional 1,320 aged 75 and over and an additional 520 aged 85 and over. Respectively they will form 19.0%, 8.9% and 2.5% of the population.

\(^2\) 2009 data is the most recent complete year available at the time of writing
The ageing population in Stockport is not simply an effect of the larger post war generation surviving into old age; it is coupled with increasing life expectancy at age 65. In Stockport, if a man reaches 65 he can expect to live for a further 17.8 years and a woman aged 65 can expect an additional 20.9 years. This benefit, however, is not experienced equitably across the population and there are significant inequalities in life expectancy within the borough.

Within Stockport, older people tend to live in the more affluent areas and population growth in this age group is also concentrated in these areas (see figure 1.4.4). Life expectancy at age 65 deteriorates more rapidly for the lower social classes. However, in the next 10 years the oldest people will be more likely to come from the higher social classes and the higher the social class, the longer people will live. Conversely, significant numbers of older people live in deprived areas and are likely to have greater needs than those living elsewhere in the borough.

The ageing population will have an impact on the use of NHS services in the next 3 to 5 years. Older people have greater health needs and whilst they represent 17% of the population
account for 32% of all inpatient admissions, 37% of all emergency admissions and 46% of all ambulatory care sensitive condition admissions.

In the next 10 years, the first significant cohort of people from a black or other minority ethnic (BME) background will reach retirement age. Local data collection systems are weak on collecting ethnicity but evidence from elsewhere suggests BME populations do not access traditional models of care for long term conditions.

1.4.3 Palliative Care in a Primary Care Setting

As part of the Quality and Outcomes Framework, GP Practices are required to identify those patients on their practice list who are on an end of life pathway and are expected to die within the next six months. Table 1.4.5 shows the trends in these numbers.

Table 1.4.5: GP Palliative Care Registers

<table>
<thead>
<tr>
<th>Year</th>
<th>Number on GP Palliative Care Register</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006/07</td>
<td>228</td>
</tr>
<tr>
<td>2007/08</td>
<td>283</td>
</tr>
<tr>
<td>2008/09</td>
<td>286</td>
</tr>
<tr>
<td>2009/10</td>
<td>359</td>
</tr>
</tbody>
</table>

Source: QOF

National prevalence models calculated in 2008 suggest an expected figure of around 290 people, a figure close to total for that year. In 2009/10 the number of people on palliative care registers has increased significantly, and interim data for 2010/11 suggest that this higher level may be sustained. In 2009/10 individual GP practices palliative care registers varied between 0 and 26 patients. The national drive to ensure that identification of 1% patients who are in the last year of life by GP practices would mean that 20 patients from a list of 2000 would be expected to be on a GSF register.

1.4.4 End of Life Care Mortality

Mortality data for the end of life care pathway is analysed each year for deaths for people aged 19 and over (adults). Deaths are categorised by their underlying cause into those that are expected and would be able to have a planned end of life and those that are unexpected. Section 1.4.4 provides more detail about the causes of death.

Expected causes of death include cancer, diabetes, dementia, certain long term neurological conditions (such as motor neurone disease), heart failure, chronic obstructive pulmonary disease (COPD) and renal failure. Unexpected causes of death include infections, acute circulatory conditions such as stroke and coronary heart disease and accidents.

Table 1.4.6 shows trends in the number and proportion of deaths each year which are expected or unexpected. Around two-fifths are expected (approximately 1,100 deaths each year) and three-fifths are unexpected. Over the last six years there has been a slight increase in the proportion of deaths that are expected, rising from 38.5% to 41.5%. This is most likely to be due to the fall in the death rate from circulatory disease which is generally unexpected whilst the death rate for cancer, the main expected cause of death, has fallen less quickly.
Table 1.4.6: Number of adult deaths by expected / unexpected

<table>
<thead>
<tr>
<th></th>
<th>2004/05</th>
<th>2005/06</th>
<th>2006/07</th>
<th>2006/07</th>
<th>2008/09</th>
<th>2009/10</th>
</tr>
</thead>
<tbody>
<tr>
<td>Expected</td>
<td>Number</td>
<td>1,059</td>
<td>1,089</td>
<td>1,077</td>
<td>1,123</td>
<td>1,143</td>
</tr>
<tr>
<td></td>
<td>Proportion</td>
<td>38.5%</td>
<td>39.2%</td>
<td>40.1%</td>
<td>42.3%</td>
<td>42.1%</td>
</tr>
<tr>
<td>Unexpected</td>
<td>Number</td>
<td>1,692</td>
<td>1,687</td>
<td>1,609</td>
<td>1,530</td>
<td>1,573</td>
</tr>
<tr>
<td></td>
<td>Proportion</td>
<td>61.5%</td>
<td>60.8%</td>
<td>59.9%</td>
<td>57.7%</td>
<td>57.9%</td>
</tr>
</tbody>
</table>

Expected and unexpected deaths categories are an artificial measure for data purposes only based on diagnosis. A comparison of the expected numbers of deaths each year in table 1.46 with the GP palliative care register shown in section 1.4.3 indicates that many expected deaths are not identified in primary care. The data from QOF for 2009/10 indicated 359 people were on a GP palliative care register, however, as this data is only collected for those who are expected to die in the next 6 months an estimate for the year would be approximately 720.

Comparing this to the total expected deaths of 1,100 suggests that around 400 expected deaths each year may not be identified in primary care. It is possible that some of these expected deaths are managed via a palliative care lists maintained by residential or nursing homes; unfortunately data is not collated centrally from these sources.

Figure 1.4.6: 2009/10 Adult Deaths by Place of Death

![Figure 1.4.6: 2009/10 Adult Deaths by Place of Death](image)

Figure 1.4.6 above shows the trends in deaths occurring in a persons’ own home, and indicates that this proportion is slowly rising. Figure 1.4.6 shows that the place of death varies for expected and unexpected deaths. Unsurprisingly, expected deaths are much more likely to occur in a hospice or in a patients’ own home, whilst unexpected deaths are more likely to occur in hospital. Similar proportions of expected and unexpected deaths occurred in residential or nursing homes.

For deaths outside the hospital younger adults (aged 19-39) are the most likely to happen at home (68%) or elsewhere (21%), especially for unexpected causes; whilst middle aged adults (aged 40-64) are most likely to die in their home (68%) or a hospice (17%). Older people are the only group likely to die in a care home (36%) but significant numbers also die in their own home (48%) or hospice (13%). Almost all expected deaths outside of a hospital setting are for cancer (74%).

The age profile of each of the causes of deaths is shown in figure 1.4.7. In the under 40 age group unexpected deaths are more likely than expected deaths, as accidents and harm are the most significant causes of death in this age group. Between the ages of 40 and 59 the age profile of both...
groups is very similar, but in the 60 to 79 age group expected causes of deaths are more common than unexpected deaths, this age group is where the cancer is the major cause of death. After the age of 80 unexpected deaths are again more common, as heart disease is the major cause of death.

![Figure 1.4.7: 2009/10 Adult Deaths by age](#)

The deprivation profile of the two categories is very similar (see figure 1.4.8) with proportions broadly reflecting the population distribution, as more people in Stockport live in affluent areas than in deprived areas.

![Figure 1.4.8: 2009/10 Adult Deaths by deprivation](#)

1.4.5 Causes of Death

In Stockport three quarters of all deaths are due to circulatory disease (33%), cancer (30%) or respiratory disease (12%). Digestive disease and external causes (accidents, assaults and self harm) account for a further 6% each. Over the last decade death rates from circulatory and respiratory disease have decreased significantly. Deaths rates from cancer have also decreased, but at a slower rate so that the proportional share has risen (see figure 1.4.9).
1.5 Commissioning Intentions

This strategy has been developed by NHS Stockport as co-ordinating commissioner on behalf of all associate PCTs who access services at Stockport NHS Foundation Trust. The strategy has been developed and agreed on the basis of the demographics of the host PCT. However, it is anticipated that the demographics of patients accessing services from outside of Stockport will not materially differ and that the service delivered to these patients will be consistent with that specified. As such this strategy is for a single service to all patients.

NHS Stockport will commission palliative and end of life services for the care of adults aged 16 years and over that:

- Ensure that the service is cost effective and efficient;
- Ensure an appropriate balance of care between acute and community services based including social care on delivering the most appropriate, highest quality of care at lowest cost;
- Focus on clear outcomes including the expected impact on improvements in patient and carer experience, the delivery of specified national and local targets, the delivery of clearly defined quality and service improvements and systematic and demonstrable delivery of agreed effective interventions;
- Enhance the experiences of patients and their families by delivering the best quality care in the most appropriate setting for their needs;
- Provide dignity and respect at a difficult time in the patient’s life;

High quality care will be provided for all patients irrespective of age, gender, ethnicity, religious belief, disability, sexual orientation or socioeconomic status. This will apply to all services regardless of the location of care, be it in hospital, hospice, other community setting, care home or in the patient’s own home.

1.6 Stakeholder engagement in developing the strategy

This strategy has been developed by clinicians and managers from the Stockport health economy in particular from NHS Stockport, the Specialist Palliative Care Team at Community Health
Stockport, General Practitioners, Stockport NHS Foundation Trust, Stockport Metropolitan Borough Council. The strategy has been subject to review and change based on discussions with Stockport Local Involvement Network (LINk) to ensure that the views of service users and their families are taken into account. This document was accepted and ratified by the End of Life Care Programme Board on 8th February 2012.

During 2008 a number of events were held to ascertain the views of service users and their families about End of Life Care services and how they felt that their views could be incorporated into local planning arrangements.

It has been shared with the Stockport Clinical Executive Committee and Stockport Clinical Commissioning Pathfinder Committee.

2. The Service Model

2.1 Background

Defining the end of life varies according to individual patients and professionals perspectives, however, in all cases the end of life should commence with a comprehensive assessment of the needs of the patient, including symptom management as well as psychological, spiritual and social support. People’s needs, priorities and preferences should be identified, documented and reviewed and acted upon wherever possible to ensure that patients and their families are appropriately supported throughout the last year of their life.

The North West End of Life Care Model (see Figure 1 below) uses a whole systems approach for all adults with a life limiting disease regardless of the need for end of life care from the point of identification to care after death. Stockport has adopted this model of care to support delivery of quality End of Life Care services.

Figure 1

The following section outlines the five stages of the Stockport model.

2.2 The Stockport Model

The Palliative and End of Life Care model consists of five phases.

1. Advancing Disease
2. Increasing Decline
3. Last Days of Life
4. First Days of Death
5. Bereavement

The provider intervention will vary dependent on an individual’s need and the complexities of their illness. The model of care delivered in Stockport will enable all patients and carers to be supported and have their care coordinated when they have been identified as being in the last year of life. How that care is coordinated and delivered will be determined by who is responsible for the health needs of each patient throughout the stages of the model.

GPs are responsible for the health needs of their patients when being cared for in the community. The coordination of care will be determined by assessment of the complexity of the illness, phase of illness and functional status which will identify the needs of patients and level of intervention needed. Clinical responsibility remains with the GP whilst the patient is cared for in primary care.

Monitoring the phase of illness, complexities of need and severity of problems will be through regular multi disciplinary Gold Standards Framework (GSF) meetings in general practice. The GSF criteria will provide an outline to govern the structure from which end of life care should be coordinated and applied to delivery of care in the community.

End of life patients are likely to need care from various service providers, often to ensure that the most appropriate care is provided, this will include transfers of care from one provider to another. Care must therefore be well managed and co-ordinated to avoid fragmentation which would be detrimental to the well being of the patient. The clinical handover of responsibility between providers must be coordinated to ensure that quality care is maintained and care is not affected. Clear care pathways are vital as are excellent working relationships between all providers of care, to enable patients to move seamlessly between services.

**Key worker**
Coordination of care will be led by the key worker; identification of the key worker for each patient and will improve quality of the patient and carer experience as well as reducing fragmentation of service provision. Coordination of care for those patients who are in the last 12 months of their life will be managed more effectively and will ensure that all patients and carers will receive the appropriate level of care and support. The key worker should be clearly defined within the team responsible for the care of the patient, this information should be shared with the patient, their family and any other providers involved with the care of the patient.

The key worker may change throughout the last 12 months of the patient’s life; this may be due to a change in the needs of the patient and a more appropriate health professional would continue the key worker role. The key worker should have a good understanding and knowledge of the services available locally to ensure continuation of care and excellent communication is vital to the role.

**Providers of End of Life Care – The Stockport Model**

<table>
<thead>
<tr>
<th>GPs</th>
<th>District Nursing</th>
<th>Hospital</th>
<th>Specialist Palliative Care</th>
<th>Hospice</th>
<th>Allied Health Professionals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Care Home</td>
<td>Domiciliary Care</td>
<td>Social Care</td>
<td>Out of Hours Providers</td>
<td>Voluntary Organisation</td>
<td></td>
</tr>
</tbody>
</table>
In order to identify the level of support and provider involvement throughout each phase of illness for patients who are in the last 12 months of life, the following key criteria have been identified to support providers with decisions and identification of the level of care and support needed.

- Phase of illness
- Provider type
- Problem severity
- Functional status

**Phase of illness** is identified by the level of need and support the patient and their family will need. The five categories are:

- **Stable**: symptoms controlled and all care needs identified and met by generalist services. Family situation is supportive and stable.
- **Deteriorating**: symptoms gradually getting worse each week or the development of a new but expected problem which needs additional support and review or change in care plan. This includes change in family support or increased social or practical needs.
- **Unstable**: a new severe problem or rapid increase in existing severe problem over days including urgent change in interventions to meet change in needs.
- **Dying**: death anticipated within a few days and support required daily.
- **Bereavement**: emotional or practical support prior to death and following death.

It is recognised that throughout the course of the disease patients needs change from stable, deterioration, unstable and dying and support to family and carers through to bereavement. There is no predetermined order of progression through the stages and patients may at any time require varying levels of support and will differ from patient to patient.

**Provider type** defines the level of provider that will deliver and coordinate care and includes GPs, district nurses, the specialist palliative care team, and hospital or hospice services. Assessment of needs will determine which providers will need to be involved to deliver the level of care needed, and will be dependent on individual needs. Ongoing assessments and GSF meetings within general practice will ensure that the appropriate level of care is provided whilst the patient is cared for in the community.

**Problem severity** is determined by the clinical complexity of the illness and the number of areas of need as well as the unpredictability of condition and level of intervention will determine the problem severity. This will be determined through ongoing assessment by the clinician responsible for the care of the patient and multi disciplinary discussions that will agree the level of support required. This may change throughout the stages of illness.

**Functional status** assesses the patients’ ability to undertake daily activities and fulfil their usual roles. A change in functional status is determined when there is a change in the individual’s independence and is usually an indication of how the disease is progressing.

All of the above criteria should be considered when determining the level of intervention, care and provider required to ensure that the most appropriate care is delivered and coordinated by the person with clinical responsibility for the patient.

The key classification groups that support identification of the level of care required and intervention by providers for the Stockport model are:
Clinical responsibility remains with the GP whilst the patient is cared for in primary care. The GP will monitor the phase of illness, complexities of need and severity of problems through regular multi disciplinary GSF meetings in general practice. These criteria will provide an outline to govern the structure from which end of life care should be coordinated and applied to delivery of care in the community.

During the last year of life patients are likely to need care from various service providers, often including transfers from one provider to another. Care must therefore be well managed and coordinated to avoid fragmentation which would be detrimental to the patient. The responsibility for identifying complexities of illness is the responsibility of the named clinician treating the patient while they are receiving inpatient care at a hospital or hospice.

The clinical handover of responsibility between providers must be coordinated to ensure that quality care is maintained and care is not affected. Clear care pathways are vital as are excellent working relationships between all providers of care, to enable patients to move seamlessly between services.

Clinical responsibility and responsibility for care coordination will differ for community care, hospital care and care in the hospice, residential and nursing homes. These are described in more detail by provider type in Appendix 1, Model of Care.

The following sections describe the key features of each stage and the expected roles and responsibilities of the different care providers within each phase.

2.2.1: Advancing Disease

This phase commences at 1 year or more prior to death. At this point identifying patients is critical to ensure that appropriate planning is undertaken so that patients receive appropriate care at the right time. It is also anticipated at this point that the individual would be assessed and clinically managed through members of GSF coordination meetings using the Gold Standard Framework (GSF) and then be placed on the GP practice GSF register, this is described in more detail below. If the patient is residing in a care home or nursing home the patient will be assessed by the GP with responsibility for care of that patient whilst in the care/nursing home and placed on the GP practice GSF register. The individual should then be discussed at monthly multidisciplinary GP practice or care home meetings.

The Gold Standards Framework (GSF)

The Gold Standards Framework (GSF) is a systematic evidence based approach to optimising the care for patients nearing the end of life delivered by generalist providers. It is concerned with helping people to live well until the end of life and includes care in the final year of life for people with any end stage illness in any setting. GSF improves the quality, coordination and organisation of care in primary care, care homes and acute hospitals. This enables more patients to receive the
type of care they want, in their preferred place, with greater cost efficiency through reduced hospitalisation. (http://www.goldstandardsframework.nhs.uk/).

