



**Public Awareness &
Consultation Event on
End of Life Care services
28 August 2009**

**Supporting your right to the best
health and social services in**

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Introduction from York LINK Steering Group

York LINK (Local Involvement Network) was launched in September 2008 to take over the role of the Patient and Public Involvement in Health Forum (PPI Forum) in the York Area. The PPI Forum was a group of volunteers who inspected health services in York on behalf of the public. The main difference between the LINK and the PPI Forum is that the LINK can inquire about social services issues as well as health services.

The money to fund LINKs comes from the Department of Health and is divided between every Local Authority in England with responsibility for providing social services. The City of York Council contracted a 'Host' organisation to help develop the LINK. This is so that the LINK is not directly managed by the Council, giving the staff and volunteers freedom to make recommendations about services without being influenced by council decisions. York LINK's host organisation is North Bank Forum (NBF), based in Hull.

At the LINK launch event in September 2008, an Interim Steering Group was formed to agree the constitution and rules for the LINK before the first Annual General Meeting (AGM).

The AGM was held in March 2009 and a Steering Group made up of individual volunteers and volunteers from York organisations was established.



The Interim Steering Group decided to use a voting system to prioritise the work of the LINK and create the work plan for 2009/10. A debate on the issues that had been referred to the LINK from a variety of sources took place during the AGM, and members then voted for their preferred issues. To try to include as many members of the community as possible, and have a recorded process that provided evidence for LINK

priorities, the voting document was also sent to all registered members prior to the AGM and was available on request from the LINK office. The 'provision of end of life care services' was one of the issues with the most votes and so was adopted as part of the LINK work plan for 2009/10.

The role of the LINK is to discover what people in the York area think about health and social services and look into any issues that are affecting more than one person. When the issues have been examined, the LINK can make recommendations to organisations to amend or improve their services. When reports are published, they are sent to the organisations concerned together with a letter outlining the recommendations. The organisations then have 20 working days to reply to the LINK.

York LINK Steering Group

March 2010

Background



The National End of Life Care Strategy

In July 2008 the Department of Health (DoH) published a national End of Life Care Strategy. This is the first such strategy for the UK and it aims to promote consistently high quality of care for all adults at the end of their lives. It acknowledges that, in the past, the profile of end of life care within the NHS and social care services has been relatively low and the quality of care delivered has been very variable.

It is envisaged that implementation of this strategy will make a 'step change' in access to high quality care for all people approaching the end of life. High quality care should be available wherever the person may be: at home, in a care home, in hospital, in a hospice or elsewhere.

The strategy stresses the need for Primary Care Trusts (PCTs) to work with local authorities, hospitals, hospices, carers etc to agree and implement ways to promote consistently high quality of care for people as they approach the end of their life.

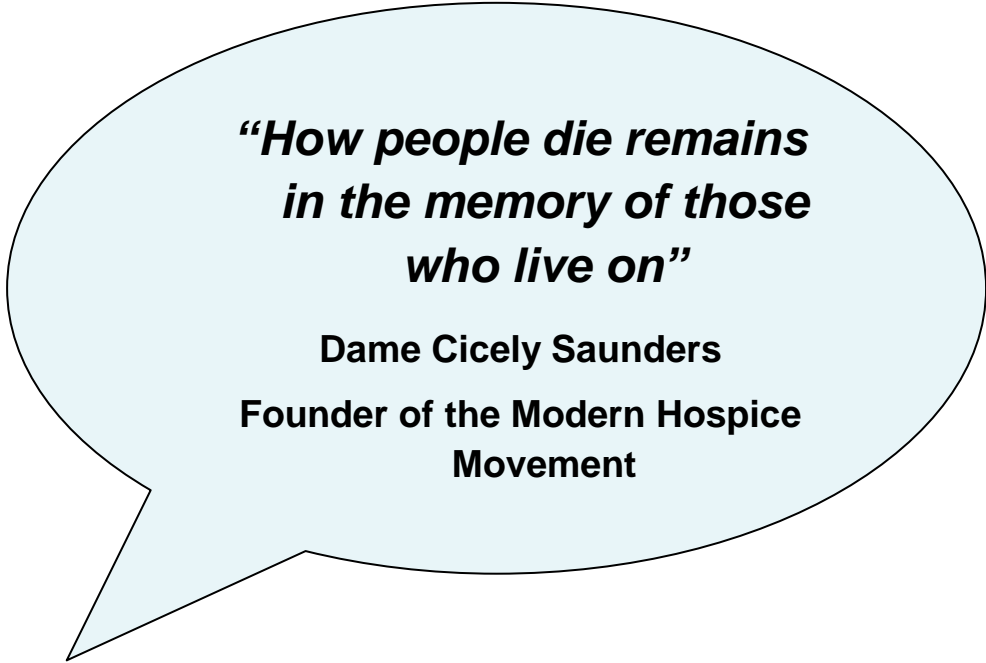
Key areas addressed by the National Strategy

