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1. Foreword

In England, about 1,300 people die every day. Around 900 of them will have wanted to die at home, but less than half will do so. Some 975 may have needed palliative care to relieve suffering but 469 will not have received it (Dying Matters Coalition 2010). At this moment, about 25% of all hospital beds are occupied by someone who is dying. The National Audit Office estimates that at least 40% of those people have no medical need to be there.

Most of us now live longer than ever before. However, increasingly more of us, as we age, will live with the consequences of chronic conditions that can have a debilitating effect on our health and general well-being. As the population of older people in Milton Keynes increases in coming years, so too will the prevalence of long term life limiting conditions such as dementia. Good quality palliative and end of life care will be important to us all.

People’s preferences regarding place of death were summarised within the 2008 National End of Life Care Strategy, in that “most people would prefer to be cared for at home, as long as high quality care can be assured and as long as they do not place too great a burden on their families and carers”.

We now know that where a patient has a plan in place, and everyone who is involved in the care of that patient knows about that plan, s/he is much more likely to die in their preferred place. Good community support can realise 70% of deaths at home and halve unplanned hospital admissions (National Council for Palliative Care/dying Matters Coalition 2011). To achieve this, requires a cultural and behavioural shift in how end of life care is perceived and in how it is delivered.

The overall aim of this strategy is to raise the profile and importance of choices in death and dying across all care settings and disease groups, by opening up discussions which consider care settings, treatment, communication and support for those bereaved.

The strategy outlines the proposed improvement of end of life care for all patients through the integration of services, working towards standards of good practice over the next four years.

Key stakeholders make up the membership of the End of Life Care Strategy Group, and we are committed to ensuring that the people of Milton Keynes have access to high quality end of life care, irrespective of their condition, or where they live.

Mick Hancock

Assistant Director for Joint Commissioning
2. **Executive Summary**

A working definition for End of Life Care has been developed by the National Council for Palliative Care (2009):

End of life care is care that helps all those with advanced, incurable conditions to live as well as possible in the last year of life. 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 physical care, management of pain and other symptoms and provision of psychological, social, spiritual and practical support.

End of Life Care generally describes the period 12 months before death, this being marked by a progressive deterioration of a person’s condition which can vary depending on the particular disease trajectory. It can be identified by using the ‘trigger’ question – ‘would I be surprised if this patient died within the next 12 months?’

Health and social care services for people with end of life care needs have improved considerably over recent years. The work of the hospice movement has provided an important impetus for this, as has the development of creative partnerships between public, independent, community and voluntary sector organisations, working together to design, develop and deliver services. As people live longer, and with the increasing prevalence of chronic conditions, it is essential that health and social care services collaborate further to meet the challenge of planning and delivering high quality palliative and end of life care for increasing numbers of patients and clients in Milton Keynes.

This strategy provides a vision and direction for service planning and delivery, and will be implemented by the End of Life Care Strategic Implementation Group. This Group consists of representatives from all relevant stakeholders including the public; clinicians; health and social care providers and commissioners; and independent and voluntary organisations.

This strategy builds upon a large amount of work that has already been undertaken in Milton Keynes, for example, implementation of the Liverpool Care Pathway (LCP), Advance Care Planning (ACP) and Gold Standards Framework (GSF).

For the purpose of this strategy, End of Life Care encompasses:

- Adults with any advanced, progressive, incurable illness
- Care given in all care settings, including a person’s own home
- Care given in the last year of life
• Patients, carers and family members, including care given after bereavement

Driving the service improvement expectation of this strategy, requires ownership and leadership from across all areas including clinicians in all settings/sectors, commissioners and providers in partnership with the public, patients and carers. The roles of public, independent, community, and voluntary sector organisations, and the collaborative arrangements that exist between them are essential to end of life care. The strategy reinforces the need to continue to strengthen these creative partnerships, through local and regional infrastructure and strategic planning.