GSF supports generalist staff in providing appropriate, patient-led care, for those with any condition on an end of life pathway. GSF is intended to be used in any generalist setting including general practice, care homes and hospitals.

Currently within Stockport all of the 52 GP practices in Stockport have adopted GSF. Under the Quality and Outcomes Framework (QOF2) of the GP contract, GP practices are awarded points and receive funding if they undertake the first level of GSF. To achieve this GP practices must:

- Have a register of all end of life care patients;
- Hold a meeting to discuss end of life care patients

Although this has been adopted by GPs under QOF arrangements the implementation of this is variable in depth and practice meetings to discuss end of life patients can vary from monthly to three monthly intervals.

There are multiple providers and individuals roles involved with patients who are approaching end of life. Best practice indicates that it is in the patients’ interest to identify patients with an advanced progressive disease as early as possible. Although identification can be undertaken by various clinicians the central point for assessment, clinical management and coordination of care is the patients’ GP through multi disciplinary meetings within general practice.

The Providers involved at this stage include:

- **General Practitioners (GP)** – responsible for prescribing, delivering and clinical management of care when being cared for in the community. Assessment and identification of changes in patient’s condition and implementation of GSF. To hold monthly multidisciplinary meetings as a minimum within the practice to ensure appropriate care is prescribed, managed and delivered and support is in place to ensure care is coordinated according to need. The GP will be reactive to changes in the care needs of the patient to ensure any management of additional care needs are met.
- **District Nursing team** – to coordinate and provide care to patients with nursing needs, the level of input will depend on the complexity of the illness and level of need. To manage symptoms and be reactive to changes in condition linking closely with the GP and participating in GSF meetings. Discussing and recording preferences regarding care and advanced care planning.
- **Specialist Palliative Care team** – to provide specialist advice and support to generalist care providers to support with planning holistic care for patients with complex or intractable physical, psychological, social or spiritual care needs.
- **Allied Health professionals** – to provide specialist intervention and assess the physical and functional needs of the patient working alongside the multi disciplinary team.
- **Hospital staff** – to provide care at the point of need this may be at various points within the patient journey and be planned or unplanned episodes of care. Hospital services should support preferred place of care processes and ensure speedy communications to the patients GP at the point of discharge to ensure that rapid discharge processes are in place and processes in place to liaise with community services to ensure that care within the community at discharge is appropriate.
Social care staff – to provide support to health professionals by ensuring responsive services are provided to those patients and their carers with social needs such as housing needs, domiciliary care, benefit services and equipment for the home.

Out of Hours providers – to provide generalist support including symptom management and assessment of need and to ensure that information is shared between out of hours providers, the patients GP to enable continuity of care.

Care/Nursing home staff – to be aware of the patients within their care that are on the GSF register and monitor changes in condition and to ensure that the patients GP is informed of changes in condition, needs and preferences.

Domiciliary Care providers - to be aware of the patients within their care that are on the GSF register and monitor changes in condition and to ensure that the patients GP is informed of changes in condition, needs and preferences and to liaise with other members of the multidisciplinary team.

Voluntary Sector providers such as Age UK, Beechwood and Signpost – to provide supportive services alongside mainstream health and social care services including psychological support, counselling and bereavement support.

2.2.2: Increasing decline (6 months prior to death)

This phase commences at approximately 6 months prior to death. At this stage there should be a review of eligibility for benefits (DS1500) and a referral should be made to the Welfare Rights Officer where appropriate. Discussions with the patient and family regarding their Preferred Priorities for Care (PPC) should be noted, an opportunity to complete an Advance Care Plan (ACP) should be agreed and this stage should be a trigger for an assessment of need for continuing healthcare funding.

For those patients who are in the last two weeks of life and require District nursing involvement there will be options for service provision that will include social and health care. Packages of care will be based on need and should be in place to support the patient and family throughout the last two weeks of life prior to death.

There are various processes and tools that help health professionals plan care and to identify changes in health and social needs, these enable the documenting of patients and carers wishes and preferences. These include:

Preferred Priorities of Care (PPC)

The Preferred Priorities for Care arise from discussions about future planning and enables wishes and preferences to be written down and can be referred to during the last year or months of a patient’s life. It is written documentation that will help patients and carers plan care during the last months of life and will mean that everyone involved in both health and social care knows how the patient and their family wish to be cared for.

The document enables healthcare professionals to facilitate patient choice in relation to the patients care when approaching end of life. Through good communication between the patient, carer and provider this enables patient and carers choices to be documented, and patients and carers become empowered through the sharing of this information with all professionals involved in their care.

The PPC provides the opportunity to discuss difficult issues that may not otherwise be addressed to the detriment of patient care. The explicit recording of patients and carers wishes can form the
basis of care planning in multi-disciplinary teams and other services, minimizing inappropriate admissions and interventions.

The PPC also records services available, services being accessed and reasons for changes in the care trajectory. PPC is a process, which facilitates service review, further empowering professionals to negotiate service requirements on the behalf of patients, becoming an integral part of service commissioning and design.

The Preferred Priorities for Care document should include information such as:

- How the patient feels about their illness and what is their understanding about their prognosis
- Any fears the patient may have such as being in pain, or being a burden to their family
- Particular needs those caring for the patient may have
- Who the patient would like to care for them now and in the future
- Where the patient would like to die – at their home or normal place of residence, in a hospice or hospital
- What the patient does or does not want to be told, for example how long they may have to live
- Anything the patient may like to do while there is still time, such as having a holiday

This is not an exhaustive list and it is the patients’ choice whether they include some, all, or none of these issues. This is not a legal document but it is covered by the Mental Capacity Act (2005).

**Advance Care Planning (ACP)**

Caring for people at the end of their lives is an important role for health and social care professionals. One of the elements introduced to support people at the end of their lives is to find out what their preferences and wishes are in relation to their future care.

Advance Care Planning (ACP) is a voluntary process of discussion between an individual and their care providers irrespective of discipline. The process should be instigated by the key worker or health and social care professional involved with the care of the patient and their family and if the individual wishes, their family and friends may be included in the discussions. With the individual's agreement, this discussion should be recorded, regularly reviewed and communicated to key persons involved in their care.

Advance Care planning should be used as a process that supports the individual to make decisions about how their care and treatment may affect them in the future and if they wish to set a record of their choices about care and treatment as well as any decision to refuse treatment in specific circumstances so that they can be referred to in the event they may loose capacity to decide as their illness progresses. This process can be undertaken by effective communication carried out with compassion and sensitivity by the care provider and can only be undertaken by an individual who has capacity to decide.

At this stage involvement from various agencies will be triggered dependent on need. Discussions at the monthly GSF meetings within general practice will enable changes the patients or carers need to be identified. The GP has responsibility of care in the community will then refer the patient to providers for specialist care or advice and can be in relation to health needs or social and financial support, this may include:
- A referral to the Consultant in Palliative Medicine
- A referral to the Specialist palliative care team for support with complex care needs
- A referral to Social Services – this may be for domiciliary support, equipment or housing needs
- A referral to welfare rights for assessment of financial need (DS1500)
- Referral for Continuing Healthcare funding

The Providers involved at the increasing decline stage include:

- **General Practitioners (GP)** – clinically responsible for prescribing and managing decisions about care when patients are being cared for in the community. GPs should hold monthly multidisciplinary meetings (GSF) within the practice and managing care decisions and prescribing care to meet individual needs ensuring care is coordinated and delivered according to need and reactive to changes in care needs of the patient to ensure any additional care needs are met. The GP should assess the needs of carers and families and refer for support from providers dependent on need.

- **District Nursing team** - coordinators of care for the patient when being cared for in the community and to provide care to patients with nursing needs, the level of input will depend on the complexity of the illness and level of need. To manage symptoms and be reactive to changes in condition and participating in GSF meetings. Discussing and recording preferences regarding care and advance care planning. Assessing the needs of carers and families and refer to support services coordinating support dependent on need. For patients in the last 2 weeks of life support with health and social care needs will be provided.

- **Specialist Palliative Care team** - to provide specialist advice and support to generalist care providers to support the GP, District Nurse, Hospital and Hospice with planning care for patients with complex or intractable physical symptoms. Assessing the needs of carers and families and refer to support services coordinating support dependent on need. The Specialist Palliative Care team will provide expert clinical advice and complex holistic care for patients and families referred with palliative or complex or intractable physical, psychological, social or spiritual care needs that cannot be managed by the GP.

- **Allied Health professionals** – to provide specialist intervention and assess the physical and functional needs of the patient working alongside the multi disciplinary team.

- **Hospice**– to provide specialist care and treatment for patients with complex needs that cannot be managed within the community setting assessing the needs of carers and families and coordinating support dependent on need. Hospice services should support preferred place of care processes and ensure speedy communications to the patients GP at the point of discharge to ensure that care within the community is appropriate.

- **Hospital staff** - to provide care at the point of need this may be at various points within the patient journey and be planned or unplanned episodes of care. Hospital services should support preferred place of care processes and ensure speedy communications to the patients GP at the point of discharge to ensure that rapid discharge processes are in place and processes in place to liaise with community services to ensure that care within the community at discharge is appropriate. Assessing the needs of carers and families and coordinating support dependent on need.

- **Social care staff** - to provide support to health professionals by ensuring responsive services are provided to those patients and their carers with social needs such as housing needs, domiciliary care, benefit services and equipment for the home.
➢ Out of Hours providers – to provide generalist support including symptom management and assessment of need and to ensure that information is shared between out of hours providers and the patients GP to enable continuity of care.

➢ Care/Nursing home staff – to be aware of the patients within their care that are on the GSF register and monitor changes in condition and to ensure that the patients GP is informed of changes in condition, needs and preferences.

➢ Domiciliary Care providers - to be aware of the patients within their care that are on the GSF register and monitor changes in condition and to ensure where possible that the patients GP is informed of changes in condition, needs and preferences.

➢ Voluntary sector support services such as Beechwood, Age UK, Signpost – various levels and types of support are provided by a number of voluntary sector providers. Support can range from practical support with shopping, information and signposting to services as well as psychological support.

2.2.3: Last days of life

This phase is concerned with the last few days of life. The Liverpool Care Pathway for the Dying Patient (LCP) is a plan of care for people who are dying and are in the last few days of life. A detailed assessment by a healthcare professional is needed to plan care including symptom control, and give clear information about the care that is needed to the patient and their family. The LCP is a multi professional assessment and should be used by professionals within the community, the hospital, hospice or care home.

Ongoing assessments of the patient’s condition and any changes will support health professionals in recognising when to implement the LCP. The criteria for applying this pathway are determined by deterioration in a patient’s condition that suggests the patient is dying. The LCP aims to support but does not replace clinical judgement. The initial LCP assessments (see section on next page) should be undertaken jointly by a district nurse or Macmillan nurse and a GP following the decision to commence the LCP the GP will inform out of hours GP provider of the change in the patients condition and that a death may be expected. End of life drugs which ensure the patient symptoms are controlled and should be prescribed and obtained and the LCP should be implemented. Ongoing review and assessment should be every three days. Assessment and implementation of the LCP will vary dependent on the location of the patient whether this is hospital or the community.

The Liverpool Care Pathway ensures that evaluation and care is continuous and consistent and that professionals using the Pathway ensure that both patient and carers understand that the structure and focus of care has now changed and the focus is now on care and comfort during the end stages of life.

The LCP covers all aspects of care including:

➢ Keeping the patient comfortable by controlling their pain and symptoms;
➢ When to prescribe certain drugs to prevent symptoms before they start;
➢ When to discontinue some treatments or aspects of care;
➢ Psychological and spiritual support;
➢ Support for the family;
➢ Bereavement support;

The Liverpool Care Pathway process enables healthcare professionals to focus on care in the last hours or days of life irrespective of diagnosis and to stop and think about assessment and change
care appropriately for individual patients and their carers. The LCP should be implemented wherever the patient is being cared for including in a hospice, at their home or normal place of residence, in hospital or in a care home following an assessment by the clinician responsible for the patient’s treatment. In the community this could be the GP, the Specialist Palliative Care Team or the District Nursing Team. In the hospital this would be by the hospital Macmillan nursing team or doctor responsible for the care of the patient, in the hospice this would be by the nursing team and the doctor responsible for the patient.

The assessment will have identified a change in condition where they believe the patient is dying and in the last days or hours of life. The LCP supports healthcare professionals to ensure that the best quality care is coordinated and delivered. At this point medication that is not helpful will be stopped and medication for symptom control will only be given when needed.

Using the LCP in any environment requires regular assessment and involves regular reflection, challenge, critical senior decision-making and clinical skill, in the best interest of the patient. A robust continuous learning and teaching programme must underpin the use of the LCP. The recognition and diagnosis of dying is always complex, irrespective of previous diagnosis or history. Uncertainty is an integral part of dying. There are occasions when a patient who is thought to be dying lives longer than expected and vice versa. Changes in care at this complex, uncertain time are made in the best interest of the patient and relative or carer and needs to be reviewed regularly by the multidisciplinary team (MDT).

Good comprehensive clear communication is pivotal and all decisions leading to a change in care delivery should be communicated to the patient where appropriate and to the relative or carer. The views of all concerned must be listened to and documented.

The Providers involved at this stage includes:

- **General Practitioners (GP)**–clinically responsible for management of care of the patient in the community for the non complex patient. To hold multidisciplinary meetings within the practice to ensure care is managed appropriately and care is coordinated according to need and to carry out assessments in respect of the LCP. To be reactive to changes in the care needs of the patient to ensure any additional care needs are met and symptoms are managed. Assessing the needs of carers and families and referring for support dependent on need.

- **District Nursing team**–to coordinate care of non complex patients in the community and provide care to patients with nursing needs, the level of input will depend on the complexity of the illness and level of need. To participate in GSF meetings, in collaboration with the GP to coordinate care and manage symptoms and be reactive to changes in condition, applying the criteria to implement the LCP as well as recognising the need to carry out ongoing assessments for the LCP. Assessing the needs of carers and families and coordinating the support will include the provision of support with health and social care needs of the patient.

- **Specialist Palliative Care team** - to coordinate care for those patients with complex needs. To provide specialist care, advice and support to patients and carers with complex needs. To provide specialist advice to generalist care providers for those patients with non complex needs when planning care for patients with complex or intractable physical symptoms. To identify changes in patient’s condition, applying the criteria for the LCP and undertaking ongoing assessments within the LCP for those patients who have been identified as being in the last 2 days of life and monitor changes in the patient’s condition to ensure appropriate care is coordinated and delivered. Assessing the needs of carers and
families and coordinating support dependent on need. The Consultant in Palliative Medicine will provide expert clinical advice and treatment for patients referred with complex or intractable symptoms providing increased support to primary care clinicians. Clinical responsibility for the patient will remain with the GP.

- **Allied Health professionals** – to provide specialist intervention and assess the physical and functional needs of the patient working alongside the multi disciplinary team. Providing specialist advice and support with respiratory function, mobility, and fatigue and swallowing difficulties.

- **Hospice** – to provide specialist care and treatment for patients with complex needs that cannot be managed within the community setting, assessing the needs of carers and families and coordinating support dependent on need. To carry out ongoing assessments that will support the identification of those patients within the hospice who are in the last 2 few days of life and implement the LCP. To carry out ongoing assessments that will identify a change in condition and need and be reactive to ensure appropriate level of care is provided. Hospice services should support preferred place of care processes and ensure speedy communications to the patients GP at the point of discharge to ensure that care within the community is appropriate.

- **Hospital staff** - to provide care at the point of need this may be at various points within the patient journey and be planned or unplanned episodes of care. To carry out ongoing assessments that will support the identification of those patients in hospital who are in the last 2 days of life and to implement the LCP. To carry out ongoing assessments that will identify a change in condition and need and be reactive to ensure appropriate level of care is provided. Hospital services should support preferred place of care processes and ensure speedy communications to the patients GP at the point of discharge to ensure that rapid discharge processes are in place and processes in place to liaise with community services and social care services to ensure that care within the community at discharge is appropriate. Assessing the needs of carers and families and coordinating support dependent on need.

- **Social care staff** - to provide support to health professionals by ensuring responsive services are provided to those patients and their carers with social needs such as housing needs, domiciliary care, benefit services and equipment for the home.

- **Out of Hours providers** – to provide generalist support including symptom management and assessment of need and to ensure that information is shared between out of hours providers and the patients GP to enable continuity of care. To be reactive to changes in the care needs of the patient to ensure any additional care needs are met and symptoms are managed and apply the LCP criteria if appropriate.

- **Care/Nursing home staff** – to be aware of the patients within their care that are on the GSF register and monitor changes in condition and to ensure that the patients GP is informed of changes in condition, needs and preferences.

- **Domiciliary Care providers** - to be aware of the patients within their care that are on the GSF register and monitor changes in condition and to ensure where possible that the patients GP is informed of changes in condition, needs and preferences.