The National Strategy sets out recommendations and actions in a number of key areas:

- PCTs and local authorities need to work in partnership to consider how to engage with their local communities to raise the profile of end of life care. This will involve liaising with schools, faith groups, funeral directors, care homes, hospices, hospitals, home care services, employers etc and agree ways to speak to people about dying and ask their views on current services.
- An integrated approach to planning, contracting and monitoring of service delivery should be taken across health and social care. Improved services should be commissioned as the contracts for present services come to an end, taking the needs of the community into account.

- Health and social care staff need sufficient training to identify people who are approaching the end of life. Workforce training is needed, so that staff have a greater ability to recognise people who are at risk and the correct care can be implemented.
- Everyone who is identified as approaching the end of their life should have their needs assessed. This assessment must include their wishes and preferences about how they are cared for and where they would want to die
- Everyone approaching the end of life should receive coordinated care from all services at all times of day and night. This could be achieved by providing a single point of access through which all services can be co-ordinated.
- Rapid access to care is essential. PCTs must work with local authorities to ensure that medical, nursing, personal care and carers' support services can be made available in the community 24/7 and can be accessed without delay.
- High quality care should be delivered in all locations. These will include services provided in hospitals, in the community, in care homes, sheltered and extra care housing, hospices and ambulance services.
- Increasingly the Liverpool Care Pathway, or an equivalent tool, is being adopted. It was first developed for use with cancer patients but has now been modified for use for people with other conditions. It can be used in hospitals, care homes, hospices and in people's own homes.
- The family and carers of people approaching the end of life have a vital role in the provision of care. They need to be closely involved in decision making, with the recognition that they also have their own needs. Carers already have the right to have their own needs assessed and reviewed and to have a carer's care plan.

- It is critical that health and social care staff at all levels have the necessary knowledge, skills and attitudes needed to care for the dying. Strategic Health Authorities need to consider how training can best be commissioned and provided to ensure that staff have the necessary competencies.
- Measurement of end of life care provision is essential in order to monitor progress. Measurement will largely be through self assessment against quality standards, carried out by the organisations themselves.
- The overall cost of end of life care across health and social care is large and difficult to calculate. The key elements of expenditure are: hospital admissions; hospices and palliative care services; community nursing services; care homes. Increased government resources are committed to implement the strategy - £88m in 2009/10, £198m in 2010/11. Many improvements can be achieved by better use of existing health and social care resources. For example, at least part of the additional costs of providing improved care in the community and in care homes will be offset by reductions in hospital admissions and length of stay.



***“How people die remains
in the memory of those
who live on”***

**Dame Cicely Saunders
Founder of the Modern Hospice
Movement**

The Gold Standards Framework

The Gold Standard Framework (GSF) is an approach which is designed to enable a gold standard of care for all people nearing the end of life. It is concerned with helping people to live well until the end of life and includes care in the final years of life for people with any 'end stage' illness in any setting.

The Department of Health End of Life Care Strategy 2008 says that every organisation involved in providing end of life care will be expected to adopt a co-ordination process, such as the Gold Standards Framework. It is also recommended as best practice by NICE, Royal College of General Practitioners, Royal College of Nurses and other major policy groups.

GSF is extensively used in the UK, by thousands of primary care teams and care homes and increasingly in other settings through cross boundary care and also internationally.