The strategy builds upon the work of existing services within Milton Keynes such as the hospital palliative care team, community services (e.g. District Nursing), General Practice and hospice services. It recognises the need to implement recommendations made within the National End of Life Strategy (2008) and local End of Life Care Baseline Review (2007).

The key objectives of this strategy are to embed the recommendations from the National End of Life Care Strategy into Milton Keynes services, focusing on the following:

• Promote the use of Advance Care Planning to enable people to state their end of life care wishes and ensure they are adhered to.
• Ensure high quality end of life care.
• Change the perception of “Death is failure” to “A good death is a successful care outcome”.
• Develop transparent processes for access to rapid response 24/7 end of life care.
• Ensure health and social care professionals have access to appropriate and high quality training and education.
• Improve the coordination of end of life care between varied providers.
3. **Introduction**

This End of Life Care Strategy was developed in collaboration with Milton Keynes statutory and voluntary partners and local stakeholders, and sets out a vision for high quality care across Milton Keynes for all adults approaching the end of life. It is owned jointly by the End of Life Care Strategy Implementation Group.

The strategy dovetails with national and local strategies and reviews, including the National End of Life Care Strategy 2008, and the overarching Milton Keynes Joint Strategic Needs Assessment 2012.

The purpose of this strategy is to respond locally to the National Strategy for End of Life Care, and to commission and develop services for patients with end of life care needs, regardless of diagnosis.

This strategy will be implemented through the End of Life Care Strategy Group and is supported through the Joint Palliative Care Group (JPCG) and networks of local partners and stakeholders. The group will report to the Long term Conditions Programme Board.

An Implementation Plan supports implementation of this strategy and details the actions required to actively improve end of life care in Milton Keynes and ensure this improvement will continue sustainably. (see appendix 1)

For each area of focus, achievable objectives and targets have been set with appropriate timescales. These are outlined in the Implementation Plan which was produced following the launch of the Milton Keynes End of Life Care Strategy and consultation with support groups. These objectives and targets are continuously reviewed and updated to ensure end of life care continues to reflect and develop in line with public and stakeholder needs and wishes.

4. **Vision and Principle Objectives to Deliver Improvements for End of Life Care**

The Strategy Group’s vision is for everyone to have the best possible end of life experience, ensuring people are treated, wherever possible:

- As an individual, with dignity and respect
- In familiar surroundings
- In the company of family and/or friends if they wish
- To ensure that people have their psychological, spiritual and religious care needs assessed and met
• To ensure that pain and other symptoms are managed as effectively as possible.

The Strategy Group’s principle objectives are to:

• Increase public awareness and discussion of death and dying: This will make it easier for individuals to discuss their own preferences around end of life care and should also act as a driver to improve overall service quality
• Ensure that all people are treated with dignity and respect at the end of their lives
• Ensure that pain and suffering amongst people approaching the end of life care is kept to an absolute minimum
• Ensure that all those approaching the end of life have access to physical, psychological, social and spiritual care
• Ensure that people’s needs, priorities and preferences for end of life care are identified, documented, reviewed, respected and acted upon wherever possible
• Ensure that the many services people need are well coordinated, so that patients receive seamless care
• Ensure that high quality care is provided at the end of life, and after death
• Ensure that carers are appropriately supported both during a patient’s life and after bereavement
• Ensure that health and social care professionals at all levels are provided with the necessary education and training to enable them to provide high quality care
• Ensure that services provide good value for money for the taxpayer.

5. Scope

The scope of this strategy encompasses:

• Care provided in all settings (e.g. home, residential/care home, nursing home, hospice, acute hospital, prison or any other institution)
• Care provided to adults with any advanced, progressive, incurable illness
• Care given in the last year of life
• Patients, carers, the public, family members and staff (including care after bereavement)

Health and social care professionals recognise the importance of End of Life Care services for children and their families. A draft strategy for children’s services is currently under review.

End of Life Care will also need to be commissioned across a number of other locations, for example, hostels for the homeless.