- **Voluntary sector support services such as Age UK, Beechwood and Signpost** – various levels and types of support are provided by a number of voluntary sector providers. Support can range from practical support with shopping, information and signposting to services as well as psychological support.
2.2.4: First days after death

This phase refers to the first few days after the death of the patient at which time prompt verification and certification of death should occur. Good end of life care does not stop at the point of death. All staff should be familiar with good practice for the care and viewing of the body responding to the wishes of relatives and the carer as well as religious and cultural beliefs. It is also essential that key staff should be aware of the role of the coroner and the level of involvement in particular cases.

Timely verification and certification of death is a key element. Certification of a death in the community is a legal requirement of the GP who is also required to complete the relevant documentation. However, should the death occur out of hours then the certification procedures agreed by the Coroners Office in respect of the GP attending the deceased during their last illness will apply. Verification of a death can be performed by other clinically trained staff.

To avoid problems with removing the body after a death and to alleviate any distress for families and carers, procedures should be in place with out of hours providers regarding verification that a death has taken place. The relatives should be given information regarding what to do after the death including the D49 leaflet and information regarding how to register the death and how to contact funeral directors. Generalist staff, specialist staff or the GP should ensure that this information is provided.

The Providers involved at this stage includes:

- **General Practitioners (GP)** - To support the family emotionally following the death of a loved one including assessing bereavement risk, signposting and referring to bereavement support services. The GP should provide information about what to do following a death such as how to register the death and ensure that all providers involved in the care of the patient are aware of the patient’s death. The death of a patient should be discussed at the GSF meeting to identify if preferred place of care was achieved and if any lessons can be learned.

- **District Nursing team** – To support the family emotionally following the death of a loved one including signposting to GP for referral to bereavement support services and information about what to do following a death such as how to register the death.

- **Specialist Palliative Care team** – To support the family emotionally following the death of a loved one including signposting to bereavement support services and information about what to do following a death such as how to register the death.

- **Hospice** – To support the family emotionally following the death of a loved one including signposting to bereavement support services and information about what to do following a death such as how to register the death.

- **Hospital staff** – To support the family emotionally following the death of a loved one including providing information about what to do following a death such as how to register the death, the provision of bereavement support services or signposting to bereavement support services as appropriate.

- **Social care staff** - To support the family emotionally following the death of a loved one including signposting to bereavement support services and information about what to do following a death such as how to register the death. Information should also be given on processes for returning equipment and cancelling domiciliary care.

- **Care/Nursing home staff** – To support the family emotionally following the death of a loved one by providing information about what to do following a death such as how to
register the death and what the processes are for terminating the residency within the care home.

- Voluntary sector support services such as Beechwood, Age UK, Signpost – various levels and types of support are provided by a number of voluntary sector providers such as bereavement support services.

2.2.5: Bereavement

The bereavement phase could extend to 1 year or more from the death of the patient and should include access to appropriate support and bereavement services as required by the family and carers of the deceased.

Bereavement care should begin prior to the death of a patient with their carers being assessed for their potential bereavement need by healthcare professionals providing the care for the patient. Conversations with carers during the care planning phase can help identify where support will be needed following the death of the patient. Sensitive end of life care with open communication and good support during the dying phase positively contributes to a person’s experience of bereavement.

Key elements include:
- End of life and palliative care assessments for dying patients and their carers
- Primary care
- Acute hospitals
- Care homes
- Social services
- Out of Hours care providers
- Emergency services
- Mental health services
- Coroners offices
- Registrar offices

Health professionals have a responsibility to assess bereavement risk in family members before or at the time of death with evidence that pre bereavement support positively contributes to the person’s experience of bereavement and buffers the impact of bereavement on mental and physical health.

For those carers and families affected by sudden death pre bereavement support has not been in place and therefore this group are not supported during the first days of death. To ensure that the needs of this group are met greater awareness of families affected by sudden death is needed. Processes that will support the identification of level of support needed on an individual basis will need to be embedded within the Stockport End of Life Care Model assigning responsibility to the GP and hospital staff to provide information on how to access bereavement support.

NICE recommends comprehensive bereavement care should cover a range of needs. The three levels of need are:
- Level 1 - Grief is normal after bereavement and most people manage without professional intervention. All bereaved people should be offered information about the experience of bereavement and how to access other forms of support.
- Level 2 - Opportunity to review and reflect on their loss experience through group or individual support. Clear referral processes to level 3 interventions must be in place when cases involving more complex needs emerge.
Level 3 - A minority of people will require specialist interventions including provision for meeting the specialist needs of bereaved children and young people, those with mental illness, drug and alcohol misuse and parents of deceased children.

Services to assess and deliver bereavement support should be accessible with pathways in place for the identification, provision of emotional support and if appropriate onward referral of those at increased risk or experiencing a complicated grief reaction.

Most bereaved people will benefit from comprehensive support identified in level 1, but for those with more complex needs timely access to level 2 and level 3 support is necessary. Coordination of care and support should be led by the GP who will provide support at level 1 or refer into specialist services should level 2 and above support be required.

Providers of bereavement services must provide care that meets the three level component model. This will include.

Level 1
- Sensitive communication of information about the care of the deceased and cause of death to the carers of the deceased. Appropriate environments and private space should be available in which to hold such conversations
- Communication of information about the care, cause and date of death to the wider health and social care team involved with the deceased
- Information describing emotional impact of bereavement; coping strategies; local support services, groups and organisations as well as information regarding legislative and financial arrangements such as registration of death, funeral arrangements and inquests. The information should be:
  - given to the bereaved at or soon after the death
  - widely available in a variety of locations including pharmacies, GP practices, libraries, hospital, funeral directors
  - available in a variety of formats to meet the needs of the population including versions in various languages, audio, large print and web-based
  - updated annually to ensure information is correct
- Awareness raising within the local communities including hard to reach groups
- Signposting to bereavement support

Level 2
- Formal befriending support services that are supervised by trained professionals, but may be staffed by volunteers or provided by social, cultural or community groups
- A variety of befriending services should be available including:
  - bereavement groups with facilities for drop in and regular attendance
  - one to one support
  - memorial services/events
  - anniversary contact (8 weeks and 12 months post bereavement)
  - services children, adolescences and young adults
- Provide supervision to all staff / volunteers within the service

Level 3
- Therapeutic interventions delivered by trained professionals able to deal with complex bereavement reactions, dual diagnosis such as mental illness, drug and alcohol dependency, learning disabilities, deaths due to traumatic, extreme or unexpected cause
a variety of services should be available including

- one to one therapy
- group therapy
- couple and family therapy
- pre-bereavement support for both dying people and their carers
- joint, partnership and collaborative working with health and social care services delivering care to high risk groups such as drug and alcohol agencies and mental health services
- professional supervision for bereavement staff
- support to staff providing palliative and end of life care involved in the care of the dying

Bereaved people may access services at any time after the death of their relative it is therefore necessary to have clear signposting and processes in place for accessing services required to ensure that bereaved people are able to access the right level of service in a timely fashion.

The Providers of bereavement support includes:

- **General Practitioners (GP)** – To provide level 1 support leading up to and at the point of bereavement and to refer to services that have structured programmes in place dependent on the level of need (Level 1 to 3 mild to moderate support from voluntary sector services such as Beechwood or for level 4 high level support for severe anxiety or depression to mental health services.

- **District Nursing team** – To provide level 1 support leading up to and at the point of bereavement and to provide information on local bereavement support and referring to the voluntary sector services for mild to moderate support or to the GP to assess and review needs considering referral to mental health services for more high level support

- **Specialist Palliative Care team** – To provide level 1 support leading up to and at the point of bereavement and to provide information on local bereavement support and referring to the voluntary sector services for mild to moderate support or to the GP for assessment and review of psychological needs considering referral to mental health services for more high level support

- **Hospital staff** –To provide level 1 support leading up to and at the point of bereavement and to provide information on local bereavement support. Mild to moderate bereavement support at levels 1 to 3 from the bereavement services within the hospital and for more high level support from mental health services. To provide support to those families who are affected by sudden death in hospital and patients who are dead on arrival (DOA) through emergency departments

- **Hospice services** – various levels of and types of support are provided for bereaved people whose loved one accessed the hospice services.

- **Social care staff** - To provide level 1 support leading up to and at the point of bereavement. To signpost to GP for ongoing support.

- **Voluntary sector support services such as Beechwood, Age UK, Signpost** – various levels and types of support are provided by a number of voluntary sector providers such as mild to moderate support through bereavement support programmes.

- **Mental health services** – To provide high level support following referral from a GP.

- **Out of hours services** - To provide level 1 support leading up to and at the point of bereavement and to provide information on local bereavement support referring to the registered GP for referral to voluntary sector services for mild to moderate support or for assessment and review to mental health services for more high level support.
3. Holistic Assessment

For care to be delivered according to needs, this requires assessment and planning to ensure that the needs and personal preferences of each individual are taken into consideration. Holistic assessment includes the use of specific tools to undertake a process that will enable health and social care providers to determine the level of intervention. The assessment is a variety of conversational questions including physical, psychological, social, spiritual, independence and activity, family and social concerns, treatment issues and responding to information needs.

Key elements for consideration when undertaking an assessment are:

- To identify the health and social needs of the individual
- To evaluate the impact their illness has on daily living and quality of life
- To plan appropriate action with the individual

The focus should be on the outcome of the assessment of need and how responsive the services will be to those needs to ensure the patient can be cared for and can remain in the environment of their choice particularly at home if this is their wish. Openness, trust and sensitivity are needed when discussing individual’s needs and preferences to ensure that the assessment and planning process encompasses the needs of the individual including psychological wellbeing, spiritual needs and financial support.

Assessment should be an ongoing process as individual needs are likely to differ according to a number of factors such as:

- The nature of the condition;
- The stage of the condition;
- Other pre-existing conditions;
- The stage in the End of Life Pathway;
- Social circumstances;
- Deprivation;
- Mental health or learning difficulties;
- Cultural issues;
- Religious or spiritual beliefs;
- Psychological state;
- Approach to life and death.

Patients on the end of life pathway are likely to require access to a complex range of services depending upon their illness, clinical needs and personal preferences and may include:

- General Practice /Primary care based services;
- Community services such as district nurses
- Social care services;
- Acute medical services;
- Specialist palliative care;
- Psychological support services;
- Spiritual care;
- Out of hours services;
- Respite care;
- Transport services;
Speech and language therapy; 
Physiotherapy; 
Occupational therapy; 
In patient care; 
Day care; 
Pharmaceutical advice; 
Dietetics; 
Carer support; 
Hospice care; 
Care/Nursing home care; 
Domiciliary care 
Voluntary sector support; 
Advice services such as Macmillan Information Centres or Citizens Advice Bureau (CAB).

Individual roles of providers are described more fully in section 5 and provide detailed information about responsibilities of providers in delivering care to patients in the last year of life. The following section describes the Holistic Needs Assessment.

3.1 Holistic need
The process for assessing holistic needs enables full and frank discussions about what is concerning the patient the most. Assessments should be undertaken by health and social care staff that have the skills and abilities to undertake difficult conversations and are suitably trained to interpret the outcome of the assessment to ensure that actions are taken that will support the patient and their family. Comfort and privacy while undertaking the assessment are paramount to enabling dialogue between the patient and the clinician. Each assessment should record and capture all identified needs and relevant discussion relating to the needs and protocols for storage and sharing information will be in line with NHS records processes.

Physical need
A better understanding of physical symptoms and chronic problems will support the identification of the level of intervention needed. Consideration should be given to level of pain, memory loss, shortness of breath, changes to sleeping pattern, loss of weight and problems with swallowing.

Psychological need
Patient centred care ensures that a holistic approach is taken to assessing clinical, spiritual and psychological need recognising how the patient feels and how they participate in decisions about their care and treatment. Effective communication is essential to ensuring a reduction in patient and family anxiety as well as improving relationships between clinician and patient. Various levels of psychological support may be needed throughout the end of life pathway and the level of support will be dependent on need.

All providers caring for patients in their last year of life and their families will at some point provide psychological support; the level of support will be determined by changes in the patient’s wellbeing and levels of anxiety. All health and social care professionals should be able to recognise psychological distress and should be sufficiently competent to avoid causing psychological harm to patients and carers referring to specialist providers of psychological support as appropriate. The table below details provider responsibility and levels of support and intervention.

<table>
<thead>
<tr>
<th>Level of support / intervention</th>
<th>Assessment</th>
<th>Provided by</th>
</tr>
</thead>
</table>

Palliative and End of Life Care Vision - Ratified 08/02/2012
### Mild support (Level 1)
- Discussion for mild anxiety
- Communicate effectively
- Establish relationships

| Recognise increased anxiety and stress | All health professionals |

### Mild to moderate support (Level 2)
- Problem solving
- Manage acute crisis at points in the patients care
- Screen for psychological distress

| Recognise the need for additional support Elicit worries and other feelings establishing trust | Specialist services such as: Specialist Palliative Care Team Specialist Nurses Beechwood Cancer Care Centre St Ann’s Hospice |

### Moderate support (Level 3)
- Anxiety, distress, anger and depression
- Anxiety management
- Solution based therapy

| Delivered by trained and accredited individuals | Beechwood Cancer Care Centre Mental Health Services The Christie St Ann’s Hospice |

### Severe support (Level 4)
- Moderate to severe mental health problems
- Specialist psychological and psychiatric intervention
- Severe depression

| GP assessment and referral to the mental health services | Mental Health Services The Christie |

### Spiritual need
Spirituality for some people is expressed through religion, their personal identities, and relationships with others as well as ethical values and humanist philosophies. The National Council for Palliative Care defines spiritual support in end of life care as ‘helping people approaching the end of life and those close to them including relatives and carers to understand what is happening to them, identify a source of strength they can draw on and deciding whether those sources are helpful during this period in their lives’. The uniqueness of each individual means that responsiveness to spiritual need should be flexible and open ended.

Spiritual need is tailored to the needs, beliefs and values of the individual and people approaching the end of their life should have opportunity to explore their spiritual beliefs and values at regular points in their journey. This should be communicated to other professionals where appropriate respecting patient confidentiality at all times. Spiritual interventions should be documented along with the effectiveness of this support. Staff involved with patients in the last days of life should be trained to deliver basic aspects of spiritual care common to all faiths and beliefs and receive ongoing development training at an appropriate level to their role.

### Independence and activity
A change in the ability to do daily tasks such as walking, standing or climbing stairs will provide detailed information within the assessment of the particular needs of the patient and their family. Allied Health Professionals are key to supporting patients with improving independence along with the provision of equipment and social care packages that should be in place to enable patients to be cared for in their normal place of residence if this is their choice.

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3 The National Council for Palliative Care, London, 2011
Family and social needs
Family and friendship dynamics can be complex and when under pressure can increase concern within a family. Assessment of family circumstances and the level of understanding and support within the home will enable health and social care professionals to manage needs appropriately and provide information and advice that will be reactive to changes in circumstance.

Treatment concerns
The effects of treatments can be long, short term or transient and it is important to understand the impact these have on the patient and their family. In particular concern about future problems and how these will be addressed, it is important for all staff involved to be familiar with side effects and potential effects of the patient’s treatment. Information should be tailored to the needs of the patient so that they are well supported and obtain maximum benefit from the information provided.

Information needs
Standard documentation and leaflets that include high quality national and local information relevant for all stages of the patient’s experience should be available for patients and carers. Health professionals should assess the patient’s needs at key stages in the last 12 months of their life to ensure that information provided is tailored to the needs of the individual and is reactive to change.

3.2 Continuing Healthcare
Some people on an end of life pathway may also qualify for funding that supports their continuing healthcare. The continuing healthcare (CHC) process can be initiated at any point within the pathway and will assess a certain level of care need, it is not dependent on a particular disease, diagnosis or condition, nor on who provides the care or where that care is provided. The circumstances can include:

- older people with chronic illness or disabilities;
- older people suffering from mental illness or dementia;
- people suffering from mental illness;
- physically disabled adults;
- people with learning disabilities;
- people who are terminally ill;

For end of life care patients, particularly those who are in the last weeks of life, fast track assessments are a priority to ensure that preferred priorities for care are implemented. However the continuing healthcare assessment criteria include overall care needs and patients must show that the primary need is health related. Referral for continuing healthcare assessment can be made by any health professional. (The pathway for fast track of patients within the last 6 months of life is attached in Appendix 2).

The primary health need should relate to four key indicators:

- **nature** - the type of condition or treatment required (quality and quantity);
- **complexity** - symptoms that interact; therefore difficult to manage or control;
- **intensity** - one or more health needs, so severe they require regular intervention;
- **unpredictability** - unexpected changes in condition that are difficult to manage and present a risk to the patient or to others.
The assessment of eligibility for NHS funding begins with the National Screening Tool, which can be carried out by any health or social care professional. If a patient is not eligible they will be passed to the Stockport Metropolitan Borough Council to have their social care needs assessed. If a patient is eligible a multi disciplinary team should carry out the full eligibility assessment.