GSF is about:

- Enabling generalists and improving the confidence of generic staff
- Organisational system change - the right care at the right time for the right patient
- Patient led focus on meeting the needs of patients, families and carers
- Care for all those with any end stage condition, non-cancer and cancer
- Pre-planning care in the final year or so of life, proactive rather than reactive care
- Care closer to home - decreasing hospital admissions and deaths
- Cross boundary care and in all settings - care homes, hospitals, hospices etc

Local background

In North Yorkshire and York, deaths are attributable to three main areas of illness:

- Heart and circulatory disease 41%
- Cancer 26%
- Respiratory disease 12%

Of the remaining 21% some deaths will be sudden or unexpected, such as road accidents. Other deaths relate to a range of long term illnesses such as Neurological Disease or Renal Disease. Other deaths relate to frailty and very old age, without a specified diagnosis.

In York, approximately 1,822 people of all ages die each year. Approximately 56% of all deaths take place in hospital, 19% take place in peoples own homes, 5% take place in hospices and 19% take place in nursing and residential homes (PCT End of Life Review/Healthy Ambitions 2008).

In York, NHS North Yorkshire and York (the PCT) staff were already working with City of York Council Social Services staff to review end of life care services before the National Strategy was published. The work began with issues around cancer services but it was recognised that 'end of life' is a much broader area.

The North Yorkshire and York End of Life and Palliative Care Commissioning Strategy 2008-2011 was published in September 2008. An End of Life and Palliative Care work plan has been developed to deliver the strategy.

York LINK Public Awareness and Consultation Event

In order to discover more about End of Life Care services in York, the LINK Steering Group decided to hold a Public Awareness and Consultation Event (PACE) on End of Life Care services. The event took place on 28th August 2009 (see Appendix 1 for the event programme). Speakers from City of York Council Social Services, NHS North Yorkshire and York and York Hospitals NHS Foundation Trust were asked to give information on the services they provide. To include the support available from the voluntary sector a speaker from MacMillan Cancer Support was also invited. Invitations to the event were sent to individuals, local voluntary and community groups and statutory services.

Emma Taylor, End of Life Care Facilitator/ Bereavement Services Manager York Hospitals NHS Foundation Trust

Emma Taylor spoke about both the Liverpool Care Pathway and the Bereavement Suite at York Hospital.

1) The Liverpool Care Pathway

The Liverpool Care Pathway is a document that can be used by all professionals such as nurses, doctors, social workers etc. The document contains templates that doctors, nurses, social workers etc can use to provide the best care possible. This document has been put together from many studies of the evidence available (evidence-based) that has led to the best result possible (best-practice) and has involved the patient's views (patient-centred care).

The Pathway is a tool to help transfer the hospice 'model of care', which promotes patient comfort rather than a cure for their condition, to a hospital setting and will help the staff to have a York Hospital wide structure (pathway) to provide the best care for dying patients and relatives

The role of the End of Life Care Facilitator is to:-

- Lead the development, education and implementation of the Liverpool Care Pathway across York Hospitals NHS Foundation Trust.

- Carry out an audit on the use and the findings of the Pathway.
- Carry out a full review of the Bereavement Care service.
- Develop services to meet preferred priorities of dying patients.

The Pathway is structured in three sections to provide the following:-

1. An 'Initial Assessment' of the patient's needs and the care required
2. An ongoing assessment of needs and care
3. Care for the patient and family after death

When patient care is managed in accordance with the Liverpool Care Pathway, nurses must check patients' physical, psychological, religious or spiritual, and social goals every four hours.

Hospital staff do not need to ask permission from the patient to put them on the Pathway but it is best practice to let them know that staff are helping them as much as possible. Some Doctors still think that a dying patient is a failure of their expertise. This is changing and many now accept that if they have done all they possibly can it is better to help someone to die in comfort than put them through further medical procedures.

How much is the Pathway used in the hospital currently?

- In August 2009 55% of the wards in the Hospital were using a Care of the Dying Pathway - this will be replaced with the Liverpool Care Pathway after staff have received the necessary training.
- There is a roll out development programme for the remaining wards to implement the Liverpool Care Pathway. A large piece of work will be involved prior to the implementation of the Liverpool Care Pathway in the Intensive Care Unit because patients in the unit can have different needs to those on the wards.
- A computer based learning package is being developed for **all** staff including ward clerks, porters and health care assistants as it is recognised that all staff need to have awareness of this area.

- Training on End of Life Care will be incorporated in the hospital staff's mandatory training from April 2010.

An audit of services in York Hospitals NHS Foundation Trust during 2008 found that 55% of all hospital care is about end of life.

