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BEDFORDSHIRE END OF LIFE AND PALLIATIVE STRATEGY

FOR ADULTS AGED 18 YEARS AND OVER

2019 – 2022

CONTENTS

Version Control:

Version 1	**Draft Plan developed by End of Life Commissioner**	**April/May 2019**
Version 2-4	**Draft plan updated with comments from commissioning team and BCCG Clinical Lead for EOL**	**May/June 2019**
Version 5	**Draft plan further updated by End of Life Commissioner in preparation for engaging with the Bedfordshire EoL Improvement Group**	**June 2019**
Version 6	**Inclusion of EOL for LTCs in line with Audit outcomes and Safeguarding recommendation from Audit. Additions following comments from colleagues across various organizations – health, social care, voluntary, etc.**	**July and August 2019**

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END OF LIFE STRATEGY ON A PAGE

Vision:

Bedfordshire Clinical Commissioning Group's (CCG) vision is that all patients at end of life, together with those closest to them, are able to express their needs and wishes, and that as far as clinically appropriate and practically possible, these needs and wishes are met.

We are committed to enabling people to live well and die well in the place of their choice and receive quality and personalised care.

Priorities:

To ensure that Bedfordshire CCG's vision is fulfilled and patients receive quality and personalised end of life care, this strategy centres on three main components:

1. **Early identification and explanation for individuals and families**
2. **Advance Care Plans involving the individual**
3. **A system for sharing care plans across care settings in a co-ordinated way**

Evidence suggests that where these three components are achieved, patients and their families feel supported and good palliative and end of life care is delivered which can have a lasting impact on how families and carers grieve. Bedfordshire CCG aims to achieve these through the implementation of this strategy and the subsequent action plans derived from it.

Outcomes:

Key outcomes include:

- **Robust early identification of Bedfordshire residents in the end of life phase**
- **All those identified as in need of palliative and end of life care will be offered the opportunity to have an advance care plan**
- **An operational Electronic Palliative Care Co-ordination System (EPaCCS) system across all providers. EPACS is a web-based electronic register, based on sharing care summaries and plans alongside patients' electronic records, patient portals, and real-time extractions from the SystmOne records of participating organisations.**
- **An increase in the percentage of people achieving their preferred place of care and preferred place of death**
- **A reduction in unnecessary hospital admissions for those receiving end of life care**
- **People supported by health and social care staff trained in Common Core Competences**

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

Dame Cicely Saunders (1918–2005)
founder of the modern hospice movement

1. EXECUTIVE SUMMARY

End of life care affects us all at some point, either experiences with friends, relatives or ourselves. Sadly though, whilst it affects us all, death and dying is often a topic that for many reasons, most of us avoid speaking or even thinking about.

At Bedfordshire Clinical Commissioning Group (BCCG), we recognise that there is such a thing as experiencing a good death. Since death is a certainty, it would be prudent to ensure that the experience for the individual and their loved ones is a good one. At least three quarters of deaths are not sudden but expected, so by commissioning the right services, we can ensure that we prepare, plan, care and support those who are dying and those who are caring for them.

This strategy document outlines how Bedfordshire CCG proposes to do this over the next three years: 2019 to 2022. Furthermore, this will form the basis of detailed action plans produced to deliver the CCG objectives across all its commissioned providers. A Bedfordshire End of Life Care Improvement Group chaired by the CCG Clinical Lead who is a General Practitioner in Bedfordshire and attended by health and social care partners, independent and voluntary sectors and patient representatives will monitor and drive the objectives.

During 2018, 3778 people died in Bedfordshire. The majority of these deaths were in adults aged +85. Looking at trends in data over the next few years, it is expected that the number of deaths each year will increase due to the increase in population of this age group. As such, end of life care will be needed for an increasing number of people across Bedfordshire in the next three years. This highlights the need to increase efficiency and seek to increase capacity for quality End of Life care within existing resources.

In Bedfordshire, a vast range of specialist and general services are commissioned to provide health and social care. Patients and their families access many of these services at the same time, so having a shared strategy, vision and objectives will enable a coordinated, personalised approach which empowers patients to make informed choices about their care. Although challenging, End of Life Care is also one of the most rewarding areas for the professionals involved. We are privileged to be able to support and care for patients and their loved ones at this unique time in their lives. But we only have one chance to get it right.