For those patients who do not qualify for CHC funding and still require nursing support an assessment for NHS funded nursing care will be instigated. The criteria for accessing this support are:

- the patient has been assessed as requiring the services of a registered nurse
- the patient does not qualify for NHS Continuing Health Care (CHC) but has been assessed as requiring the services of a registered nurse.
- the patient is not receiving registered nursing care from the district nursing team or in any other way

NHS Funded Nursing Care (FNC) is provided to people residing in registered nursing homes only. The National Framework states that the local authority cannot provide clinical services because the NHS is responsible for any care that must be provided by a registered nurse. For people in care homes providing registered nursing care, registered nurses are usually employed by the home itself. In order to fund this nursing care the NHS makes a payment to the care home to cover the cost of providing the care for those who are eligible.

Registered nursing care can involve many different aspects of care. Typically, those with a need for registered nursing care will receive some of the following:

- supervision or monitoring of nursing needs
- planning, review or amendment of their care plan
- identification and tackling of potential health problems
- referral to other healthcare professionals (GPs, therapists, etc.)
- monitoring of and support for self-medication
- drug therapies and medication as necessary.

A single band is applied for NHS FNC on a monthly basis, the value of which is determined by Department of Health on an annual basis.

### 3.3 Welfare rights and Financial support

Many patients and carers of those who are approaching the End of Life their life will have financial needs and require support and advice regarding entitlements for grants and financial support for areas such as housing, home care, prescriptions and allowances such as carer’s allowance. The welfare rights advice service is provided locally by Stockport Metropolitan Borough Council and the aim of this service is to provide support, advice and assistance to maximize income and to signpost to relevant services.

The service accepts referrals from Macmillan Specialist Nurses, Macmillan Information Advisors, NHS Professionals, Social Workers GPs and self referrals from patients, and their families. The service can be provided in the client’s home, other community settings or the council offices. The service provides assistance with;

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4. Providers of End of Life Care

Most people with palliative and end of life care needs are cared for by generalist services notably primary healthcare services, particularly GPs and district nurses, social care services, residential care and nursing homes, and hospitals.

Palliative and end of life care is part of the role and work of all generalist professionals, many of whom have received training in the principles and practice of palliative care delivered by Specialist Palliative Care Services when their care needs are complex.

Currently NHS Stockport has commissioned a range of generalist and specialist services that provide care to patients on an end of life pathway. These are listed below and are described in more detail in section 5.

4.1 Generalist care services. These include:

- District Nursing service (24 hours)
- Palliative Care Respite service (provided by District Nursing)
- Hospital Services
- Allied Health professionals
- Specialist Nursing Teams – Long Term Conditions
- Social workers (Local Authority)
- General Practice services
- Out of Hours GP provision
- Community mental health support service (Dementia)
- Pharmacy services
- Care homes
- Domiciliary care (provided by independent companies whether or not under contract to the Local Authority or the NHS)
- Spiritual care
- Transport

Across the locality the District Nursing Teams co-ordinate the care for patients who are on an end of life pathway, aiming to plan care and prevent crises and to ensure that the best care is provided at the point of need. District nurses should be reactive to changes in condition working closely with GPs to coordinate additional care from specialist providers should the patients needs become complex. Locally, specialist palliative care services are provided by a team of clinicians and healthcare professionals within the community and hospital.
4.2 Specialist palliative care services (community and in hospital). These include:

- Consultant in Palliative Medicine
- Associate Specialist in Palliative Medicine
- Macmillan Lead Nurse Palliative Care
- Macmillan Clinical Nurse Specialists Palliative Care
- Palliative Care Dietetics
- Palliative Care Pharmacy services
- Palliative Care Social worker
- End of Life Care Facilitators
- Hospice Care

The specialist palliative care service encompasses a skilled multi-professional team and works across the hospital and community. The specialist service is comprised of the consultant and associate specialist in palliative medicine, the lead nurse for palliative care, the hospital and community Macmillan palliative care nurse specialists, the palliative care respite team, palliative care dietician and social worker.

The specialist palliative care team provide specialist clinical input, advice and support to patients and their families as well as advice, support, training and education for health and social care professionals in primary and secondary care.

All hospital wards are likely to care for patients with palliative and end of life care needs although the wards catering for older people at Stepping Hill Hospital and the Meadows are likely to see the greater proportion. There are five beds at the Meadows Unit which has a ward specifically for older people with palliative care needs under the care of Stockport Foundation NHS Trust Elderly Care Physicians.

Community mental health services provide support to patients with dementia from diagnosis to death improving the quality of life to enable patients to be cared for in their normal place of residence. Alongside health care services are other providers including voluntary organisations that have a range of expertise and are commissioned to provide various areas of clinical and psychological support. Some voluntary organisations are charities and can be funded by the NHS, Local Authority or by donations. Local voluntary sector providers of end of life care include:

4.3 Voluntary Sector services. These include:

- St Ann’s Hospice, specialist palliative care in patient, out patient and day therapy services (Heald Green, Little Hulton and Neil Cliffe Centre)
- Beechwood Cancer Care Centre – specialist day services
- Macmillan information services – specialist advice based at Beechwood
- Citizens Advice Bureau (CAB)
- Age UK

4.4 Local Authority

The local authority provides a range of social care supportive services to end of life care patients and their families. These include:
NHS Stockport Clinical Commissioning Pathfinder

- Social care providers (domiciliary care and homecare)
- Housing (sheltered housing and extra care housing)
- Welfare rights
- Care home and domiciliary care provider monitoring/regulation/contracting

There are currently 73 Care Homes in the Stockport area, six of which provide a total of 22 inpatient generalist respite beds, which are either, Adult and Communities Social Services funded or privately funded by the patient utilising the beds. There are also 30 generalist Day Care places per day provided by thirteen care homes, which may be appropriate for palliative care patients, although none offer nursing care.

In addition, there are currently 26 independent domiciliary care providers accredited by and working under contact to the Council and the NHS Continuing Healthcare service. Approximately 10,000 hours care per week is currently being delivered.

In total there are approximately 5,000 Local Authority staff, 1629 health care workers working within NHS Stockport and Community Health Stockport and 2773 health care workers employed by the Foundation Trust. All these will at some point provide end of life care.

5. Roles and Responsibilities of End of Life Care Providers

The complexities created by a multiple provider environment for end of life care is such that for coordinated care to be provided, the GP and the District Nurses will work as integral members of the community team to ensure continuity of patient care. Due to the complex multi agency environment faced by end of life care patients it is imperative that care is well coordinated.

GSF meetings within general practice provide the vehicle for which communications and decisions about care are made. The multidisciplinary team approach ensures that the two way process of communications is ongoing between the GP, District Nursing Team and Specialist Palliative Care Team to ensure that all levels of care is coordinated and delivered appropriate for the needs of the patient at various points within the pathway.

Each person approaching the end of life should receive coordinated care, in accordance with their care plan, across services and at all times of day and night.

GPs are clinically responsible for managing the care of their patients when they are being cared for within the community and are central to the Stockport model for End of Life Care. GPs should be aware of all patients registered at their practice that are on an end of life care pathway and discuss their care and treatment needs regularly through GSF multi disciplinary meetings.

The District Nurses involvement in coordinating patients’ needs should be reactive to changes in level of need throughout the end of life care pathway from advancing disease through to bereavement. For health services in the community the coordinator role will be defined so that coordinated end of life care is delivered at the point of need and provides support to patients, relatives and carers to ensure that quality end of life care is accessed at the appropriate level and is delivered in a timely manner. The coordinator role within the Stockport model is integral to managing the level of support and intervention needed.
Ensuring such care is coordinated and available as required within an individual’s patient pathway is paramount to patients on an end of life care pathway. The National End of Life Care Programme states that good end of life care will only be achieved when patients and carers have the following:

- Their physical, emotional, social and spiritual needs and preferences assessed by professionals with appropriate skills;
- A care plan;
- Their needs, preferences and care plan reviewed as their condition changes;
- Access to bereavement support;
- Systems in place to ensure that all relevant health and social care professionals have access to information about their needs and preferences;

Furthermore,

- Patients and carers should be treated with dignity and respect;
- Services should be co-ordinated across all providers;
- Care in the last days of life should be of high quality;
- Effective processes should be in place for the verification and certification of death;
- Quality and effectiveness should be measurable;
- Access to and provision of services should be equitable.

There are multiple providers involved in providing care to end of life care patients and their families with varying roles and responsibilities. All providers should ensure that they have process in place for identification, communication and assessment, have systems in place that support their workforce, and have skilled, competent, knowledgeable staff that will provide safe and effective care. They should recognise the needs of carers as well as the patient offering appropriate support according to needs and preferences. Care planning should be a priority setting out needs and preferences. Providers should also consider psychological and physical needs including spiritual needs.

This section provides more detail of individual roles and gives a clearer indication of the responsibilities of service provider’s when caring for end of life patients and their families.

5.1 The Role of the General Practitioner

The GP plays an important role in the care of all patients and in particular in the care of patients on an end of life care pathway. For patients being cared for in the community the GP is clinically responsible for the management of community care and the level of intervention needed to ensure that appropriate care is provided for the patient and that the carer and family are supported. As a minimum Stockport GP practices should:

- Use the gold standards framework (GSF) to assess the needs of patients who are approaching the end of their life and document those needs. To achieve this GP practices must:
  - Have a register of all end of life care patients irrespective of diagnosis;
  - Hold monthly multi-disciplinary team meetings to discuss end of life care patients;
  - Record the preferred place of care for each individual on GSF;
  - Record the number of patients who die in their preferred place of care;
  - Audit the proportion of deceased patients discussed at an MDT in the last year of life;
  - Develop protocols for sharing information with other health and social care professionals.
Identify, assess and document the needs of those caring for patients who are approaching the end of life and record:

- The name and contact details of the carer;
- The number of carers who have been referred for an assessment;

Provide information regarding EOLC patients to out of hours services and as such should have:

- A documented process for informing GP and District Nursing Out of Hours providers about EOLC patients;
- Record the proportion of GSF patients whose information was shared with Out of Hours services;

Develop an action plan to deliver end of life care in line with the agreed strategy and standards outlined within this document;

Ensure that all staff linked to EOLC patients have been appropriately trained;

Ensure that in the dying phase the Liverpool Care Pathway (LCP) is adopted;

Audit the quality of care provided to patients who were on GSF after their death;

Ensure decisions about the level of care and intervention are responsive to changes in circumstance, referring to other providers as appropriate;

Undertake regular audits of complaints and compliments and feed the findings of such audits into service redesign;

To ascertain and document the preferred place of care or advance wishes of patients and their families at the end of life and to facilitate good quality care for them at this time in conjunction with wider multi-professional teams.

5.2 The Role of the District Nursing Team

District nursing services may be provided either in a patients own home, normal place of residence or within residential homes. This includes:

- Nursing assessments and provision of professional nursing care.
- Palliative care including: symptom control, bereavement support, provision of information and advice.
- Wound care including: Assessment and treatment of all types of wounds, leg ulcers, pressure sores and post operative wounds.
- Assessment and monitoring of nursing aids and equipment.
- Nurse prescribing.
- Promotion of continence including: Assessment and care of patients with continence problems.

Accessing district nursing services should be based on need for nursing input and meeting the criteria for nursing support. District nurses have a central role to play in the care of patients in the last year of life. They are responsible for co-ordinating community care and are reactive and
responsive to changes in the patients condition and need and should act as the link to other services should needs change. District nurses provide generalist nursing care in the community and as a minimum should:

- Provide nursing care to patients in their normal place of residence who have nursing needs;
- Provide personal care needs in the last 2 weeks of life for to patients in their normal place of residence;
- Assess the health care needs of the patient at the point of referral to the district nursing services and put in place a plan of care that will ensure that wherever possible patients on an end of life care pathway are cared for in a place of their place of choice.
- Develop a strategy and action plan to deliver the requirements outlined within this service strategy;
- Develop excellent and effective communication and working links with local GP practices and other providers of EOLC including Specialist Palliative Care Team, Social Care providers, Hospice, Out of Hours providers, Hospital and voluntary sector organisations;
- Ensure that patient assessments are conducted in a sensitive and timely manner and are reactive to change and the end of life care tools are used to undertake ongoing assessments;
- Coordinate care for end of life care patients within the community and facilitate involvement with other providers of care as needs change;
- Assess and monitor changes in condition and support the identification of patients approaching the last year of life and liaising with the GP to ensure patients are included on the GSF register
- Attend GSF meetings as required to discuss the needs of individual patients;
- Designate a coordinator/key worker within the district nursing team who will coordinate care for individual patients on their caseload and to provide patients with a named contact;
- Maintain links with and provide effective communication with other community providers and GPs
- Use the gold standards framework (GSF) tool to assess the needs of patients who are approaching the end of their life and document those needs. To achieve this the DN service must:
  - Have access to the GSF register held by GPs within their locality and liaise with GPs in updating with current information pertinent to the patients condition
  - Be aware of all end of life care patients who are known to the service currently on the GP GSF register within their locality;
  - Attend monthly multi-disciplinary team GSF meetings at GP Practices to discuss end of life care patients;
 Implement advanced care planning and record discussions in documentation;
 Discuss and record the preferred place of care for each individual on GSF who are active on the District Nursing caseload;
 Record the number of patients who die in their preferred place of care;
 Audit the proportion of deceased patients who were discussed at an MDT in the last year of life;
 Develop protocols for sharing information with other health and social care professionals.
 Ensure that arrangements are in place to support patient’s dying at home or in a care home;
 Ensure that in the dying phase the Liverpool Care Pathway (LCP) is adopted;
 Provide a 24/7 service for patients approaching the end of their life, care out of hours should not differ from the level of service provided in hours and access should be available to support changes is need;
 Ensure that all staff providing care to patients on an end of life pathway are trained and competent in providing generalist palliative care. This should include:
  • Symptom management; including nutritional support;
  • Use of syringe drivers;
  • Needs assessment;
  • Communication skills;
  • Provision of support regarding Do Not Attempt Resuscitation (DNAR) orders and advanced decisions;
  • Level 1 psychological support
  • Spiritual care
  • Carer support
  • Support fast track discharge processes
  • Liaise with specialist teams

5.3 The Role of Allied Health Professionals
Allied Health Professionals (AHPs) should provide specialist advice and support to patients who are within the last year of life and require specialist intervention. They should work alongside generalist and specialist services as part of the multi-disciplinary team. Their role should include education and support to families, health and social care staff. Community AHPs include:
  • Dieticians
  • Occupational Therapists
  • Physiotherapists
  • Speech and Language Therapists

Allied Health Professionals as a minimum should:
- Develop a strategy and an action plan to ensure that their service delivers the requirements set out in this service strategy;

- Undertake continuous evaluation of the service delivered to ensure the highest levels of care are consistently provided;

- Undertake regular audits of complaints and compliments and feed the findings of such audits into service redesign;

- Undertake needs assessment by a competent healthcare professional

- Ensure that patients and their families are offered complex physical, emotional, psychosocial and spiritual support to help them cope with the effects of diagnosis, treatments or any other issues causing them concern including any information needs if required.

- Provide Level 1 psychological support

- Attend the monthly GSF multi disciplinary team meetings at GP practices to discuss end of life care patients;

- Act as an educational resource by training healthcare professionals within generalist services including GPs, district nurses and care home staff and develop a strategic plan regarding education and training of community based providers;

- Assess the patient’s ability to communicate and provide intervention as required, including the management of swallowing difficulties, feeding management and secretion management.

- Assess the patient’s nutritional status and provide advice as appropriate regarding specialist Enteral Feeding management.

- Assess the patient’s ability to perform activities of daily living, providing advice and promoting functional independence by ensuring timely access to equipment.

- To provide ongoing holistic intervention and support the patient to manage symptoms such as fatigue.

### 5.4 The Role of the Specialist Palliative Care Services

The Specialist Palliative Care Team provides expert advice and support for those patients with complex care needs and to coordinate care in the community for those complex patients reactive to change in need and preferences. For non complex patients the specialist palliative care team will act as a specialist resource working alongside and in support of generic services within Stockport NHS Foundation Trust and NHS Community Health Stockport.

The community based specialist palliative care team has an extremely important role to play in delivering specialist care to patients on an end of life care pathway. **As a minimum** the specialist palliative care team should:
Develop a strategy and an action plan to ensure that their service delivers the requirements set out in this service strategy;

Undertake continuous evaluation of the service delivered to ensure the highest levels of care are consistently provided;

Undertake regular audits of complaints and compliments and feed the findings of such audits into service redesign;

Undertake needs assessment by a competent healthcare professional

Ensure that patients and their families are offered complex physical, emotional, psycho-social and spiritual support to help them cope with the effects of diagnosis, treatments or any other issues causing them concern including any information needs if required.