Also:-

- 37% of Patients who died were on the Care of the Dying Pathway
- 27% of Patients could have been on the Pathway but weren't
- 36% of Patients were not appropriate for the Pathway

This means that 401 Patients who could have been on the Care of the Dying Pathway were not.

A similar audit carried out in April 2009 after the implementation of the Liverpool Care Pathway in some areas found a small improvement but hopefully this will improve further after all staff have been trained.

Further training is planned for staff who have already been trained on the Liverpool Care Pathway to include documentation and arrangements for sudden or unexpected death.

2) Bereavement Suite at York Hospital

As part of the bereavement care plan to improve services offered to newly bereaved relatives, a new Bereavement Suite is planned for York Hospital. Having been severely delayed, building work is due to commence mid March 2010, with a predicted opening date of August 2010. The project is funded by the Kings Fund Charity and from donations.

Initially the service will be similar to the current service, and will provide an enhanced environment for collection of death certificates, property and valuables. There will be an on-site Registrar of births and deaths, and a room for relatives to be seen by doctors if appropriate. The design also features quiet space outside for bereaved relatives.

Future plans for the suite will involve the use of agencies such as Cruse Bereavement Care and Sands (Stillbirth and Neonatal Death Society) to provide expert counselling and support to the bereaved.

Initially the suite will be open from 8.30am - 4.30pm Monday – Friday.

Ruth Wilson, Macmillan Cancer Support Community Network Development Coordinator

The history of Macmillan

In 1911, a young man named Douglas Macmillan watched his father die of cancer. His father's pain and suffering moved Douglas so much that he founded the 'Society for the Prevention and Relief of Cancer'.



Douglas wanted advice and information to be provided to all people with cancer, homes for patients at low or no cost, and voluntary nurses to attend to patients in their own homes.

The Society provided information on recognising, preventing and treating cancer to patients, doctors and members of the public. In 1924 the Society became a Benevolent Society and changed its name to the 'National Society for Cancer Relief'. As recent as 1975 the first Macmillan nurse was funded and the first Macmillan cancer care unit built. The nurses were so successful that only three years later in 1978 their number had increased to ten. By 1980 the Society was able to invest £2.5Million to expand the Macmillan teams throughout the UK primarily focusing on an educational programme to train doctors, nurses and students in advanced pain control and cancer care. In 1986 the first Macmillan doctor was funded. The charity is now called the 'Cancer Relief Macmillan Fund'.

At present, Macmillan directly employs 800 people but includes almost 5,000 people as many nurses etc are sponsored and employed via NHS Trusts. The Development Managers are looking at the gaps in services at present so the interest shown by York LINK is very timely.

Macmillan Grants

The Fund provides grants for travel expenses to hospices, holidays to help recuperation after treatment etc for people who otherwise have difficulty affording them. There are also small grants to support people with the practical impact of cancer such as increased fuel bills.

There are also start-up grants of £500 to help set up local support groups. The support groups can then apply for up to £3,000 in development grants to expand the group or pay for awareness sessions etc. Volunteers can also attend Cancer Voices training and then hold awareness sessions in local areas.

Cancer Networks

Macmillan organises Cancer Networks throughout the country. These are based in grouped NHS areas. In the York area there is the Yorkshire Cancer Network which includes the Huddersfield, Bradford, Wakefield, Harrogate, Leeds and York districts.

Macmillan also has local groups and asks them what they think of services. They come together to meet with professionals at the Network meetings to try to jointly improve services.

Nationally, Macmillan has organised a campaign to get free car parking for cancer patients who attend hospitals for treatment.

At present regionally, there are discussions taking place about moving the main provider of cancer treatment out of Leeds into more local areas, possibly York. Consultation on this is via the Yorkshire Cancer Network and further information is available via Colin Sloane, User Partnership Facilitator. Phone: 01423 555786 E mail: colin.sloan@ycn.nhs.uk.

The York Cancer and Palliative Care User Partnership Group can be contacted on 01904 631313 (Maggie Clough) and can provide information and advice for people at the end of their lives or their families.

Richard Tassell, Operations Manager, City of York Council Social Services

How does Social Services help?

Most people do not want to die in hospital. The pressure to discharge people from hospital quickly when they are well enough or, if they wish, at the end of their life, is high. There are specific Social Services discharge liaison staff employed to work in the hospital solely to plan discharges. The liaison staff work with Social Services locality managers to ensure a smooth service for people leaving hospital.