The National Audit Office (NAO) Report on End of Life Care found from its study of Sheffield that about 40% of those who died in hospital had no medical need to be there, and could have died elsewhere had support been available.

The NAO’s Sheffield study also estimated that if those patients with no need to be in hospital had been discharged, that would have released £4.5m pa for the PCT to invest in community-based end of life care services.

The National Confidential Enquiry into Patient Outcome and Death (NCEPOD) in 2009 looked at the care of patients who died in hospitals within four days of admission. The report describes the challenges for services, particularly doctors in making the transition from saving life to allowing natural death.

The NCEPOD report identifies that “there was a lack of awareness of staff to the needs of patients nearing the end of their lives. The skills which were particularly lacking were the abilities to identify patients approaching the end of life, adequate implementation of end of life care and the ability to communicate with patients, relatives and other health care professionals”.

Patient and family satisfaction are an important consideration as the Healthcare Commission found in 2007 nationally that 54% of serious complaints in acute hospitals involved end of life care and bereavement.

This strategy must be delivered in the face of unprecedented financial challenge. In November 2009, the NHS Chief Executive announced that, in response to the economic downturn and increasing demand for healthcare, the NHS would need to deliver between £15 and 20 billion of efficiency savings per year by 2013-14 to be reinvested in health services. Around 40 per cent of these savings are expected to come from driving efficiency in hospitals. To support NHS organisations to improve quality of care while making these savings, the NHS Chief Executive also launched the national Quality, Innovation, Productivity and Prevention (QIPP) challenge (DoH 2010). NHS Milton Keynes has a QIPP target of £104m to be delivered by 2014/15. Over the same timeframe, Milton Keynes Council must save £40m.

Lord Darzi’s 2008 report High Quality Care for All sets out the vision for an NHS working in partnership to provide care that is personal, effective and safe. The themes promoted in Lord Darzi’s report of patient empowerment, greater choice, better information, more control and influence underpin this end of life care strategy.
Whilst the National End of Life Care strategy provides a generic view and steps to achieving high quality end of life care, it also recognises that locally the detail will differ in response to the needs of local populations and provider landscapes.

7. Local Context

I. Commissioning of End of Life Care

Currently, the Milton Keynes Clinical Commissioning Group (MKCCG) commissions all health based End of Life Care services in Milton Keynes. Contractual relationships exist with GPs, the Hospital Foundation Trust, the South Central Ambulance Service, Willen Hospice and Milton Keynes Community Health Services.

In relation to End of Life Care, MKCCG has the following commissioning intentions:

- To develop a commissioning strategy for End of Life Care services, consistent with national policy that reduces the number of people dying in hospital and increases the number of people dying in their preferred place.
- Review the process for accessing fast track funding for end of life care to ensure no delays in securing both the funding and the accompanying placement.
- Review the breadth of services available to support people at the end of their life and commission appropriate support.
- To procure and embed a locality wide electronic palliative care register

II. Organisational Change

From April 2013 changes outlined in the Department of Health’s 2010 White Paper “Equity and Excellence: Liberating the NHS” mean that local health care commissioning responsibilities will be transferred from the Primary Care Trust to local Clinical Commissioning Groups (CCGs). In addition, Strategic Health Authorities will be disbanded and their roles will pass to Health and Well Being Boards. Local Authorities will have a local strategic performance and control function across health and social care through the Health and Wellbeing Boards.

The Milton Keynes End of Life Care Strategy Group has the correct representation to ensure the implementation of this strategy remains on course throughout this period of unprecedented organisational change.

III. Deaths in Milton Keynes
In 2006, the Milton Keynes age standardised death rate was lower than the rate in England and Wales for the first time in a decade.