Provide Level 1 and 2 psychological support

Provide bereavement support for those families and carers through the first days after death stage of the Stockport model and to appropriately refer to other bereavement services if necessary

To ascertain and document the preferred place of care or advance wishes of patients and their families at the end of life and to coordinate and deliver good quality care for patients with complex needs throughout stage 3 and 4 of the Stockport model;

To educate, develop and encourage nursing, medical and other staff in principles, skills and philosophy of palliative care

To accept referrals to the specialist palliative care service from GPs, District Nursing Team, the Hospice and the Hospital for any patient aged 16 or over with cancer or any other progressive life-threatening illness at any stage of their disease where there are complex palliative care needs;

To provide specialist palliative care services and advice to healthcare professionals caring for patients with complex palliative care needs including care homes and residential care facilities 24/7 and be reactive to level of need. The levels of intervention should be:

- **Level One**: Advice, information and support for healthcare professionals but no face to face contact with patient;
- **Level Two**: Single consultation preferably jointly with the coordinator of care to assess needs and plan care, as well as offer advice on current or future management
- **Level Three**: Short term interventions with the patient or family when specific complex problems occur
- **Level Four**: Ongoing involvement in care for patients with complex or intractable problems

To visit and assess and provide support to patients with complex palliative care needs between 8:30am and 4:30 pm, 7 days per week;
To advise, plan and coordinate care for patients regarding management of complex or intractable physical symptoms

To assess needs and plan care for patients, families and carers who are experiencing emotional or psychological distress by providing psychological support through one to one discussion and support

To provide specialist advice to healthcare professionals regarding criteria for accessing support from the hospice

To anticipate potential complex bereavement support requirements for carers and their families after a patient’s death

Ensure that processes are in place to identify patient’s choices and where possible fulfilled. This includes:

- Developing operational policies including mechanisms for rapid discharges from hospitals or hospices for patients who wish to die at home; availability of appropriately trained staff at short notice; rapid access to medicines and equipment and policies for communication and collaboration with other service providers to ensure seamless care;
- Reporting on actual place of death and actual choice of place of death in annual reports of activity;
- Auditing preferred priorities for care and advanced care planning;

Meet weekly as a multi disciplinary specialist palliative care team to discuss the care of individual patient’s on the caseload;

Attend the monthly GSF multi disciplinary team meetings at GP practices to discuss end of life care patients;

Act as an educational resource by training healthcare professionals within generalist services on palliative care issues including GPs, district nurses and care home staff and develop a strategic plan regarding education and training of community based providers;

Ensure that in the dying phase the Liverpool Care Pathway (LCP) is adopted;

5.5 Equipment services

To enable patients to be cared for at home or their normal place of residence providers should ensure that appropriate equipment packages that support the needs of the patient are in place on discharge from hospital or the hospice or as changes occur in need whilst being cared for in the community. Equipment needs will differ from patient to patient and can include pressure relieving equipment such as beds, mattresses and hoists or equipment to support with symptom control such as syringe drivers. Providers will ensure that procedures for appropriate assessment and ordering of equipment are in place that are reactive to need and changes in condition and will ensure systems are in place to provide equipment in relation to rapid discharge processes or deterioration of condition of the patient.
5.6 The Role of Palliative Care Respite service

The respite team should provide support on a sessional basis during the day between 9.00am and 5.00pm, as well as cover in the evening and throughout the night. Priority is given to those patients who are in the last two weeks of life and are approaching death.

Referral to the respite team should be made by any healthcare professional. Support is provided according to the needs of the patient and carer, and the referral should, wherever possible be pre-planned. Although this is not a rapid response service the team will always try to respond quickly to an urgent situation.

All patients must be registered with a Stockport GP; the service is available to persons 16 years old or over and access to the service can be by referral from the district nursing team or the specialist palliative care team. The Respite team Co-ordinator in liaison with the district nursing service will undertake ongoing assessment to ensure that intervention is appropriate and that the level of service they provide is reactive to change and addresses the needs of the carer.

Type of care offered by the respite team includes:

- Provide support to patients families in their normal place of residence who have nursing needs;
- Provide personal care needs in the last 2 weeks of life for to patients in their normal place of residence;
- Assessment of the health care needs of the patient at the point of referral to the district nursing services and put in place a plan of care that will ensure that wherever possible patients on an end of life care pathway are cared for in a place of their place of choice.
- Develop a strategy and action plan to deliver the requirements outlined within this service strategy;
- Develop excellent and effective communication and working links with local GP practices and other providers of EOLC including Specialist Palliative Care Team, Social Care providers, Hospice, Out of Hours providers, Hospital and voluntary sector organisations;
- Ensure that patient assessments are conducted in a sensitive and timely manner and are reactive to change and the end of life care tools are used to undertake ongoing assessments;
- Attend GSF meetings as required to discuss the needs of individual patients;
- Designate a coordinator/key worker within the palliative care team who will coordinate care for individual patients on their caseload and to provide patients with a named contact;
- Maintain links with and provide effective communication with other community providers particularly district nursing and GPs
- Use the gold standards framework (GSF) tool to assess the needs of patients who are approaching the end of their life and document those needs. To achieve this the palliative care respite service must:
Have access to the GSF register held by GPs within their locality and liaise with GPs in updating with current information pertinent to the patients condition

Be aware of all end of life care patients who are known to the service currently on the GP GSF register within their locality;

Attend monthly multi-disciplinary team GSF meetings at GP Practices to discuss end of life care patients;

Implement advanced care planning and record discussions in documentation;

Audit the proportion of deceased patients who were discussed at an MDT in the last year of life;

Develop protocols for sharing information with other health and social care professionals.

Ensure that arrangements are in place to support patient’s dying at home or in a care home;

Ensure that in the dying phase the Liverpool Care Pathway (LCP) is adopted;

Ensure that all staff providing care to patients on an end of life pathway are trained and competent in providing generalist palliative care. This should include:

- Symptom management; including nutritional support;
- Use of syringe drivers;
- Needs assessment;
- Communication skills;
- Provision of support regarding Do Not Attempt Resuscitation (DNAR) orders and advanced decisions;
- Level 1 psychological support
- Spiritual care
- Carer support
- Support fast track discharge processes
- Liaise with specialist teams

5.7 The Role of the Acute Hospital

Patients with life limiting illnesses are likely to have contact with acute hospitals prior to diagnosis, during the last year of life or in the last days of life. This may be planned care for treatments, surgery or consultations or unplanned care due to exacerbations of symptoms where patients will attend A&E or be admitted as an emergency. The care for End of Life patients should not differ according to how the patient has accessed hospital services. As a minimum acute hospital’s should:

- Develop a strategy and action plan in line with this service strategy for the care of patients on an EOLC pathway including;
• Having access to specialist palliative care available 7 days per week with access to the
24 hour specialist advice line;
• Out of Hours provision in an acute setting should not differ in the level of service
provided in hours

➢ Have a process in place for identifying and recording patients who are approaching the last
year of life and communicate this to the patients GP for inclusion on the GP GSF register;

➢ Have an effective mechanism to identify patients attending hospital who are approaching
the end of life or who are already registered on GSF.

➢ Ensure that education and training programmes for end of life care are available and that
relevant staff are trained depending upon their individual roles and needs including:

• The provision of training for front-line clinicians in identification of patients who are
approaching the end of their life;
• The provision of communications skills training for front-line clinicians;
• The provision of End of life care training for all staff that will include the use of the End
of Life Care tools such as Gold Standards Framework (GSF), Advanced Care Planning
(ACP), Preferred Priorities for Care (PPC) and Liverpool Care Pathway (LCP);

➢ To ensure that those staff involved in discussing end of life issues with patient’s, carers and
families are trained and competent in;

• Assessment and care planning for End of Life Care patients;
• Symptom management;
• The provision of bereavement support;
• The provision of spiritual support;

➢ Develop care plans for patients who are approaching the end of life;

➢ Undertake advance care planning by having mechanisms in place to discuss, record and
communicate the preferences of those approaching the end of life;

➢ Ensure that written records are maintained of patients preferences including preferred
priorities for care (PPC), advanced care plans, advance decisions and do not attempt to
resuscitate (DNAR) orders;

➢ Ensure that processes are in place to identify the patient’s preferred place of care and where
hospital is not the patient’s preferred place of death, to ensure that processes are in place to
provide rapid, safe discharge;

➢ Ensure that relevant information is communicated appropriately to other relevant health and
social care professionals involved in the patient’s care and entered onto the GP Practice
GSF where appropriate;

➢ Ensure that appropriate information is gleaned from patients presenting at A&E including
preferred priorities for care (PPC), advance care plans, advance decisions and do not
attempt to resuscitate (DNAR) orders;
Identify a key worker for each individual as part of the care package whilst in hospital;

Ensure processes are in place for liaison between other providers including GPs, primary care, secondary care and social care providers to ensure care is seamless and maintained;

Adopt the Liverpool Care Pathway for the Dying Patient (LCP) for the care of the dying and the care of the body after death including those who die suddenly;

To anticipate potential complex bereavement support requirements for carers and their families after a patient’s death;

Assess the needs of family members and carers and provision of support during patient’s hospitalisation and if the patient dies in hospital, in the period after death. This should include those who die suddenly and those who are pronounced dead on arrival at hospital;

Have designated space and quite areas available for discussion with families and carers regarding sensitive information about care and treatment and post bereavement to collect documentation and personal belongings;

Have appropriate facilities for viewing the deceased in a dignified manner;

Communicate effectively with the patient’s GP regarding end of life care decisions and inform the GP within 24 hours of a patient’s death;

Undertake audit of the quality of care provided to patients where end of life care was provided by the hospital;

5.8 The Role of Chaplaincy services

Chaplaincy services provide valuable spiritual support to patients and their families. Respect for privacy and dignity and the respect of religious and cultural beliefs should be embedded within provider organisations. Providers should ensure that accessible and suitable space for prayer and for religious services are provided for patients and should recognise that different religions have specific requirements, and more than one space may be required with flexibility of furnishing and use of religious symbolism to allow for the multiple use by different faith traditions as required.

The Chaplaincy service should advise providers on appropriate faith community requirements. Providers should ensure that space for prayer and religious services are seen as a place of calm in time of anxiety and as a sanctuary from other pressures. An appropriate location and 24 hour access to Chaplaincy services is vital and the very minimum should be some "sanctuary space" for prayer and reflection. The role of the Chaplaincy should reflect not just multi faith groups but those with no formal faith who require spiritual/existential care.

5.9 The Role of Hospice Services

Hospice care is for patients aged over 16 years with complex problems who cannot be managed effectively in other settings and who would benefit from the continuous support of the multi disciplinary specialist palliative care team. Patients referred for hospice care will have a diagnosis
of an advanced progressive life-limiting illness that has associated complex specialist palliative care needs. The hospice will:

- Provide a range of Specialist Palliative Care services of the highest standard which are responsive to patient/carer need for all people with life-limiting illness including:
  - In-patient care
  - Day therapy
  - Specialist Palliative Care Medical outpatients
  - Lymphodema Management service
  - 24 hour specialist advice line
  - Social work service
  - Palliative day care services

The services should be delivered by Specialist Multi-Disciplinary Teams which include:

- Consultants in Palliative Medicine
- Doctors and nurses with Palliative Care experience
- Complementary Therapists
- Physiotherapists
- Occupational therapists
- Dietetics
- Counselling
- Psychological support staff

- Provide expert symptom management advice to patients and their families and carers
- Provide specialist in patient services 24 hours a day 7 days per week for patients with complex needs that cannot be managed in the community setting;
- To give advice and support to any healthcare professional within the acute and primary care teams in managing patients with palliative and end of life care needs at home or in hospital via the 24 hour advice line;
- Identify a key worker for each individual as part of the care package whilst in the hospice;
- To ensure that processes are in place for liaison between primary care, secondary care and the hospice services to ensure care is seamless and maintained;
- To ensure all staff are trained appropriately; and ensure that those staff involved in discussing end of life issues with patients, carers and families are trained and competent in;
  - Assessment and care planning for end of life care patients;
  - Symptom management;
  - The provision of bereavement support;
  - The provision of spiritual support
- To promote the use of evidence-based practice by continued development of clinical staff

- Communicate effectively with the patient’s GP regarding end of life care decisions and inform the GP within 24 hours of a patient’s death;
Provide day therapy specialist supportive and palliative care which provides specialist assessment and review of patients needs, enabling provision of physical, psychological, social and spiritual interventions

Provide expert symptom management advice to patients their families and carers;

Demonstrate through clinical audit a continuous cycle of improvement in the quality of care provided;

Proactively seek user views and engagement with users to inform and support clinical services development;

Ensure that processes are in place to identify the patient’s preferred place of care and where the hospice is not the patient’s preferred place of death, to ensure that processes are in place to provide rapid, safe discharge;

Ensure that relevant information is communicated appropriately to other relevant health and social care professionals involved in the patient’s care;

Provide out of hours Specialist Palliative Care advice to staff through the 24 hours advice line;

Adopt the Liverpool Care pathway (LCP) for the care of the dying and the care of the body after death including those who die suddenly;

Anticipate potential complex bereavement support requirements for carers and their families after a patient’s death;

Assess the needs of family members and carers and provision of support during patient’s stay at the hospice and if the patient dies in the hospice, in the period after death;

Have designated quiet areas available for families and carers to be seen post bereavement to collect documentation and personal belongings;

Have appropriate facilities for viewing the deceased in a dignified manner;

Provide specialist supportive outpatient services to patients with complex palliative needs;

Promote the use of evidence-based practice by continued development of clinical staff;

Utilise specialist palliative care integrated pathways to enhance patient assessment and facilitate seamless communication to healthcare professionals, patients and carers;

5.10 Out of Hours providers

End of Life Care patients with urgent needs can have interventions by various providers. In some instances this may not be related to the illness and out of hours providers should take into
consideration the patients wishes as detailed in the patients Advanced Care Plan. Excellent communication between primary care and out of hours services supports quality care and alerts clinicians to react to patients wishes and care plans in place. Medical practitioners providing out of hours care should be competent in providing palliative care, including symptom management, assessment of need and communication skills.

Providers should ensure that systems are established to ensure that up to date information is shared between daytime services and out of hours providers including preferred place of care, current drugs and advanced care plan.

Where End of Life Care patients require unscheduled care that is related to the illness, appropriate arrangements should be in place that takes into consideration the patients wishes and any unscheduled care episodes should be recorded and information shared to ensure integrated care.

The services should be a continuation of in hours services and where possible prevent unnecessary attendance and admission for patients on an End of Life Care pathway.

Out of hours providers include:

- Out of Hours GPs;
- Pharmacy services;
- Ambulance services;
- Hospital services – A&E;
- Hospice services;
- District nursing services;

As support is required 24 hours a day it is essential that services attain a standard that the patient would expect from their usual GP or healthcare provider.

Full integration of all out of hours services will need IT systems in place that support secure and accessible communication software systems between providers to provide seamless support and deliver responsive care at the point of need in line with the wishes of the patient.

5.10.1 Out of hours General Practice services

GP out of hours services should be integrated with daytime general practice processes. Excellent communication is essential and notification of all patients on a GSF register should be recorded both within the patients registered GP Practice and on the out of hours GP systems. Out of hours providers should have processes in place to support the educational needs of all doctors and nurses working for the service regarding use of end of life care holistic assessment tools such as the Liverpool Care Pathway for the Dying Patient.

GP out of hours services include should include a centralised service which accepts and triages telephone contacts from End of Life Care patients, relatives and healthcare professionals. The service should ensure that End of Life Care patients with a complex need are reviewed in the correct place in a timely manner by the appropriate member of the team and should include:

- advice and guidance over the telephone;
- access to face to face assessment and treatment where appropriate;
- admission to hospital or hospice where required;
- referral back to the care of the patients GP should occur in hours where this is appropriate;
referral to the Specialist palliative care team where appropriate;
referral to generalist services i.e. district nursing where appropriate.

5.10.2 Out of Hours District Nursing service
Out of hours nursing care should be provided to patients in their normal place of residence who have nursing needs and require additional support out of hours. A district nurse should assess the health care needs of the patient and identify the level of additional support out of hours. At the point of identification of out of hours nursing need a plan of care should be put in place that will ensure that wherever possible patients on an end of life care pathway are cared for in a place of their place of choice. Services should be provided either in a patients own home, or within their normal place of residence.

The out of hours district nursing service should be available 365 days a year up to 11pm within the evening service and provide a range of services to end of life care patients including:

- Nursing assessments and provision of professional nursing care;
- Palliative care including: - pain and symptom control, bereavement support, provision of information and advice;
- Wound care including: - Assessment and treatment of all types of wounds, leg ulcers, pressure sores and post operative wounds;
- Assessment and monitoring of nursing aids and equipment;
- Nurse prescribing;
- Promotion of continence including: - Assessment and care of patients with continence problems;
- Chronic disease management in conjunction with specialist services, of patients with long term conditions.

District nursing out of hours services should be integrated with daytime district nursing processes. Excellent communication is essential to ensure that coordination of care is maintained.

5.10.3 Out of Hours Specialist Palliative Care
The Specialist Palliative Care should be provided 7 days a week and will provide expert advice and support for those patients with complex care needs. Coordination of care by the specialist palliative care team in the community for patients with complex needs should be reactive to change in need and preferences.

For non complex patients the specialist palliative care team will act as a specialist resource working alongside and in support of generic services within Stockport. Referral to the service should be within normal working hours where care can be pre-planned to respond to ongoing needs out of hours. This service is not a rapid response service.