Who pays for what service?

Health authorities and councils were requested to agree their respective responsibilities for health and social care services by 1 March 2002. This is an agreement on who pays for social and health care. Councils pay for social care funded via their 'Financial Settlement' from National Government and locally raised rates. Primary Care Trusts pay for health care.

Local agreements on the responsibilities to pay for services have been in place since 1 October 2002. Councils then use Fair Access criteria to determine eligibility for the services for which they are responsible.

Assessing need

Social Services staff assess an individual's needs then prioritise the needs that they are eligible to fund.

The issues and problems that are identified when individuals contact, or are referred to, councils are defined as the "presenting needs".

Those presenting needs for which a council will provide help because they fall within the council's eligibility criteria, are defined as "eligible needs".

When considering needs, councils should not make assumptions about the capacity of family members or close friends to offer support.

City of York Council has agreed to provide End of Life Care to people who require this in their own home as it meets the eligibility criteria used by Social Services.

Fair Access to Services

The eligibility framework is graded into four bands, which describe the seriousness of the risk to independence or other consequences if needs are not addressed. The "Eligibility criteria" describe the full range of eligible needs that will be met by councils having taken their resources into account.

The four bands are:

1 Critical

- when life is, or will be, threatened;
- and/or significant health problems have developed or will develop;
- and/or there is, or will be, little or no choice and control over vital aspects of the immediate environment;
- and/or serious abuse or neglect has occurred or will occur;
- and/or there is, or will be, an inability to carry out vital personal care or domestic routines;
- and/or vital involvement in work, education or learning cannot or will not be sustained;
- and/or vital social support systems and relationships cannot or will not be sustained;
- and/or vital family and other social roles and responsibilities cannot or will not be undertaken.

2 Substantial

- when there is, or will be, only partial choice and control over the immediate environment;
- and/or abuse or neglect has occurred or will occur;
- and/or there is, or will be, an inability to carry out the majority of personal care or domestic routines;
- and/or involvement in many aspects of work, education or learning cannot or will not be sustained;
- and/or the majority of social support systems and relationships cannot or will not be sustained;
- and/or the majority of family and other social roles and responsibilities cannot or will not be undertaken.

3 Moderate

- when there is, or will be, an inability to carry out several personal care or domestic routines;
- and/or involvement in several aspects of work, education or learning cannot or will not be sustained;
- and/or several social support systems and relationships cannot or will not be sustained;
- and/or several family and other social roles and responsibilities cannot or will not be undertaken.

4 Low

- when there is, or will be, an inability to carry out one or two personal care or domestic routines;
- and/or involvement in one or two aspects of work, education or learning cannot or will not be sustained;
- and/or one or two social support systems and relationships cannot or will not be sustained;
- and/or one or two family and other social roles and responsibilities cannot or will not be undertaken.

The City of York Council sets the eligibility criteria at 'moderate' so anyone requiring services at a higher level will need to pay towards the cost. The criteria covering when life is threatened is 'critical'.

Liz Vickerstaff, Senior Commissioning Manager NHS North Yorkshire & York

NHS North Yorkshire and York's End of Life and Palliative Care Strategy was published in September 2008. This strategy reflects national strategy and was developed by patient groups, service providers, statutory and voluntary organisations from across York and North Yorkshire. It also includes information from the following sources:

- NICE Supportive and Palliative Care 2004
- Healthy Ambitions (Darzi Review)

The Strategy includes the following; also contained in the National Strategy for End of Life Care:

Although every individual may have a different idea about what would, for them, constitute a 'good death', for many this involves:

- Being treated as an individual, with dignity and respect
- Being without pain and other symptoms
- Being in familiar surroundings
- Being in the company of close family and/or friends.

To enable the above, the overall aims of the Strategy are focussed on:-

- Assessment and planning of care (advance care planning). This will be done by discussions between staff and patients as their end of life approaches
- Coordination of care. This will be done by assessing, planning and reviewing care
- Providing specialist care when necessary
- Ensuring quality and dignity in delivery of services
- Providing care for Carers/Bereaved
- Monitoring care/audits surveys to ensure the strategy is working

- Sharing best practice

The aims of NHS North Yorkshire and York are

- That people who are in need of palliative care, or have reached the end of their lives, should receive the best possible care, in the setting of their choice where this is possible, and that when death finally comes, that they are able to die with dignity.
- That carers of those who are receiving palliative care, who are dying or have recently died, should have their needs met throughout the process of caring for their loved one.