This strategy outlines a local vision for end of life care to deliver personalised and well-co-ordinated care that empowers patients to make informed choices about their care.

2. INTRODUCTION

This strategy sets out how Bedfordshire CCG proposes to improve the quality of end of life care for those with a life limiting or terminal illness, and support their carers and families over the next three years: 2019 to 2022.

The strategy will form the basis of detailed action plans produced to deliver the Bedfordshire CCG objectives across all its commissioned providers. The Bedfordshire CCG objectives within this plan mirror the ambitions set out within the national document: Ambitions for Palliative and End of Life Care. In developing this strategy, Bedfordshire CCG has worked in partnership with the following organisations who are also engaged in the development of action plans.

- Bedford Hospital Trust
- Luton and Dunstable Foundation Trust
- East London Foundation Trust Community Health Services
- Bedford Borough Council Social Care
- Central Bedfordshire Council Social Care
- Hospices including: St John's Hospice, Keech Hospice, Garden House Hospice and Willen Hospice
- Primary Care
- Community Mental Health Teams
- Independent providers including: Tibbs Dementia Foundation, Age UK.

The scope of the strategy incorporates:

- All adults over the age of 18 years old with any advanced, progressive or incurable illness
- Care provided in all settings including hospitals, care homes, hospices, people's own homes
- Care provided in the last year(s) of life
- Patients, carers and family members.

This strategy will be reviewed annually to ensure that it remains in line with current policies.

3. NATIONAL AND LOCAL CONTEXT AND DRIVERS FOR CHANGE

3.1 National Context

The population of England has increased steadily over recent decades. At the same time the population has also been ageing and in 2017, the percentage of the population aged 85 years and over was 2.7 times greater than it was in 1971.

The number of people aged 85 years and over is expected to increase substantially in the future. In 2017 there were 1.35 million people aged 85 and over in England. By 2023 this is projected to reach 1.54 million (an increase of 14%) and in 2031 (when 'baby boomers' born after World War 2 move into this age group) it could reach 2.01 million.

The ageing population is reflected in the changing distribution of deaths by age. In England and Wales in 1971, deaths among those aged 85 and over made up 15% of all deaths. By 2016 they made up 39% of all deaths.

The size of the population aged 85 years and over is therefore, an important determinant of demand for health and social care as older people have the highest usage.

The number of deaths will increase considerably in the next few years if the population continues to experience recent rates of mortality. If this is the case, it is anticipated that in the year 2023 there will be around 550,000 deaths. That is just over 50,000 more deaths than in 2017, a 10% increase.

3.2 National Strategy

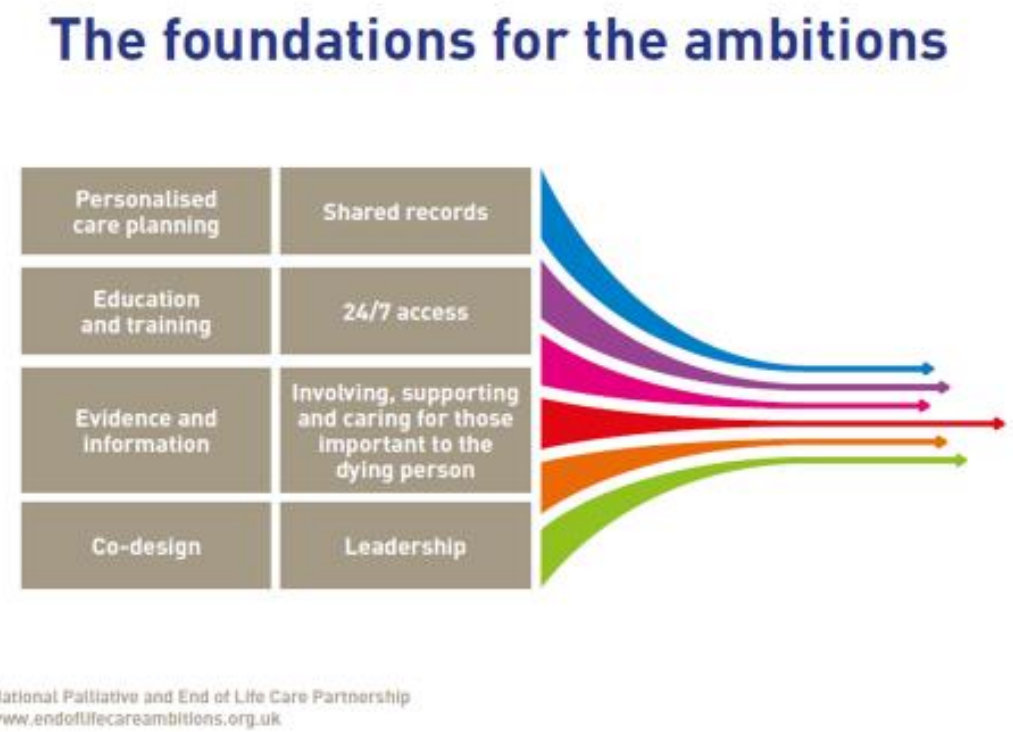
In 2008 the first national strategy for end of life care in England galvanized the health and social care system with three insights: that people didn't die in their place of choice, that we need to prepare for larger numbers of dying people and that not everybody received high quality care.