<table>
<thead>
<tr>
<th>Average deaths per year in Milton Keynes (all causes)</th>
<th>1,488</th>
</tr>
</thead>
<tbody>
<tr>
<td>Proportion of male deaths</td>
<td>47.7%</td>
</tr>
<tr>
<td>Proportion of female deaths</td>
<td>52.3%</td>
</tr>
</tbody>
</table>

Source: Public Health Service from Hospital Episode Statistics (HES)

From the 1,488 deaths in Milton Keynes each year, a third are attributable to people less than 75 years old. The leading causes of death in Milton Keynes are the same as those in the country as a whole; circulatory diseases (especially heart disease and stroke), cancer and respiratory disease. Death rates from the major killers, especially heart disease, are falling in Milton Keynes, but the city has higher than average rates of respiratory deaths (chronic obstructive respiratory disease, lung cancer and pneumonia).

The 1,488 deaths equate to 4 people a day. Approximately half of these people die in hospital.

If national statistics were applied to these deaths then this would indicate that approximately 5 people a week die in Milton Keynes Hospital, who had no medical need to be an inpatient at the time of death.

8. **Current End of Life Care Provision and Development Needs**

There are a number of development needs identified across the end of life care pathway in Milton Keynes. For example, there are some inequalities in access to some end of life care services.

Further consultation needs to take place to review the potential for ongoing improvement.

All representatives on the Strategy Group are committed to improving service quality. A selection of individual team / organisation’s current arrangements and plans are detailed below:

I. **General Practitioners**

The following statement quoted from the RCGP End of life Strategy represents the GP’s vision for end of life care:

“Caring for people nearing the end of their lives is part of the core business of General Practice. The GP and the primary care team occupy a central role in the delivery of end of life care in the community. This role is greatly valued by patients and remains pivotal to
the effective provision of all other care. The importance of the holistic role of the family
doctor is poised to come into its own in a way never previously encountered... This strategy
affirms the College’s commitment to promote excellence in end of life care.” (RCGP End of
Life Care Strategy June 2009).

In Milton Keynes the GP works with all teams that deliver End of Life Care, in particular
with District Nurses, the Willen team and when necessary Secondary care. Often the GP is
the face that the patient has known longest and thus has built up trust in that relationship.
Practices keep a register of their patients who have a terminal prognosis and meet
quarterly with the team involved with patients care, to discuss the management of these
patients.

Milton Keynes Clinical Commissioning Group intend to identify a GP lead for End of Life
Care to support and advise GPs in new developments, service changes and dissemination
of information about resources available that are not directly related to health such as
financial support that are of concern to patients and their families.

II. Age UK Milton Keynes

Assisting people in later life to deal with issues that affect their well being and quality of
life is at the core of Age UK Milton Keynes activities. We help, support and encourage
older people to make informed choices and make decisions about their lives and none is
more important than their wishes and preferences about their end of life care.

It is our intention to provide training and guidance to our workforce to ensure they have
the necessary skills and confidence to raise this usually sensitive subject when appropriate.
We will engage with older people and work with them to ensure they have the information
and advice they need to make choices that are right for them. We will also work with
carers and families should the need arise. We will ensure end of life care planning and care
is regularly discussed at team meetings to keep it on the agenda of our workforce.

III. Milton Keynes Hospital NHS Foundation Trust MKHFT

Several developments in palliative and end of life care have taken place in Milton Keynes hospital:

- The palliative care Advanced Nurse Practitioners are aligned to each of the in patient
  wards and other areas such as the emergency department and department of critical
care so that they can offer intervention as early as possible in the terminal phase of
life without waiting for formal referrals. They are also there to facilitate support and
education to medical and nursing staff, such as communication about death, dying
and preferred place of care; use of syringe drivers; pharmacological knowledge;
using the Liverpool Care Pathway
- From March 2012 the hospital will have a palliative care service at weekends, which will provide out of hours advice and review of palliative and end of life care patients admitted at weekends.
- There is a new patient information leaflet that describes what the palliative care team does, what it can offer the individual patient, and what they can expect to receive from our service as a minimum.
- An updated Liverpool Care Pathway (LCP) with a step-by-step flow chart and prescribing process with medication recommendations for symptom control.
- A performance target that 70% patients who die in Milton Keynes hospital do so with an LCP in place as a best practice standard.
- The palliative care Advanced Nurse Practitioners are all commencing post registration education to become independent prescribers so that they can ensure patients receive appropriate medication.
- The palliative care consultant is completing a comprehensive guidance document on symptom control and management of the palliative and end of life care patient.
- The hospital is embarking on an exciting partnership with Guys and St Thomas’ hospital to pilot a project called AMBER that supports early identification of patients at risk of dying in the next two to three months and plan with them and their carers future care including preferred place of care. Initial results from Guys and St Thomas have been very promising. It is hoped that the successful implementation of AMBER in Milton Keynes hospital will support best practice in end of life care and also support patients and their carers in achieving their preferred place of care at the time of death.