The outcomes to be delivered by the strategy are:

- The delivery of person Centred Care – Palliative
- The delivery of person Centred Care – End of Life
- Quality services
- Quality staff performance
- Sustainable services

N.B. Palliative care and end of life care are distinctly different. Palliative care is given to maintain the best quality of life when a cure is not possible – this could be for several years. End of life care is usually in the last weeks of life and involves symptom control, pain relief and meeting spiritual needs.

An End of Life and Palliative Care work plan has been developed to deliver the strategy. The work plan contains the following areas to target:-

- Identify Patients
- Assess documentation
- Coordination of services / policies
- Community/District Nursing and Key worker involvement
- Provision of out of Hours Care

- Provision of specialist Palliative Care
- Ensure access to Equipment and Medication
- Involve Acute Care providers
- Provide treatment in alternative settings
- Provide bereavement care/spiritual care
- Ensure Patient & Carer involvement
- Social Care involvement
- Psychological Care
- Training and Education for staff

The final version of the PCT's strategy was agreed by the board in November 2009, including the above work plan. Following the 'refresh' of the PCT's five year strategic plan, the End of life Care strategy is now part of the delivery of this plan, including the work streams which are now part of the community systems work stream.

St Leonard's Hospice

In order to find out about hospice services in York, the LINK Steering Group arranged an informal visit to St Leonard's Hospice on 15th December 2009.

The Hospice was founded in 1985 It is a registered charity caring for people with life-threatening illness. Its aim is: 'To provide for the needs of patient, carers and families in a setting which is as homely and informal as possible and from which the patient will benefit with enhanced quality of life and greater physical and mental comfort.'

It offers:

- In-patient care in a purpose-built, 20-bed unit. Patients can receive short-term care, respite or terminal care.
- Day care at the hospice for people living in their own homes. This provides a combination of practical help and relaxation.
- A lymphoedema clinic where outpatients can be seen by specialist staff.
- Bereavement support for families and carers after a patient has died.

The Hospice is currently running a one year pilot Hospice at Home scheme to support people in their own homes. Hospice at Home aims to enable patients with advanced illness to be cared for at home, and to die at home if that is their preference. Care may be provided to prevent admission to, or facilitate discharge from, inpatient care.

Doctors and nurses work with a team of other professionals and are supported by volunteers. Referral to the Hospice is made by the patient's own family doctor or hospital consultant. No charge is made to patients or relatives, the Hospice is financially supported almost entirely by the generosity of the local community.

Central to the Hospice philosophy is the care of every patient as an individual. The philosophy of the Hospice is that patients should be consulted about medical treatment and have their questions answered honestly; they should be treated with dignity and sensitivity; they should be cared for as a whole person, with compassion and understanding.

Findings the LINK gathered before, during and after the PACE event:

Information was gathered from 20 individual people, and from a variety of publications and websites (see Bibliography for details of publications and websites).

After the first draft of this report was written, a letter about one family's experience was sent to the LINK office. This was in response to a letter in The Press (24 March 2010) from the Vice Chair of the LINK, asking for experiences (good or bad) of end of life care services. Although this letter was received too late to be included in the main report, the LINK decided to include it because it illustrates Dame Cicely Saunders' quote: "How people die remains in the memory of those who live on". It is published in full (with identity details removed) as Appendix 2.

It is acknowledged that due to unforeseen circumstances this report has taken almost a year to complete therefore services may have improved. Nevertheless, this is what the LINK has found.

Key findings	Source
Home care staff do not always know how to care for people with MND. For example, one patient was given tablets whole rather than crushed	York Against MND
NICE clinical guidelines on Parkinson's Disease state that the needs in the palliative care stage of Parkinson's disease are not always identified or satisfied. Their recommendations include that people with PD and their carers should be given the opportunity to discuss end of life issues with appropriate healthcare professionals	NICE clinical guidelines

<p>Qualified nurses are available during the day, but not at night. One patient's partner reported that they stayed up most nights to look after the patient</p>	<p>York Against MND</p>
<p>One patient with MND refused to be admitted to York hospital when she was dying, stating that the care she had received previously was appalling and she would rather "suffer than go into the hospital"</p>	<p>York Against MND</p>
<p>One patients last wishes were not taken into account by a locum GP</p>	<p>York LINK member</p>

Recommendations from York LINK.