5.10.4 Out of Hours Palliative Care Respite service
The respite team provides support on a sessional basis during the evening and throughout the night. Priority is given to those patients who are in the last two weeks of life and are approaching death.

Referral to the respite team should be made by any healthcare professional and should lead to discussion with the service to ensure the needs of patient and carer are identified and support is provided. The referral should, wherever possible be pre-planned within normal working hours as
this is not a rapid response service. The service should always try to respond quickly to an urgent situation.

All patients must be registered with a Stockport GP; the service should be available to persons 16 years old or over and access to the service should be by referral from the district nursing team or the specialist palliative care team in normal working hours to ensure that provision can be managed and planned. The Respite team Co-ordinator in liaison with the district nursing service will undertake ongoing assessment to ensure that intervention is appropriate and that the level of service they provide is reactive to change and addresses the needs of the carer.

Type of care offered by the respite team includes:

- Personal Care
- Psychological Care
- Social Care

5.10.5 Out of Hours Pharmacy services

Pharmacy services available out of hours are essential to ensure that patients who have been identified as being in the last days of life and being cared for in their own home have access to the appropriate drugs at stages in the end of life pathway, this will ensure the patient’s symptoms are controlled and pain free and comfortable especially when the patient has been placed on the LCP. Pharmacies with responsibility for providing out of hours provision should ensure communications with out of hours providers such as GPs and District Nursing are ongoing and that any changes in service provision are notified.

The GP is clinically responsible for the patient’s wellbeing while being cared for in the community and the District Nurse or Specialist Palliative Care Nurse as coordinator of care should ensure that arrangements are in place with out of hours pharmacy services so that the LCP drugs can be accessed out of hours.

5.10.6 Out of Hours Ambulance services

Out of hours Ambulance services are provided by the NHS provider North West Ambulance Services who respond to requests for transport from healthcare professionals, patients and their families. Transport services are an important part of supportive care for patients who are on an end of life pathway and these patients will often rely on NHS transport services due to the complexities of need. Out of hours Ambulance services should be reactive to the varying levels of need for end of life patients and such as rapid transfer or urgent/emergency transfer via a blue light to try and avoid unnecessary hospital admissions.

Having the processes in place that ensure patients and their families are aware of what to expect in the final days and hours of life; including advice on what to do in the event of an emergency and the role and limitations of ambulance services will help them understand that the ambulance service is not always the most appropriate service to call.
Effective information sharing systems and protocols should be in place to enable ambulance services to pre-alert of any advance care planning discussions if a person has been identified as being at the end of life.

The criteria for providing ambulance services to end of life care patients out of hours should include:

- Processes for accessing emergency transport in an urgent booking situation from normal place of residence to hospital or hospice to hospital;
- Processes that are in place that will accept ambulance bookings for end of life patients who require a rapid transfer; this can be from a care facility to home, transfer to a care facility or for symptomatic patients who require urgent ongoing care.
- Process for recording requests for rapid discharge/transfer of patients for whom an order of Do Not Attempt Resuscitation (DNAR) has been put in place.
- Assurance that notification of DNAR is copied to responding ambulance crew
- Assurance that processes are in place to support carers and relatives who wish to escort patients.

5.10.7 Out of Hours Hospital services

Out of hours services within acute hospitals are provided 24 hours a day providing treatment and acute care to patients who present without prior appointment, either by their own means or by ambulance. Due to the unplanned nature of patient attendance, hospital services must provide initial treatment for a broad spectrum of illnesses and injuries including those who are on an end of life care pathway. Patients may present at hospital through Accident and Emergency or GP Assessment Unit dependent on the reason for referral to hospital.

Most patients will be assessed and then passed to another area of the department, or another area of the hospital, with their waiting time determined by their clinical need. However, some patients may complete their treatment at the triage stage, for instance if the condition is very minor and can be treated quickly, if only advice is required, or if the emergency department is not a suitable point of care for the patient. Conversely, patients with evidently serious conditions, such as cardiac arrest, will bypass triage altogether and move straight to the appropriate part of the department.

5.10.8 Out of Hours Hospice services

Out of hours hospice services provide 24-hour specialist care in comfortable, homely environments by a multi-disciplinary approach. Hospices provide a holistic care package that will manage the patients and families wellbeing while controlling pain and other symptoms. Hospice services should be available 24 hours a day and hospice providers should ensure they have processes in place to support requests for admission from providers caring for any patient with urgent needs requiring hospice care and support out of hours.

An advice line service should be delivered locally within the local hospice that provides specialist support and advice 24 hours a day to clinicians managing patients with palliative care needs in the community or hospital enabling generalist services such as GPs and district nurses to be able to
care for patients without delay or admission to hospital/hospice unnecessarily. The service should be provided by appropriately qualified and trained healthcare professionals.

Advice and support 24 hours a day through the advice line is also available to patients and carers to offer support and information relating to their illness and supports families with self management of complex physical symptoms such as pain, sickness, tiredness or loss of appetite.

- psychological care and emotional support to cope with the complex feelings experienced around death and bereavement
- spiritual care addressing the spiritual or religious needs of residents and families
- understanding the patient’s wishes in advance should their condition deteriorate
- support for the family giving practical and emotional support before and after the death of the resident

5.11 The role of Social care providers

As well as having health related needs patients on an end of life care pathway may also have social care needs and to ensure an integrated approach across the pathway social factors should be considered as these contribute to the quality of outcomes for patients. Services should therefore address the issues of access, early engagement and continued support and care. Social care services must be responsive to need and flexible and are likely to include:

- Domiciliary care (including both those who are and those who are not commissioned by the Council or the NHS to provide care)
- Home services such as meals on wheels
- Social work
- Housing
- Benefit services
- Assessment and loan of equipment
- Acting on recommendations from CQC regulation of care homes and domiciliary care agencies

Social care and NHS commissioners working in partnership should actively encourage providers of care to provide:

- A named lead professional to provide support and navigation for end of life care patients and carers with social needs;
- An action plan for end of life care that is congruent with the strategic plan developed for the locality by the Commissioner;
- Awareness raising with staff and recognition of stages within the end of life care pathway
- Support to health professionals in providing quality end of life care by ensuring responsive services and timely delivery of equipment
- Mechanisms in place to discuss, record and where appropriate communicate the wishes and preferences of the service user approaching the end of life;

Care Quality Commission regulates care provided by the NHS, local authorities, private companies and voluntary organisations.
- Protocols for sharing information relating to end of life care provision across relevant agencies;

- Compliance with the use of End of Life Care tools such as:
  - Gold Standards Framework (GSF)
  - Six Steps Programme
  - Advanced Care Planning
  - Preferred Priorities for Care
  - Use of a recognised End of Life Care pathway such as Liverpool Care Pathway (LCP)

- Documentation of processes for assessing and recording preferences;

- Assurance that the service user’s needs for end of life care are assessed and reviewed on an ongoing basis;

- Assurance that all service users who are dying are entered onto a care pathway;

- Assurance that other service users are supported following a death of any service user within the care home;

- A system in place for audit and review of the quality of end of life care;

- Processes in place to identify the training needs of staff;

- Processes to review all transfers into and out of the services and service environment for service users approaching the end of life.

5.12 The Role of Care Homes or Nursing Homes (these include both those with and without nursing beds)

All care homes and nursing homes providing services to people approaching the end of life should as a minimum be encouraged to develop protocols and an action plan in line with this service strategy for the care of patients on an EOLC pathway. This should include:

- Workforce plans;
- Training needs assessment, staff development and skills relating to assisting residents and their carers in the end stage of life;
- Plans to adopt (if not already in use) the Gold Standards Framework by 2012; or undertake a commitment to the ‘six steps programme’
- Support GP identification of patients in last year of life and ensure residents are added to GP GSF register;
- Being aware of all end of life care patients currently on the GP GSF register within their care home and encourage ongoing monitoring of changes in residents condition;
- Contributing to primary care MDTs as required to discuss the needs of individual patients

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6 Six steps programme was developed by the Greater Manchester and Cheshire Cancer Network and is being implemented locally to support Care Homes to implement good quality end of life care and make changes to service delivery.
Ensuring processes are in place to support access for residents to support from a medical practitioner;
Ensuring processes are in place to support access for residents to specialist palliative care advice;
Ensuring that processes are in place to encourage and support staff to discuss the wishes and needs with residents and relatives within the first month of admission
Ensuring that staff are aware of the Liverpool Care Pathway (LCP) for patients who are in the dying phase and are encouraged to support health staff to monitor changes in condition
Ensuring plans are in place for audit and evaluation of services and support offered by the care home for residents that die in hospital or care home.

Care home and nursing home managers should be active in addressing the educational needs of its staff caring for patients at end of life. This should include:

- Communication skills training;
- Advanced care planning with residents and their carers on admission;
- Principles of the Gold Standards Framework;
- The Six Steps Programme;
- Ensuring that those staff involved in discussing end of life issues with patient’s, carers and families are trained and competent;

### 5.13 The Role of Domiciliary Care providers

All domiciliary care agencies providing services to people approaching the end of life should as a minimum be encouraged to develop protocols and produce an action plan in line with this service strategy for the care of patients on an EOLC pathway. This should include:

- Workforce plans;
- Training needs assessment, staff development and skills relating to assisting service users and their carers in the end stage of life;
- Undertaking a commitment to the ‘six steps programme’
- Undertake a commitment to principles of GSF
- Being aware of all end of life care patients currently on the GP GSF register to whom they are providing service and encouraging ongoing monitoring of changes in service users’ condition;
- Contribute to primary care MDTs as required to discuss the needs of individual patients
- Contribute to the processes that may be in place to support access for service users to support from a medical practitioner;

Domiciliary care agency managers should be active in addressing the educational needs of its staff caring for patients at end of life. This should include:
➢ Communication skills training
➢ Advanced care planning with service users and their carers at the beginning of a care service
➢ Principles of the Gold Standards Framework
➢ The Six Steps Programme
➢ Ensuring that those staff involved in discussing end of life issues with patient’s, carers and families are trained and competent

5.14 The Role of the Voluntary Sector

Voluntary sector services provide support to health and social care services. They should be seen as a resource that compliments health and social services that provides care and support for Stockport patients, families and carers who are affected by a life limiting illness. The types of support will vary dependent upon the organisation, services provided by voluntary sector providers includes outreach services such as transport to hospital appointments, befriending, respite, and psychological support to in patient hospice services.

The level of services provided by the voluntary sector should be sustainable and supportive working alongside mainstream health services. Psychological support through day centres are an important aspect of the whole systems approach to care and these should include providing Level 1, 2 and 3 psychological support such as 1-1 assessments, counselling and bereavement support, family therapy as well as support for carers and families. Supporting families and carers with respite or sitting services will enable more patients to be cared for in their normal place of residence if this is their wish.

Access to the services should be on a level of need basis and referral to these services by a healthcare professional. The voluntary sector providers should also have a system in place for onward referral to mainstream services should these be deemed more appropriate.

Voluntary sector providers should:

➢ Develop a strategy and an action plan to ensure that their service delivers the requirements set out in this service strategy;
➢ Have processes in place for assessing referrals and ensure that assessments are conducted in a sensitive and timely manner and are reactive to change and the end of life care tools are used to undertake ongoing assessments;
➢ Ensure that relevant information is communicated appropriately to other relevant health and social care professionals involved in the patient’s care;
➢ Undertake continuous evaluation of the service delivered to ensure the highest levels of care are consistently provided;
➢ Undertake regular audits of complaints and compliments and feed the findings of such audits into service redesign;

Contractually these services should be performance managed to ensure maintenance of quality and value for money.

5.15 The Role of Transport services

Transport services for end of life care patients are provided by various providers ranging from Paramedic escorted NHS Ambulance services, NHS Patient Transport services to voluntary organisations that provide transport from volunteers as part of their services.
Ambulance providers should:

- Have in place criteria for accepting ambulance bookings for end of life patients who require a rapid transfer; this can be from a care facility to home, transfer to a care facility or for symptomatic patients who require urgent ongoing care.

- Aim to resource the booking of a request within 2 hours of the booking request being made, or if the service is experiencing significant 999 pressures to resource the booking within 4 hours of the booking request being made.

- Have a process for recording requests for rapid discharge/transfer of patients for whom an order of Do Not Attempt Resuscitation (DNAR) has been put in place.

- Ensure notification of DNAR is copied to responding ambulance crew

- Ensure processes are in place to support carers and relatives who wish to escort patients.

- Undertake audit of services provided to end of life care patients

- Undertake audit of complaints and compliments and feed the findings of such audits into service redesign

The level of transport provided for patients on an end of life pathway is dependent upon the needs of the patient and the stage or progression of their illness. Transport services should be easily accessible and available from both the voluntary sector and NHS provider.

**NHS providers**

North West Ambulance Services provide various levels of assisted transport including rapid transfer, escorted ambulance and planned care ambulance. Transport services are an important part of supportive care for patients who are on an end of life pathway and these patients will often rely on NHS transport services due to the complexities of need. North West Ambulance Services have two types of transport to enable End of life patients to be transferred.

A Paramedic Emergency Service vehicle is an ambulance that would be used to transfer patients in their last hours and days of life. Intermediate Care Ambulances are also used for the Rapid Transfer of patients who have high dependency, complex needs in their last hours and days of life. These forms of transport ensure the transfer of the patient is private and dignified during transfer.

The Patient Transport Service ambulances are used to transfer patients who are identified as being in the last 12 months of life, this service is for patients who have non complex needs and have good mobility.

**Voluntary sector transport provision**

Transport services provided by voluntary sector providers as part of their portfolio of services should be supportive to those patients who are on an end of life pathway and have difficulty in travelling to health appointments. Voluntary sector services are normally placed in the heart of the community to provide this service. These services should provide:

- Transport services in a timely manner
- Staff or volunteers that are appropriately skilled to deliver the service
- Operate within the terms and conditions of any contract with NHS Stockport
Local voluntary sector providers of transport include:

- Beechwood Cancer Care Centre
- Stockport Care Schemes
- Easy go Community Transport

6. Service Delivery

End of Life Care services will be available for adults (aged 16 years and over) with advanced, progressive life-limiting disease, malignant and non-malignant, who are registered with a Stockport General Practitioner. Some services such as bereavement support will be available to the families and carers of patients referred into palliative care and end of life care services.

6.1 Transition Support for Adolescents (aged 16 to 18 years)

Ensuring a seamless transition from childrens services to adult services is challenging. Young people with complex needs who are nearing the end of their life will benefit from additional support through transition from both adult and childrens services. Processes should be clear and flexible to ensure a holistic approach is taken and assessment of the young person’s level of understanding will determine the rate at which transition will take place. Providers should have processes in place to clearly define planning for transition support that take into consideration autonomy, understanding, independence, psychological support that include communications with the patient and their family.

6.2 Access

Access to end of life care should be for any patient who is within the last 12 months of life irrespective of diagnosis and should be accessible for all with advanced progressive, incurable illness. End of life care should be delivered in many settings and care should meet the needs of the individual as well as their carer and family.

Holistic assessment considering physical, psychological and spiritual, cultural and social need will ensure that patients and their families are involved in decisions about their care and where care is provided. Services must be responsive to the needs of patients and their families, and this must be reflected in the hours that the service is open for business. The provider will be required to arrange transport and reimburse travel costs to those who qualify in accordance with NHS guidance. Adequate car parking and refreshment facilities should also be available. All facilities must, as a minimum, comply with Disability Act requirements, and consequently premises must be accessible to people with disabilities.

Access to appropriate language and interpreting services must be available for people with additional needs. For example, patients for who English is not their first language, or those who have sensory disabilities. Information promoting services must be made available in alternative formats to meet these needs.

NHS Stockport is committed to commissioning and delivery of services that are fully compliant with equality and diversity legislation. Such legislation includes:

- Race Relations (Amendment) Act 2000;
- Disability Discrimination Act 2005;
Services must comply with these policies and be embedded into the service delivery model for end of life care services. Furthermore, NHS Stockport expects providers to be compliant with all relevant equality employment regulations and all relevant EU directives in respect to Race, Disability, Gender, Sexual Orientation, Religion & Belief, Age and Human Rights.

**6.3 Support for vulnerable people**

End of Life services must ensure appropriate support for vulnerable people. This should include:

- People at risk of mental health problems;
- People with learning difficulties;
- People with complex needs;
- People who are in the last weeks and days of life;
- Refugees and asylum seekers;
- Homeless people.

Additional levels of support may need to be put in place to support patients with complex care needs or to ensure that they can be cared for in their normal place of residence is this is their wish.

**7. Business Processes and Quality Standards**

Providers must have clear processes and criteria in place for accepting referrals, confirmation of appointments, cancellations and rebooking and a mechanism for information and reports to be returned to referrers as well as arrangements for minimising patients who do not attend their appointment.

Processes must also be in place to ensure onward referrals are managed in line with service acceptance criteria and changes in patient need.

**8. Provision of a customer centred service**

The strategic intent for End of Life Care is that the approach to providing care should be centred on the needs and preferences of the individual. Care and support should be coordinated and integrated responding to changes in the patients’ condition and wishes. The overarching principle for quality end of life care is that care should be centred on the patient and their family.