Since then, the focus on person centered care has quite rightly come to the fore with emphasis on this being reflected in everything we do. This is seen in national strategies, reports, best practice and evidence based national publications specific to palliative and end of life care. Some of these include:

- Every Moment Counts: A narrative for person centred care (March 2015) • The Care Act (October 2014)
- NHS Five Year Forward View (October 2014)
- The Forward View into Action: Planning for 2015/16 (December 2014)
- One chance to get it right (June 2014)
- Actions for End of Life Care (November 2014)
  RCGP End of Life Care Commissioning Guide (April 2013)
- NICE guideline NG31 Care of dying adults in the last days of life
- NICE quality standard for end of life care for adults (August 2011)
- NICE guidance for commissioners on end of life care for adults (December 2011).
- RCGP Daffodil Standards

The most recent publication **Ambitions for Palliative and End of Life Care: A national framework for local action 2015–2020** re-frames all the previous publications within today's local context. The emphasis is on leadership, service delivery and accountability. At its core are six overarching ambitions. These are:

As well as the above ambitions, the national framework emphasises eight principles which are the foundations to build and realise the ambitions. The eight principles are:



These ambitions and principles are very much the focus for Bedfordshire's strategy to ensure alignment to national direction and achieve good delivery of care and support to people and their families.

3.3 Bedfordshire Context

Bedfordshire Clinical Commissioning Group is made up of two place based areas: Bedford Borough and Central Bedfordshire, with both areas governed by different local authorities. Although Central Bedfordshire and Bedford Borough are neighbouring authorities, the two areas are different demographically and in population growth, distribution and needs are not identical. Consequently the response to health and wellbeing requirements for the two populations are likely to be slightly different.

Bedfordshire CCG serves a total population of 487,924 people served by 47 GP practices. In line with the NHS Long Term Plan, Bedfordshire is working with primary care colleges and community colleagues to develop Primary care networks (PCNs). PCNs are groups of practices that collaborate locally, in partnership with community services, social care and other providers of health and care services. They allow practices to continue doing what they do best, while working together to share other services that require additional scale. Going forward, care in Bedfordshire will be provided at a PCN level.

The older population is projected to increase at a much higher rate than those under 65 years of age. The 65 and over population is projected to rise by 17.4% from 2018 – 2025. The 85+ population is estimated to increase even higher by 32% in Bedford Borough and 52% in Central Bedfordshire by 2021. The chart below shows the Bedfordshire population growth.

This increase in the number and proportion of older people within the population will lead to an increase in demand on end of life services not only in the number of deaths but also with the increasing in complexity of needs of older people.