1. There is a major mismatch between people's preferences for where they should die and their actual place of death (Department of Health End of Life Care Strategy in England 8 months on by Prof Mike Richards March 2009). Research suggests that the majority of people (between 56 and 74 %) express a preference to die at home. However mortality statistics for 2006 show that 35% of people die at home or in a care home (National Audit Office, End of Life Care, 24 November 2008). However, they may struggle to get services quickly enough to enable this to happen.
 - a) 'Fast track' discharge from hospital needs to be available for people wishing to die at home. Hospital and ambulance services need to be able to respond to this.
 - b) The 24/7 community nursing service in York needs to provide a rapid response for patients who are nearing the end of their lives. Timely access to advice and medication would mean that people approaching the end of their life are less likely to be unnecessarily admitted to hospital.

2. Hospices are widely agreed to be 'beacons of excellence' in the provision of end of life care. However, in York, there are only 20 beds available at St Leonards Hospice and so can only deal with a minority of patients at the end of their lives.
 - a) The Liverpool Care Pathway is being introduced throughout York Hospital and this should be regarded as a starting point to developing 'hospice standard' care (NB St Leonards Hospice do not currently use the Liverpool Care Pathway).
 - b) The Hospice should be encouraged to consider what roles it wants to deliver within an integrated local service, responding to local peoples' needs e.g. awareness raising, education and research, co-ordination, specialist outreach services.

- 3 Patients and carers end of life care needs must be met regardless of who is delivering the service.
 - a) Co-ordination of resources, and collaborative working across health, social services and the voluntary sector should be a priority. The Marie Curie Cancer Care Delivering Choice Programme demonstrates the effectiveness of establishing a central coordinating facility providing a single point of access through which all services can be co-ordinated. (Recommended in the Department of Health End of Life Care Strategy July 2008).
 - b) All organisations involved in providing end of life care should adopt a co-ordination process such as the Gold Standards Framework. (Department of Health End of Life Care Strategy – What the End of Life Care Strategy means for patients and carers, July 2008).

- 4 Improved education and training is needed for all staff involved in End of Life Care, both in health and social care. In addition, for some clinicians and NHS managers a change of culture is necessary so that death is not seen as a failure. Cancer consultants and other cancer services staff in hospitals are now accessing improved communications training which will support this (for cancer service provision). Professionals should not be reluctant to initiate end of life discussions, especially with patients who have long term neurological conditions where the illness may be less predictable than other illnesses such as cancer (NHS Evidence – Supportive and Palliative Care Specialist Collection, National Library for Palliative and Supportive Care, October 2009).

- 5 Time and an appropriate quiet environment must be available for professionals to have conversations about end of life care planning with patients. (NHS Evidence – Supportive and Palliative Care Specialist Collection, National Library for Palliative and Supportive Care, October 2009)

- 6 Bereavement care should:
 - a) Ensure that counselling and support are available 24/7.
 - b) Provide support for those bereaved through sudden death and include the needs of children (The Department of Health End of Life Care Strategy Rationale Chapter 5 – Support for Carers and Families)

- 7 Local End of Life Care services must include all sections of the community, including those regarded as 'hard to reach' such as people in prisons and hostels for the homeless, gypsy and traveller communities. The Department of Health End of Life Care Strategy Rationale (Chapter 4 Care in different settings) says that prisons and hostels for the homeless should be included in local plans and examples of good practice identified.

- 8 End of Life Care services for people with long term neurological conditions can be more difficult to identify and satisfy. Advance care planning is necessary, in an appropriate quiet environment. In some cases a day hospice environment may be beneficial to patients and carers (NHS Evidence – Supportive and Palliative Care Specialist Collection, National Library for Palliative and Supportive Care, October 2009)