The following section outlines the required measures and quality markers each provider should meet to ensure they deliver quality services. The quality markers are adopted from the Department of Health End of Life Care Strategy, Quality Markers and Measures for End of Life Care (2009), and are based on structures and processes of care that are most likely to achieve good outcomes for those people who are approaching the end of life.

**8.1 Quality standards and measures**

Specific measures should be in place to improve identification, communication and assessment and should aim to be consistent across providers to ensure an equitable approach in delivering high quality end of life care. Each care provider may be involved at various stages of caring for patients.
on an end of life pathway and the varying levels of responsibilities of providers is integral in getting end of life care right. To ensure high quality integrated end of life care in Stockport providers should:

- Have an action plan for the delivery of high quality end of life care, which encompasses patients with all diagnoses and is reviewed for impact and progress
- Institute effective mechanisms to identify those who are approaching the end of life
- Ensure that people approaching the end of life are offered a care plan
- Ensure that individuals preferences and choices when they wish to express them are documented and communicated to appropriate professionals
- Ensure that the needs of carers are appropriately assessed and recorded
- Have mechanisms in place to ensure that care for individuals is coordinated across organisational boundaries 24/7
- Have essential services available and accessible 24/7 to all those approaching the end of life who need them
- Be aware of end of life care training opportunities and enable relevant workers to access or attend appropriate programmes dependent on their needs
- Adopt a standardised approach (the Liverpool Care Pathway) to care for people in the last days of life
- Use holistic assessment tools to support healthcare professionals to assess and evaluate the level of need and support patients and carers needs.
- Have clear plans for providing the referrer with timely information;
- Have clear plans for providing timely information to other providers, where patients have complex care needs;
- Monitor the quality of services and submit relevant information for national and local audits

NICE Quality Standards for end of life care for adults have been developed to ensure that services are commissioned from providers across the whole end of life care pathway and cover all settings in which care is provided by health and social care providers. The standards suggest that an integrated approach to the provision of end of life care is fundamental to the delivery of high quality care for people approaching the end of life.

[www.nice.org.uk/guidance/qualitystandards/indevelopment](http://www.nice.org.uk/guidance/qualitystandards/indevelopment)

The NICE quality standards aim to improve the structure, processes and outcomes and include the following areas:

- Identification;
- Communication;
- Assessment;
- Support for carers and families;
- Information;
- Care planning;
- Physical and psychological symptoms;
- Social support;
- Emotional and spiritual care;
- Access to services and coordinated care;
- Access to community services;
- Access to hospital services;
- Access to urgent care services;
- Access to specialist palliative care in all settings;
- Access to transport services;
Care in the last days of life;
Care after death immediate support and bereavement;
Workforce and training and planning.

When considering standards and measures and how these shape end of life care services it is important to ensure that roles of health professionals providing End of Life Care are responsive to individual needs focussing on packages of care that is manageable and coordinated. Excellent communication processes between providers across all services will support the delivery of integrated care for patients at all stages of an end of life care pathway. Performance monitoring of provider contracts will ensure that standards and measures enhance services and improve quality.

8.2 Evaluation and development of the service

In order to develop future End of Life Care services it is crucial to undertake regular evaluation beyond the standard contract performance mechanism. Such evaluation must include measuring, evaluating and reporting on the degree of satisfaction experienced by patients, carers and their families as well as relevant clinicians. A process outlining how outcomes of such evaluations will be fed into a continuous process of service development is essential.

8.3 Patient Engagement

Detailed understanding of the population’s health and needs helps to shape quality services, influences behaviour and drives change. The involvement of Stockport people in End of Life Care services is vital and with the involvement of stakeholders Stockport will lead the way in supporting services. Future services will reflect the needs of the community and will be developed to reflect demand and requirements.

Commissioners are committed to engaging with patients and through consultation with representatives from LINk this ensure service users views are represented in the development of services. LINk representation on the End of Life Care Programme Board brings together managers, clinicians and service users enhancing two-way communication and feedback to users of end of life care services creating an open and transparent culture. Further local engagement groups such as the End of Life Care engagement group will meet regularly and hold awareness raising events to ensure that the public’s views are captured.

8.4 Patient Experience

In order to deliver a service that meets the needs of the population it is essential to understand the levels of patient satisfaction with the services provided. Commissioners will seek the views of patient groups and may in some instances also use surveys and focus groups, therefore regular patient surveys by providers are required. Surveys should be undertaken in agreement with the commissioner. The findings of such surveys should be linked to service development via the future development of this strategy. The provider should supply the commissioner with preliminary survey findings promptly and agree any service changes required to improve patient experience.

9. Capacity and Demand

Scheduled care

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The End of Life Care Programme Board is a local joint strategic group that focuses on developing strategy and service improvements End of Life Care for the Stockport locality.
For 2010/11 NHS Stockport has agreed the following commissioning assumptions:

The ageing population will have an impact on the use of NHS services in the next 3 to 5 years. Older people have greater health needs and whilst they represent 17% of the population they account for 32% of all inpatient admissions, 37% of all emergency admissions and 46% of all ambulatory care sensitive condition admissions.

It anticipated that despite the ageing population death rates in Stockport will continue to fall as the average age of death increases. For Stockport two fifths of the numbers of deaths are expected (approximately 1,100 deaths each year)

_Unscheduled Care_

In delivering a service that places emphasis end of life care as a pathway of care that will undoubtedly have changing needs should the patients condition become complex, there will be occasions when patients need access to services outside of the planned care pathway, this may be an unplanned contact with out of hours GPs, the hospice or healthcare professional or an admission due to exacerbation of symptoms. It is the responsibility of the provider to develop processes to manage access to inpatient and community services. It is expected that the provider will work closely with NHS Stockport to achieve reductions in unscheduled admission rates.

**10. Operational Management**

It is expected that the service provider will develop detailed operational plans to manage services to ensure that the experience for the patient and their family is of an excellent standard. Systems to support lean processes such as triage services should be considered.

**10.1 Performance Management**

Evidence that service aims and targets are being reached is essential. Commissioners therefore require regular performance reports. Metrics are included for:

- The percentage of patients expected to die in hospital who are recorded as being on the Liverpool Care Pathway
- Proportion of adults supported to die in a place of their choosing
- Proportion of hospital deaths within 48 hours of admission
- Proportion of admissions already on the GSF/Palliative Care register
- Proportion of adults with an Advance Care Plan in place
- Proportion of adults identified as being in the last year of life
- Proportion of adults who have their pain controlled in the last 24 hours of life

Information will be required by the commissioner to ensure that the service is delivering best care, best health outcomes and best value. Information will be required to fulfil the following functions:

- Contract performance – for example the number of patients and number of contacts
Service delivery – for example staffing ratios

Key performance indicators will be developed in collaboration between NHS Stockport and the providers of palliative care and end of life services. Performance will then be reported on a bi-monthly basis to the End of Life Care Programme Board. It should be noted that performance information requirements are subject to change and will be modified as required in agreement between commissioner and provider.

10.2 Risk Management

The provider must have in place robust arrangements to ensure they are providing safe practice and learning lessons both from their own and others’ practice. Central to this are risk management processes, including evaluation of organisational culture, risk assessment, training, induction, guidelines, communication, audit and learning from adverse incidents, claims and complaints.

The provider should have governance and assurance systems to improve the delivery and quality of care, by creating an environment in which clinical excellence is paramount. Risk management should therefore be a robust, integral part of all clinical activity, service delivery and service development. The management of risks should be seen as an opportunity for learning and development.

An open, supportive management culture which encourages the reporting of risks, incidents, hazards and near misses, and uses disciplinary action in cases where there is evidence of a breach of law, professional misconduct, malpractice, repetitious incidents, deliberate non-reporting of incidents or collusions with the non-reporting of such incidents should be adopted.

The provider should adopt a risk strategy that aim to:

- Identify, analyse and control risks via adverse event and near miss reporting;
- Foster an open culture of fairness, learning and support;
- Develop a clear accountability framework encompassing leadership, risk groups, reporting arrangements, strategies and policies;
- Progressively reduce the severity and future potential risk of adverse events;
- Achieve compliance with all relevant risk management standards;
- Establish clear accountability and responsibility for the undertaking of serious untoward incidents reviews.

11. Clinical

End of life care health provision focuses on clinical assessment and situations that require an intervention including management, care plan or review. The generalist services and specialist services provide integrated care and support alongside social elements of care.
11.1 Clinical Governance and Quality

In commissioning and providing clinical services patient safety is fundamental. A comprehensive clinical governance framework should be in place including a mechanism for monitoring the quality of care and enabling continuous improvement of services. Clinical accountability should be paramount and as a minimum it would be expected that providers have:

- A clear line of responsibility for risk management, performance and quality improvement;
- A full clinical audit programme covering compliance with NICE and other relevant guidance and including detailed action plans shared with all levels across the organisation and available for external scrutiny;
- A range of patient satisfaction and experience tracking mechanisms with findings shared with all levels across the organisation and with the public, and including detailed action plans describing areas for further improvement;
- A localised risk management policy that identifies risks, ensures incidents are reported and graded and ensures that full root cause analysis is carried out for all serious untoward and regularly occurring incidents and that findings are shared across the organisation and with the commissioner;
- A robust recruitment and training policy with procedures that fully ascertain clinical competency of all members of staff and protect patients from harm;
- Evidence of systems that fully comply with Care Quality Commission registration requirements.

The End of Life Care Programme Board will monitor information regarding clinical governance and escalate any issues to the Stockport Clinical Commissioning Pathfinder Executive Committee.

11.2 Clinical Effectiveness

To achieve good clinical effectiveness requires adherence to the principle of doing the right thing to the right person at the right time and in the right place.

In practice service providers must therefore:

- Have an evidence based approach by implementing NICE Guidelines, National Service Frameworks, and other nationally recognised standards set out in guidance from the Royal College of Physicians, Royal College of Nursing and Care Quality Commission;
- Have a lead clinician for audit and an audit programme in place agreed between provider and commissioner to ensure that clinical practice is continually monitored and improved;
- Contribute to appropriate research with the intention of improving care;
Hold regular meetings between provider and commissioner with agreed reporting mechanisms.

### 11.3 Clinical Pathways

Clinical pathways describe the patient journey from referral to treatment including potential investigations, healthcare interventions, treatments and options. Pathways must comply with evidence based guidelines for the provision of high-quality clinical care, throughout the provision palliative and end of life care.

The Map of Medicine (MoM) is a national software tool that has been implemented for the development of clinical pathways based on evidence or expert consensus. NHS Stockport and Stockport Foundation Trust are committed to the development of localised pathways by clinicians in primary and secondary care and have adopted the Map to be the vehicle for sharing the agreed pathways in a standardised manner. Pathways are available for end of life care in adults; localised pathways have not yet been developed.

**Prognostic Indicators**

Clinicians should use the following triggers to identify changes in a patient’s condition; these will support clinicians with determining progression of illness and identification of patients who are approaching the end of their life:

1. The surprise question: “Would you be surprised if this patient were to die in the next 12 months”? This can be used to trigger the appropriate actions at each stage of the illness.

2. Clinical prognostic indicators are a set of clinical triggers used to support the clinical judgement and assess patients’ needs for palliative, supportive or hospice care. The indicators require clinical judgement and help to alert clinicians to the need for extra supportive care particularly for patients who are nearing the end of their life. Co-morbidities are the biggest predictive indicator of mortality and morbidity; the clinical indicators are specific indicators of advanced disease for each of the three main end of life group’s including cancer, organ failure and elderly frail/dementia.

3. General indicators of decline such as discussions about treatment and choice for comfort care only rather than curative treatment.

The aim of prognostication is to improve prediction of decline, leading to better anticipation of need for support and when used with Advance Care Planning discussions will help to identify deterioration and unmet needs.

Communication between providers is essential to ensure that changes in condition are identified and appropriate care is delivered and coordinated. Close relationships between hospital, hospice and primary care is paramount.

**The table below describes the Map of Medicine pathways available:**

<table>
<thead>
<tr>
<th>Pathway Name</th>
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<tr>
<td>End of Life Care in adults – assessment and care planning</td>
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Identify people approaching end of life:
- Cancer
- Organ failure
- Elderly

Assessment and care planning
Coordination of care
Prognosis less than 6 months
Prognosis of weeks
Prognosis of days
Advance decision to refuse treatment

**End of Life Care in adults – palliative care services**

Palliative care services
Ambulance and out of hours services
Hospital/Hospice services
GP and community services
Manage emergencies and complex symptoms
- Cancer
- Long term neurological conditions
Manage specific physical symptoms
Manage social problems
Meet nursing and care needs
Provide access to support groups and meet patients information needs

**End of life care in adults – management of psychological symptoms**

Manage psychological distress
Address spiritual and religious needs
Managing social needs

**End of life care in adults – care in the last days of life**

Recognition of approaching death
Consider ongoing or complex problems
Physical (comfort measures)
Psychosocial
Religious and spiritual
Communication
Referral for complex problems
Multi disciplinary team assessment
Patient diagnosed as dying
Patient not diagnosed as dying
Communication with patient, relative or carer
Commence Liverpool Care Pathway(LCP) for the dying patient
Consider multi disciplinary team reassessment
Care after death

**Death and Bereavement**

Diagnosis and confirmation of death
Consider organ donation
Expected death
Sudden death
Care of the body and needs of the bereaved
Care for the body
Notify all appropriate healthcare teams and document actions
Provide immediate support and information for the bereaved
Care for the deceased’s property
Certify the death
Arrange transfer of the body
Significant risk factors for poor bereavement outcome
Provide information about bereavement services
Provide information about registration of death and funerals
Provide appropriate bereavement support

11.4 Effective Use of Resources

It is the responsibility of commissioners and providers to ensure that resources are used effectively. NHS Stockport has developed an effective use of resources policy that outlines area that may pose an ineffective use of resources.

Alternative therapies provide therapeutic support to end of life patients and their carers and NHS Stockport operates a policy whereby funding for complementary and relaxation therapies is not routinely granted, requests for NHS funding of these services is considered on an individual basis.

11.5 Clinical Risk Management and Assurance

Clinical risk management and assurance is essential therefore providers must have a comprehensive risk management policy as well as systems and processes including as a minimum the identification and assessment of clinical and non-clinical risk; precautions to handle identified risk; health and safety issues; patient safety; identification, reporting of, and learning from, adverse patient incidents; arrangements for responding to emergencies, as appropriate, protection of vulnerable adults and children at risk. Any existing arrangements with sub-contractors for the provision of clinical services should be agreed

11.6 Clinical Supervision

Providers should have a formal process for professional support and learning that enables individual practitioners to develop knowledge and competence, assume responsibility for their own practice and enhance the care and safety in complex care conditions.

11.7 Infection prevention and control

Providers should have processes in place to manage infection control statutory requirements. The processes for avoiding infection should be followed by anyone giving or receiving care at home, at a health centre or clinic, or elsewhere in the community.

Including:
ways of avoiding infection, including hand washing, using gloves and aprons, using sharps safely, and educating patients and their carers about infection

ways of avoiding and controlling infection for people who need a urinary catheter, enteral feeding or a central venous catheter

11.8 Consent

Providers should operate a patient consent policy that complies with good clinical practice, good health and or social care practice and any legal requirements. The policy should include provisions for patients who have been assessed as unable to provide consent in accordance with the patient consent policy in which case the provider will act in accordance with the appropriate legislation.

11.9 Clinical emergencies, incidents and serious untoward incidents

Where clinical emergencies occur providers must have in place systems and processes to expedite the care of the patient. The service must also have in place policies and processes for the identification and reporting of all patient safety incidents including near misses. Such processes must feed through to the National Patient Safety Authority and regulatory bodies where required. As well as processes for the reporting of incidents the service must have in place mechanisms for learning from all incidents including the analysis of trends and the effective management and investigation of serious untoward incidents (SUIs) via full root cause analysis.

A serious untoward incident (SUI) may be defined as an adverse or near miss event, act or omission which has produced, or has the potential to produce, serious injury or serious psychological injury or death, pose a risk to the objectives of the provider organisation and which has produced, or has the potential to produce, significant legal/media or other interest. A specific policy and process for the management of SUIs must be in place which includes reporting the incidents and the findings to the commissioner.

11.10 Complaints and compliments

All providers should have processes in place to deal with complaints. For non NHS providers the complaints process should mirror the NHS complaints legislation. A compliments, comments and complaints procedure enables patients and their families to express their views about their experiences of palliative and end of life care services. Such procedures should comply with legal requirements and should be adequately publicised to service users. Information regarding complaints should be made available to commissioners on a regular basis and lessons learned process should be in operation to ensure that complaints are acted upon.

11.11 Patient confidentiality

Providers should maintain confidentiality and only use confidential information in connection with the care of the patient. Information may be shared by NHS bodies in connection with the care of the individual but such information should not be disclosed to third parties or used to the detriment of the individual who has disclosed the information.