IV. HMP Woodhill MKCHS

The healthcare team at HMP Woodhill is in the process of developing a Palliative/End of Life Care Policy. When a prisoner is dying, the healthcare team work closely with the Specialist Palliative Care teams at MKGH and Willen to ensure high quality care is delivered. The Liverpool Care Pathway is initiated as appropriate, in accordance with the guidelines. Further work is planned on the End of Life Care Pathway and LCP to ensure that all staff are competent and able to implement the above policy. HMP Woodhill are looking to work with Specialist Palliative Care Teams to develop this important work.

V. Milton Keynes Council Adult Social Care

The Older People and Physical Disability Service is striving for improved communication and joint working with significant partner agencies to ensure that all barriers to timely, effective and acceptable assessment of eligible social care needs and provision to meet
these needs are eliminated. We recognise the importance of joined up working and will be represented on the End of Life Care Strategy Group by the Manager of our Community Social Work Team in order to facilitate this.

VI. Neurological Conditions Team MKCHS

End of life care and advance care planning, including preferred priorities of care, for people with neurological conditions is actively considered for individuals, as appropriate, proactively supported by individual clinical specialists within the neurological conditions clinical specialist team. The team is keen to maintain and build upon their existing provision and continue to develop and improve upon the end of life care for people with neurological conditions, ensuring the needs of this group are recognized and supported, at all levels. Future plans will look at bereavement care for carers of people within this patient group. The team is keen to maintain and improve upon the close links with the End of Life care team and palliative care services in Milton Keynes and promote collaborative working to ensure the best care possible is achieved. The team members will continue to use the ADRT guidelines for relevant individuals in conjunction with the preferred priorities of care documentation. The team will continue to commit to provide ongoing education in relation to end of life care provision in neurological conditions and act as a resource for other professionals as required.

Currently the neurological conditions clinical specialist is available on a part-time basis only, which has led to ongoing capacity issues especially as the patient group covered often have rapidly deteriorating conditions which need to have high levels of support, which cannot be planned for. This at times results in difficulty providing the level of service within the hours provided.

VII. Willen Hospice

The multi-disciplinary team at Willen Hospice are delighted to be part of this innovative strategy. Hospice staff are committed to working collaboratively with partners in the Local and Regional Health Care economies focussing on promoting excellence in palliative care and end of life care.

The hospice is in the process of developing our Bereavement Service with funding from Macmillan Cancer Support. By incorporating our Chaplain into the newly formed Social and Spiritual Care Services it is envisaged that more input from our team will take in pre-bereavement phase of our patient’s pathway in order to provide a seamless service during the most difficult time for the families in our care. Under the direction of our new Social Care Manager a new Bereavement Support Group has been formed in addition to sessions such as ‘A Time to Remember’ offering care and support.

In February, 2011, the hospice launched our Practice Development Initiative – the key components of which are Service Improvement and Quality, Audit, Research and
Education. It is envisaged that our new education strategy will be a valuable resource to our colleagues in a variety of health care settings.