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www.york.gov.uk

www.stleonardshospice.org.uk

www.mcpcil.org.uk/liverpool-care-pathway

www.nice.org.uk

Appendix 1

Public Awareness & Consultation Event

End of Life Care Services

Friday 28 August 2009 - City Mills, Skeldergate York

Programme

- | | |
|---------------|---|
| 10.30 – 11.15 | The Liverpool Care Pathway in York Hospital, Emma Taylor, End of Life Care Facilitator, York Hospitals NHS Foundation Trust |
| 11.15 – 12.00 | Services from Macmillan Cancer Support, Ruth Wilson, Macmillan Community Network Development Coordinator |
| 12.00 – 12.30 | Support from City of York Council Social Services, Richard Tassell, Operations Manager, City of York Council Social Services |
| 12.30 – 12.45 | Tea / coffee & cake |
| 12.45 – 13.00 | NHS North Yorkshire & York and City of York Council Social Services End of Life Care Strategy – Liz Vickerstaff, Senior Commissioning Manager, NHS North Yorkshire & York |
| 13.00 – 13.30 | Discussion and recommendations for the future |

Appendix 2

Response from a York resident after a letter from York LINK's vice chair was published in the York Press (24th March 2010) asking for feedback about experiences (good or bad) of end of life care services in York.

“ My close relative was in York Hospital for many weeks during 2009 suffering from an internal abscess, septicaemia and MRSA. He was also diabetic. In November the doctor at the hospital said that my relative had reached a ‘plateau’ and would have to leave hospital and go into a nursing home. We were able to have him admitted to Fulford Nursing Home. They treated him with kindness and did all they could to make him comfortable. Unfortunately he was only there for five days before he was re-admitted to York Hospital suffering from pneumonia. We dearly wished that he had been admitted to Fulford Nursing Home much sooner and at least he would have received comfort and care in the last weeks of his life.

There were untoward incidents in the period that my relative was in York Hospital, but there were also positive aspects to his care. We found that general attitudes towards patients were often uncaring, although some of the nurses did help as much as possible. My relative was aware of what was taking place, but he did not complain very much. Occasionally he became upset and exasperated by the way in which he was treated. Some of the staff were quite rigid in their working methods, e.g. sick and elderly patients had to wait for attention if meals were being served. If staff were doing the final bed change in the evening, they would insist on doing everything in a certain sequence, even if a patient needed attention, the patient had to wait.

The separate room that my relative was in was not very warm, especially as the cold winter weather set in. When I visited I needed to keep my overcoat on. My relative was always supplied from home with warm clothing, including jumpers and pyjamas, but often he was wearing none of these things, but just an incontinence pad and a skimpy, short sleeved cotton top (hospital issue). Consequently he often felt cold. This way of dressing a patient may have been an easy method of dealing with patient care, but it did not make the patient warm and comfortable. The food was often unpalatable and eventually we needed to take food in to persuade him to eat.

His next of kin was treated shabbily when she tried to obtain information about his illness. She struggled with this problem the whole time he was in

hospital until his death. When she spoke to a nurse she was often told that he was 'fine', when this was clearly not the case. The same answer usually came over the telephone. If he had been particularly unwell the previous evening, she tried to phone the ward the next morning. It often took at least six attempts to get through to the ward, and when an answer was finally obtained, it was vague and lacking in information. If she enquired on the ward, the nurse often said she did not know anything or that she had 'just come on duty' or that he 'was not their patient'. No attempt was made to find out what the situation was. A request for an interview with the consultant was granted and although he explained something of my relative's illness he did not mention MRSA.

I do not believe that we were alone in our difficulties with communication. I often heard relatives trying to speak to staff and not receiving satisfactory answers. On Christmas day 2009 we were at the hospital from mid afternoon until 8pm. My relative was not fully conscious, but a nurse came to take his blood sugar reading. We objected to this being done at that stage in my relative's life but the nurse said it was 'protocol' and went ahead and took the sample. Although my relative was on his own in a separate room, no other staff came to see him or talk to us. We did not get any advice about his condition and we did not know what to do. We left him reluctantly. When his next of kin took hold of his hand it was covered in blood. This was the last time we saw him. The hospital phoned the next morning at 6.30am to let us know that he had died at 6.15am. We did not go back to the hospital, we were too upset to do this.

We did not know what to do or where to turn for help and advice in my relative's last illness. We did wonder if it would have been possible for him to be admitted to St Leonards Hospice but we did not know if it was feasible, or how to take steps to find out. I consider that lack of communication is a big problem for patients and relatives. If a proper system of communication was put in place I think that this would help to clear many problems."



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