Disclosure of confidential information may be required in connection with litigation or where compliance with legislation is required.
12. Workforce

Whilst palliative care is an integral part of the role of generalists such as GPs and district nurses, it is likely to form only a small part of their workload. However, generalists working in the community, hospital and in care homes provide the majority of palliative care to patients. Specialists in palliative care are highly trained but are a scarce resource.

A competent and skilled workforce is paramount to delivering best quality care across health and social care. It is essential that the workforce in place meets the needs of the service user and provides support and care throughout the end of life care process and through to bereavement.

End of life care incorporates all elements of the daily life of a person nearing the end of their life and many people who aren’t end of life care specialists will at times find themselves supporting an individual who is in the final stages of their life. It’s important that they are prepared and able to make a positive contribution when it is needed.

The principles and competences for a skilled workforce form a common foundation for everyone whose work includes care and support for people nearing and reaching the end of their lives, whether their primary involvement is health or social care and support-related.

The core competences and principles for a skilled workforce should include:

- Communication skills
- Assessment and Identification
- Advance care planning
- Symptom management, comfort and well being

Sustained leadership and drive will influence the workforce locally to ensure that services are consistent and supportive for users of end of life care services and will ensure that education and training is an integral part of support for staff working within end of life care.

To deliver quality end of life care services the level of the workforce, the competencies and the skills of those delivering the service should reflect the needs of the local population. Integration of end of life care across health and social care providers will improve communications and will support the reduction of fragmented care.

Development of the workforce to ensure staff are skilled to apply end of life care holistic assessment tools such as the GSF, PPC and LCP will ensure good practice and best care for Stockport patients and carers. Staff delivering any aspect of end of life care has a responsibility to ensure that they have the necessary skills and competencies to enable them to deliver high quality end of life care.

Workforce groups include:

- Staff working in specialist palliative care and hospices that essentially spends their whole time dealing with end of life care should have the highest levels of knowledge and skills including; communication skills, assessment, advanced care planning and symptom management.
- Staff who frequently deals with end of life care as part of their role (secondary care staff e.g. A&E staff, acute and respiratory medicine, primary care staff e.g. GPs, district nurses).
This group have the greatest need and should be supported through continual professional development in particular GPs and District Nurses who may trigger discussion at the start of the pathway.

- Staff that infrequently have to deal with end of life care e.g. care home staff, social care staff. It is expected that this group must have a good basic grounding in the principles of end of life care and be enabled to know when to refer or seek expert advice or information.

12.1 Workforce strategy, policy and processes

Providers will have policies in place that reflect the strategic objectives of the organisation and support the contractual requirements of Commissioners. Policies should support the culture and values of staff as well as areas such as capacity and skills and working flexibly. It is essential that providers have processes in place that will be responsive to change and support staff to deliver improvements. Good management practices will need to be embedded in processes to enable managers to engage more effectively with staff and respond to change.

12.2 Recruitment and retention

Providers must seek to recruit the best people to its workforce to ensure the provision of a high quality, flexible service and excellent standards of care and guarantee an appropriate, diverse and robust workforce to meet the demands of the service. This workforce must not only be adequate in terms of the size of the team and ability to cover all necessary workload, the workforce must also be appropriately qualified, skilled and experienced to provide the required service.

The provider must be committed to a fair and consistent approach to recruitment and selection in full compliance with NHS, UK and EEC statutory and other legislative requirements in relation to the recruitment of staff.

There must be a nominated officer that is responsible for the introduction, application and monitoring of recruitment policy and the overall service provision in relation to recruitment and selection. It is important that there is provision of advice, guidance and support to recruiting managers, including identifying best professional practice, including techniques of attracting and selecting suitable candidates, observing relevant legislation and providing procedures that are open, timely and fair.

There must be a process regarding re-deployment, ensuring that the process is fair, in accordance with the Operating Framework aim to maximise job security and any change policy and that the requirements of employment legislation are applied.

Training and development must be available to support the implementation of recruitment policies and procedures.

Providers must have established systems to monitor adherence to the policy and provision of statistical information to manage workforce information. Providers will be required to monitor its workforce by race, gender and disability as a minimum on a six monthly basis. This requirement may change in line with any developments in legislation concerning equality.

All procedures should comply with the NHS Employment Checks Standards March 2008 for occupational health, eligibility to work, professional registration, criminal records bureau, qualifications, references and employment history. In addition NHS Pre- and Post-Appointment
Checks Directions 2002 (HSC 2002/008) and the directions contained within the Issue of Alert letters for Health Professionals in England (HSC 2002/001)

Emphasis will be placed on the avoidance of all forms of discrimination as specified in the Trusts Policy on Equal Opportunities with particular reference to the Equality Act 2010 and the Public Sector Equality Duties (2011).

Providers must operate within the framework of the European Working Time Regulations 1998 and adheres to the principles and practice of all employment legislation.

A systematic recruitment process must be in place to provide a clear and simple process to assist managers in selecting the best candidate for the job and to ensure equality of opportunity for all applicants.

In order to retain key skills and promote excellent staff motivation and morale the provider must ensure that its terms and conditions employment policies and practices are in place to promote a positive workforce environment, a diverse workforce and to provide best practice in terms of:

- Staff health and wellbeing
- Leadership, management and supervision
- Performance management
- Appraisal, training and development
- Employment relations.
- Health and safety

Providers must make employment policies available to staff in the form of a staff handbook or electronically, outlining: employment terms and conditions; existing or proposed HR policies; existing or proposed health and safety policies; existing processes that are in place for resolving any employee relations issues which may arise. As a minimum this should include staff involvement, consultation and communication; disciplinary; bullying and harassment; allegation management and safeguarding adults, grievance; whistle blowing; confidentiality; equal opportunities; compensation and benefits; performance management appraisal; training and development; sickness absence; leave/cover arrangements; lone/remote working; drug and alcohol misuse; smoking; and relocation.

Voluntary sector providers

Providers must have policies in place that ensures staff within their employ have Occupational Health Clearance, clearance for working with vulnerable adults (and children if applicable), Criminal Records Bureau clearance and are qualified and competent to work at the level at which they are employed.

12.3 Competency

Providers must be committed to providing high quality care through the effective management and development of all its employees and effective management of employee performance is an essential part of this.

Employees must be made aware of the specific requirements of their job and any KSF competencies and to whom they are responsible. This includes ensuring all staff employed or
engaged by the provider to work within the contract are informed of the requirements of the contract and the performance standards they are expected to deliver.

Adequate induction training must take place within a reasonable period of time from starting a post and appropriate additional training must be provided to supplement previous education, training, and experience.

Providers will at all times endeavour to ensure that employees achieve and maintain a high standard in their work. The organisation will at all times ensure that standards are established, performance is monitored on an ongoing basis throughout the year, and employees are given appropriate training and support to meet these standards. When it is apparent that an employee is not capable of achieving the required level of performance, the organisation will deal with the situation in a reasonable and competent manner. There should be policies in place to deal with unacceptable levels of performance that are due to capability and alternative policies for issues more appropriately dealt with outside of capability procedures.

Providers should undertake regular performance appraisal of all staff and abide by the provisions for handling performance and conduct concerns of doctors in the NHS as contained in the DH publication HSC 2003/012 ‘Maintaining High Professional Standards in the Modern NHS’, updated in 2005 and the proposals for the licensing and revalidation of doctors present in the GMC publication “Developing medical regulation: A vision for the future”.

Employee potential should be maximised by improving and maintaining their development and capability, providing a system whereby poor performance can be addressed in a positive manner, without necessarily resorting to the Disciplinary Policy Procedure. The purpose should be to provide clear, fair and consistent methods of recognising and addressing a genuine lack of capability.

Providers will oversee the introduction, operation, and monitoring of competence issues and ensure that policies are fairly applied and managers and provided with training, guidance and support to operate the policies in accordance with accepted standards of good practice and employment legislation.

12.4 Registration

Providers must have a policy in place to ensure that the organisation employs nurses covered by the Nursing and Midwifery Council (NMC) and medical staff covered by the General Medical Council (GMC) or any professional body. The policy must include all employees required to be registered with a professional organisation including bank staff. Appropriate checks must be undertaken when engaging staff through an employment agency before allowing them to work.

Whilst the responsibility for maintaining professional registration rests with the individual practitioner providers must ensure that staff remain registered with the relevant body and that they fulfil the requirements of their professional regulatory body. All providers must provide a training plan to ensure that staff meets their CPD requirements and comply with the requirements of the Care Quality Commission for the supervision of clinical training. Appropriate clinical supervision must be available as required and an ongoing workforce development programme must be developed.
If a health professional fails to notify a provider that their registration has been temporarily/permanently discontinued at any time in their employment, the provider is expected to have a policy to deal with the matter for example that it will be treated as a disciplinary matter.

12.5 Equal opportunities

NHS Stockport is committed to eliminating all forms of discrimination and promoting equality of opportunity. In undertaking work on behalf of the NHS, we expect our service providers to operate fairly and comply with the same legal and statutory duties as NHS organisations.

Under the terms of this contract, the Provider shall comply with the requirements of equality legislation which may include, but is not limited to, the Equality Act (2010), the public sector equality duties, and codes of practice issued by the Equality & Human Rights Commission.

- The Provider shall ensure that their recruitment and employment processes and fair and equitable.
- The Provider shall not discriminate between service users on the grounds of age, disability, gender, gender identity, marriage / civil partnership, pregnancy / maternity, race, religion or belief, sexual orientation or any other non-medical characteristics.
- The Provider shall provide appropriate assistance for service users who do not speak, read or write English or who have communication difficulties (including, without limitation, hearing, oral or learning impairments).
- The Provider shall provide to the Commissioners such information as the Commissioners may reasonably require:
  - to monitor equality of access to Services;
  - to monitor equality of treatment with regards to Complaints and Patient Feedback Surveys;
  - to monitor equality of opportunity in staff recruitment, training and promotion; and
  - to fulfil their obligations under the Law.

12.6 Training

Providers must support the development of a highly skilled and knowledgeable workforce, capable of being pro-active and responsive to the increasingly complex environment of health care delivery. The priorities and requirements for education, training and life-long learning should be drawn from the strategic objectives of the service and a comprehensive training needs analysis collated from the personal development plans of the workforce including provision for end of life care mandatory training including communication skills training and use of holistic assessment tools.

The approach to training should attract, develop and retain good quality staff and increase the awareness of education, training and development (ETD) opportunities across the organisation. ETD should be integral to everyday work with individuals being trained and developed to achieve their full potential in the job for which they are employed. The provider should ensure that managers are be supported to implement ETD; the development of underperforming staff and to ensure where applicable staff meet the Continuous Professional Development (CPD) requirements.
of their regulatory body and the requirements of the Health Care Commission for the supervision of clinical training. Appropriate clinical supervision must be available as required and an ongoing workforce development programme must be developed. ETD provision should be allocated in a fair, equitable and consistent manner. All employees should have equal access to ETD opportunities, regardless of sexuality or race, religious or political conviction, age, disability or gender, trade union activity or employment pattern.

12.7 Corporate social responsibility

Commissioned services should comply with the six core characteristics of an organisation that exhibits good corporate social responsibility. These are:

- understanding society;
- building capacity;
- questioning business as usual;
- ensuring excellent stakeholder relations;
- developing a strategic view;
- harnessing diversity.

12.8 Codes of Practice

The provider must adhere to the codes of practice issued by the UK Government advisory bodies which give practical guidance to employers and service providers on the elimination of discrimination and the promotion of equality of opportunity these include:

- Commission for Race Equality (CRE);
- Equal Opportunities Commission (EOC);
- Disability Rights Commission (DRC);
- Commission for Equality and Human Rights (CEHR)

13. Infrastructure

13.1 Facilities and Services

Facilities and services must be maintained to the standards set out by the Department of Health (DH 2008). Any changes to facilities must be compliant with national regulations regarding the type of construction or fabrication of the facility and the strategy of any materials and mechanical and electrical services.

All providers should make available details all non clinical facilities management (FM) services provided including details of each specific service including scope and hours of cover and the details of providers of the FM services, including any subcontractors.

13.2 Operational Hours

End of Life Care Services should be provided 24 hours a day 7 days a week; however, there are variations across primary care providers and social care. Services should be delivered in line with the contractual agreements between commissioners and providers.
13.3 Housekeeping Standards

All facilities must meet NHS standards and guidance and Care Quality Commission standards (if applicable) on cleanliness, privacy and dignity, housekeeping and catering. The facility should have an identified process flow for patients, supplies, waste disposal and foul drainage which should be shared with the commissioner.

14. Information Management and Technology (IM&T)

High quality data, information and IT should underpin End of Life Care services and maximise the delivery of clinically effective and efficient services. Providers must therefore have access to appropriate information systems, technology and electronic connectivity.

Multiple electronic systems across provider’s means that information is disjointed with various extracts of care held on separate records. An overarching system would provide up to date information at the point of need and would be accessible to clinicians for recording changes in a patient’s condition or treatment as they occur. An integrated electronic care record will improve healthcare and safety and should be held locally to bring together the vast amount of information regarding care, treatment options and individual wishes and preferences to be recorded and viewed by those involved in the care of end of life patients.

An electronic palliative care coordination system that links health and social care professionals viewing rights for access to patient data and system reporting arrangements should be in place to ensure that up to date information is recorded and accessible. A data sharing agreement should be in place to promote a consistent approach for sharing information within the system.

Providers accessing the system will include:
- Acute Hospital
- Primary Care Services
- General Practitioners
- Out of Hours GP services
- Local Authority
- Hospice services
- Voluntary sector providers
- North West Ambulance services
- Mental Health services

14.1 Information systems and flows

Service providers must have appropriate IM&T solutions for maintaining patient information and must be able to manage information with particular emphasis on:

- The management of patient throughput and reconciliation of activity volumes;
- Excellent information flows to referring clinicians including discharge information;
- Robust communication of information between relevant parties;
- Monitoring of the key performance indicators;
➤ Central and local NHS management information requirements;

➤ NHS commissioning requirements including the provision of CDS data via SUS;

➤ Monitoring equality data (Race, Gender, and Disability & Age as a minimum).

Service providers must comply with the requirement to accommodate new reporting requirements as they arise and have flexible information systems that can be modified to include such new requirements. Service providers must be able to support the communication of activity outputs and other clinically relevant information between themselves, other relevant NHS organisations and voluntary sector providers.

14.2 IT Infrastructure

Providers must be registered with appropriate NHS services and comply with their technical and procedural requirements including:

Organisation Data services (ODS);
Secondary Uses Service (SUS);
NHS mail;
UNIFY2 (NHS data Collection Portal);
Personal Demographics Service (PDS).

Providers must also integrate their IM&T solution with NPfIT at the national and local level, including NHS CRS (including Spine and local LSP CRS); infrastructure services such as the national NHS network, N3; Choose and Book; ETP; and PACS solutions.

Voluntary sector providers must ensure their systems comply with the data requirements of commissioners.

15. Business Continuity and Disaster Recovery

Given the importance of information and patient records, service providers should have robust business continuity and disaster recovery plans for IM&T which should be subject to regular testing and be proven to be effective in the event of an incident.

16. Information governance, data quality and data standards

Service providers must adopt robust information governance procedures including achieving a minimum level 2 performance against all requirements in the NHS information governance toolkit.

Providers must have protocols for records management and ensuring security and protection of patient personal data having regard to their duties under the Data Protection Act 1998 and the Freedom of Information Act 2000 as well as the requirements of the Caldicott Report 1977, the NHS Confidentiality Code of Conduct and the Connecting for Health Security Board.

Service providers must also comply with the prevailing data or technical standards including but not limited to the following:

➤ CDS;
➤ NHS Data Dictionary;
clinical coding standards;
> Information Standards Board (ISB);
> EGIF;
> STEP.

17. **Data to support equality and diversity monitoring**

There is a requirement to disaggregate some data by race, gender and disability to comply with the legislative needs around equality. Such reporting will be agreed with the provider and may change if there are changes in legislation.

18. **Future Development of the Palliative and End of Life Service Strategy**

The palliative care and end of life service strategy outlines the needs of the resident population of Stockport and the requirements for providers to meet those needs. This document was ratified by the End of Life Care Programme Board on 8th February 2012. The contents of this strategy are likely to change as the standards for palliative care and end of life services must be advanced in line with national and local requirements. This document will therefore be subject to periodic review and updating.
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APPENDICES

1. THE STOCKPORT MODEL

Stockport model final version 300112.doc

2. PATHWAYS

Fast Track Pathway Tool for Continuing Hi

3. END IF LIFE CARE STRATEGY – 3rd Annual Report

EoLC 3rd Annual Rept.pdf

4. END OF LIFE CARE STRATEGY

end of life care strategy July 08.pdf

5. END OF LIFE CARE – Quality Markers

Quality markers June 2009.pdf

6. END OF LIFE CARE – Core Competencies


7. NICE Quality Standards – End of Life Care for Adults

EoLCFinal quality standards.pdf

8. LCP PATHWAY – Community Health Stockport

algorithm re dn's.doc
9. SIX STEPS TO SUCCESS – Programme for Care Homes

Six_Steps_to_Succes
s_Programme_1.pdf