VIII. Carers MK
Carers Milton Keynes is able to offer one-to-one support for family members who are looking after someone at the end of their life. The service provides information, financial advice, and advice for working carers, advocacy, therapies and social events. Emotional support is offered both on a one-to-one basis and in group settings. This support continues for as long as it is needed and includes support for former carers. Working with carers at this difficult time affords the service an insight into what carers need to help them. By participating in a special ‘carers work stream’ as part of the End of Life Care Strategy Group we hope to improve the way in which all services work with family carers, treating them as Equal Partners with the professionals.

IX. District Nursing MKCHS
The District Nursing service welcomes this strategy. District Nurses work closely with our partners across Milton Keynes to provide quality care and support to patients and carers in their own homes. Many of the tools for EoL are now embedded into the service which has enabled a consistent approach to care. District nurses work closely with those with palliative care needs, this relationship is crucial to enable patients to make informed decisions about their care. The service has recently appointed a professional development nurse and one of their roles will be the development of a training programme of core skills for nurses working in the community. Palliative and EoL care will be key components of this programme.

X. South Central Ambulance Service NHS Foundation Trust
South Central Ambulance is committed to provide a high level of service to ensure that Patients, their Families and carers requests are respected as they reach their end of life. The Trust in conjunction with the South Central Strategic Health Authority has worked collaboratively to develop an action plan to embed End of Life into its structure and Trust policies. The Trust has an End of Life Care lead in post that has a strategic overview for all areas of the Trust and engages with the Area Management Teams to ensure there is a link to external stakeholders within their own localities. This will enable the Trust and its Area Management teams to meet the requirements of the population in the diverse and multicultural areas that it serves.

XI. Milton Keynes Urgent Care Services MKUCS
Milton Keynes Urgent Care service aim to support patients requiring end of life care by ensuring any plans already in place are carried out to support the patient with symptom management and their choice of place to die. MKUCS liaises with community teams, patients and relatives to provide GP support out of hours. MKUCS maintains special patient’s notes to provide our clinical team with as much information regarding a patient’s condition as possible. We aim to further develop our nursing team so we can provide nursing support for particular situations in patients homes in the out of hours period.

XII. End of Life Care Clinical Psychology Service MKCHS
The service provides highly specialist clinical psychology interventions to patients at the end of their lives and their families. In addition, the service also provides training, supervision and consultation to staff. The service aims to continue to provide individual and couple therapy in a timely and responsive manner, to develop the programme of training offered and to provide increased opportunities for staff supervision.

9. End of Life Care for People with Dementia
In March 2012 the Prime Minister announced plans to make the UK a world leader on dementia. The Dementia Challenge Programme aims to deliver major improvements in dementia care, dementia awareness and dementia research by 2015. The specific actions set out in the Prime Minister’s challenge include improving end of life care for people with dementia.

People with dementia who are dying should have the same access to end of life care services as those without dementia. However, treatment decisions for people with dementia differ from decisions for other people approaching end of life, in two ways.

- The time from diagnosis to death is usually much more difficult to predict and dementia may last several years, or just days because of concurrent illness.

- The deterioration in communication skills for people with dementia prevents them from expressing their views and wishes later in the disease pathway.

It is important that people with dementia and their carers receive information and support that helps them think and plan early for future care. Therefore, health and social care providers should ensure that early diagnostic and assessment services for people with dementia are available, and that they provide good quality information about dementia.

A considerable transformation programme in relation to the diagnosis and treatment of those with dementia in Milton Keynes is currently underway, with the implementation of a memory
screening clinic and an ageless dementia service. Refocusing services to enable more
diagnosis, treatment, care and support in primary and community services requires a trained
workforce. Current dementia work streams include a full care pathway review and the
coordination of a local workforce development plan.

End of life care will of course be pivotal to these work streams. In developing the ideal journey,
certain elements have been identified as being of particular importance to achieving good
quality care and experience:

- Early diagnosis of dementia and sensitive communication with the person and their family
to enable them to make the necessary plans and advance decisions for their future.
- Effective signposting to appropriate services as necessary and appropriate
- Adoption of a palliative approach from the point of diagnosis, utilising multi-disciplinary
tools and documentation, that leads to the acknowledgment of the dying phase and
implementation of the associated appropriate care
- Increase choice for people with dementia by supporting them in their preferred priorities
for care (PPfC) through the implementation of advance care planning (ACP)
- Improve recording of the presence of dementia on death certificates to enable more accurate data
collection and an understanding of the level of need.

10. Financial Issues

I. Investing in success

Achieving the aims and objectives of this strategy requires a re-examination of the financial
investment in end of life care. To advance a strategic approach to investment there must be
greater engagement in discussion about death and dying across the Milton Keynes population;
improved communication; better provision of operational and financial information; the
establishment of an end of life pathway; improved community based end of life care and
support; and greater IT interaction to identify and support the coordination of care to end of
life patients. This approach will enable service gaps to be filled and duplication of response to
be removed, leading to more efficient use of resources.

In June 2011 the Audit Commission reflected that whilst national strategies have tasked
commissioners with appropriately shifting resources from hospital to community settings for
several years now, little has in fact changed. The Audit Commission concluded that this was
due to the difficulties involved in making this change happen and that successfully shifting the
care location from the hospital to the home when appropriate required sustained and well co-
ordinated cross organisational efforts. In Milton Keynes the End of Life Care Strategy Group
will be responsible for driving through the changes needed to operational pathways and cost profiles.

Using the ‘Potential cost savings of greater use of home and hospice based end of life care in England 2008’ Audit Commission and the Acute Hospital Beds Admissions data, for the 1488 deaths per annum an estimated £2,819,333 per annum is attributed to Milton Keynes 789 hospital deaths.

II. Future Financial Model Changes
Within Adult Social Care, Individual Budgets are becoming increasingly common and Personal Health Budgets are to be implemented from April 1\textsuperscript{st} 2014 for patients who receive Continuing Health Care Funding.

The End of Life Strategy Group will retain a watching brief on any potential developments during the 2012 to 2015 period and plan for these accordingly.

11. Demography Considerations
The need for ever improving and more cost efficient end of life care is further highlighted by the Milton Keynes over 80 years of age population projections. The number of people in this group is expected to rise by approximately 16% over the next four years and double by 2026 to 14,400 from the 2010 level. As the population lives longer, the proportion of people with various long term conditions continues to rise and the End of Life Care pathway needs to adjust to these changes appropriately.

The services implementing the strategy will take account of the increasing ethnic diversity of people in Milton Keynes and the considerable life expectancy variations between the most affluent and most deprived parts of the borough.

12. Improved Communication / Public Awareness of End of Life Services
The national strategy recognises that as a nation we face multiple challenges in responding to the needs and preferences of people who are approaching death. Focus is therefore clearly placed on improving and changing the way in which we respond to end of life care and how we communicate difficult news and information. This strategy acknowledges the need to develop new approaches and initiatives which can initiate a cultural change and enable patients, friends, relatives and carers of patients approaching the end of their life’s to openly discuss their personal needs and preferences and choices.
Part of the process of achieving this outcome must come from on-going consultation, information, debate and discussion with the citizens of Milton Keynes. The subject of death and dying remains a taboo nationally and it will take time for the population to accept and change its perspective. Locally we recognise that we face a challenge to raise awareness about end of life care and the support available; however we believe we can initiate change through a coordinated and systemic response. Access to information, emotional support and advice will be integral part of high quality end of life care for both patients and carers. Increased awareness, improved communication workforce development and coordination of care are all key areas requiring action.

13. Workforce Implications

Workforce development plays an integral role in the delivery of high quality, responsive end of life care. As part of both national and local reviews it has been recognised that there are major deficiencies in the knowledge, skills, attitudes and behaviours of staff groups who come into frequent contact with people at the end of their lives. Issues for improvement identified by the Learning and Development leads for the PCT, Foundation Trust, Hospice and End of Life Care Strategic Group, include recognition of last year of life, training on advance care planning, breaking of bad news, recognising symptoms for palliative care, recognising symptoms of imminent death, accessing and using assessment history, pathway and services information for staff and patients and carers.

In response to these shortfalls, we have begun to identify current and future training needs in line with the national strategy guidance and workforce development framework. This work will inform and influence the development of a combined Workforce Development plan across the PCT, Foundation Trust, Hospice and Council and the commissioning of induction, awareness and specialist training programmes.

14. End of Life Care Tools

The National End of Life Care Programme reinforces the need to offer all adult patients, nearing the end of life, regardless of their diagnosis, the choice and access to high quality end of life care. To achieve this, three key tools are recommended for implementation:

   I. The Gold Standards Framework (GSF)
   II. Liverpool Care Pathway for the Dying Patient (LCP)
   III. Advance Care Planning (ACP)

I. Gold Standards Framework (GSF)

The GSF provides a framework for a planned system of care in consultation with the professional, patient and their family. This tool enables the development of a system to
improve the organisational quality of care for patients in the last year of their life in the community. It is to ensure that people live well until they die. The GSF is not a prescriptive model but a framework that can be adapted to local needs and resources. A supportive register should be compiled by each General Practice or care home to include patients identified as having end of life care needs.

GSF enables those approaching the end of life to be identified, their care needs assessed, and a plan of care with all relevant agencies put in place. The framework focuses on optimising continuation of care, teamwork, advanced planning, including out-of-hours, symptom control, patient, carer and staff support. The GSF has an anticipatory approach to care and that improved planning of a proactive, coordinated care and associated communication links with all those involved with the patient should avert unnecessary hospital admissions.

II. Liverpool Care Pathway (LCP)

The LCP is an evidenced based, quality improvement framework for the delivery of appropriate care for dying patients and support to their family and friends. It should be used for patients in the final days/hours of life and encourages a multi-professional approach to delivery of care. Care is focused using a holistic approach to enhance the physical, psychological and spiritual comfort of patients and their families. This tool helps to empower generalist staff to deliver high quality standardised end of life care that can be audited.

III. Advance Care Planning (ACP)

An ACP ensures the process of planning for any possible health care decisions that may arise in the patient’s future, which particularly relates to End of Life Care.

ACP is a discussion between an individual and their care providers irrespective of their discipline, and with the patients consent, family and friends can be included. The process of the ACP is to make clear a person’s wishes when there is an anticipated deterioration in the individual’s condition in the future. The ACP covers an individual’s preferences, wishes and beliefs about future care to be a guide for future best interest decisions in the event that an individual loses capacity to make decisions. All discussions must be documented, reviewed regularly and communicated to all involved in the patients care. It includes:

- Individual concerns
- Important values or personal goals for care
- Their understanding about their illness and prognosis
- Their preferences for care and treatment that may be beneficial in the future and the availability of these
To be most effective, the records taken as part of ACP must be available to all appropriate health and social care professionals in a timely manner. This is best achieved by an appropriate end of life care software system that can be available across hospital, hospice, GP and community based care settings, and which is fully utilised by relevant professionals as part of their standard working practice. Such a system does not currently exist within Milton Keynes. A review of potential software packages will form part of the Implementation Plan.

15. **Strategy Implementation Plan**

An Implementation Plan has been constructed by the End of Life Care Strategy Group. It outlines the prioritised actions to be implemented within the next three years.

The Implementation Plan takes into account the responses from the summer 2012 public consultation on the strategy itself.

The Implementation Plan includes details of the prioritised actions; the groups of people who will be involved; and the timescale of implementation.

The Implementation Plan will be reviewed annually and amended where necessary to ensure that the actions put in place will achieve sustainably high quality care.

To help with the formal implementation of the strategy, the Department of Health Quality Markers will be used to review commissioning and service provision.

16. **References**

Department of Health (2010). Equity and Excellence: Liberating the NHS


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National Institute for Clinical Excellence - NICE (2011) Quality Standards for End of Life Care