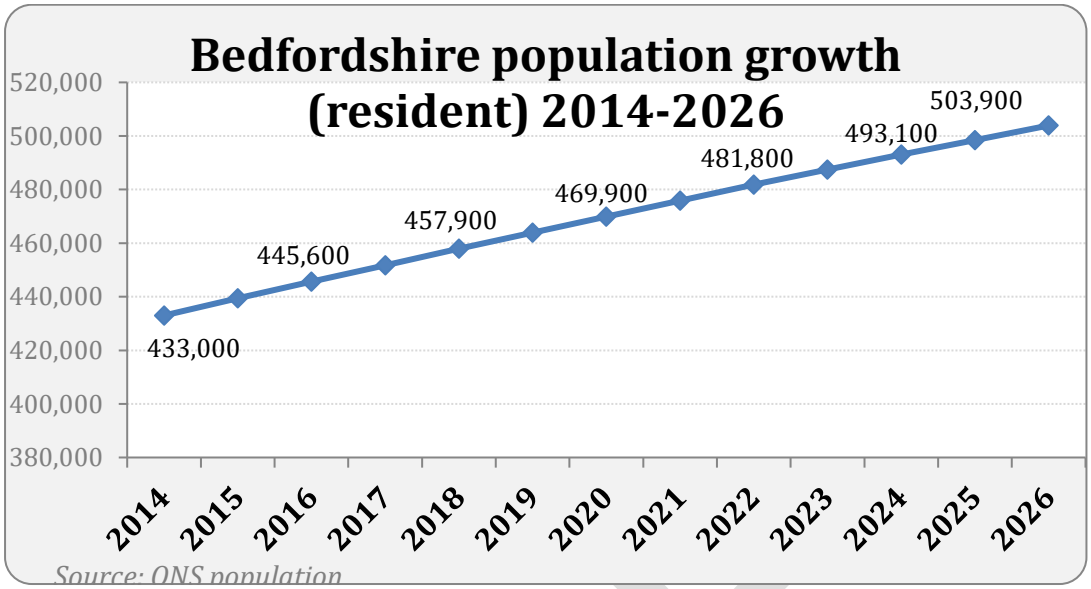


Table showing Bedfordshire population growth and projection between 2014 and 2026.

Life expectancy within Central Bedfordshire is higher than the national average at 81.5 years for men and 83.8 years for women, with the life expectancy of residents increasing at rate of 4.0 years per decade for men and 2.1 years per decade for women. In Bedford Borough average life expectancy for men and for women continues to increase although it is slightly lower than the national average at 79.3 years for men and 83.3 years for women (ONS, 2012-2018).

Across Bedfordshire CCG the number of non-elective admissions for the age 65 plus age groups has been increasing since 2010 with larger increases in the age 85 years and over group.

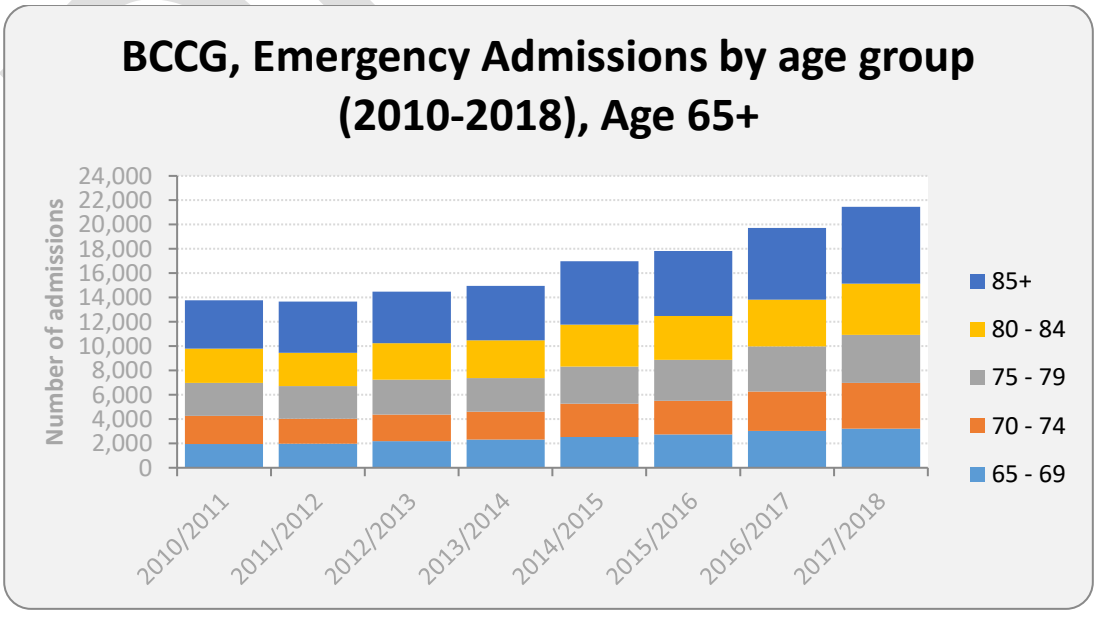
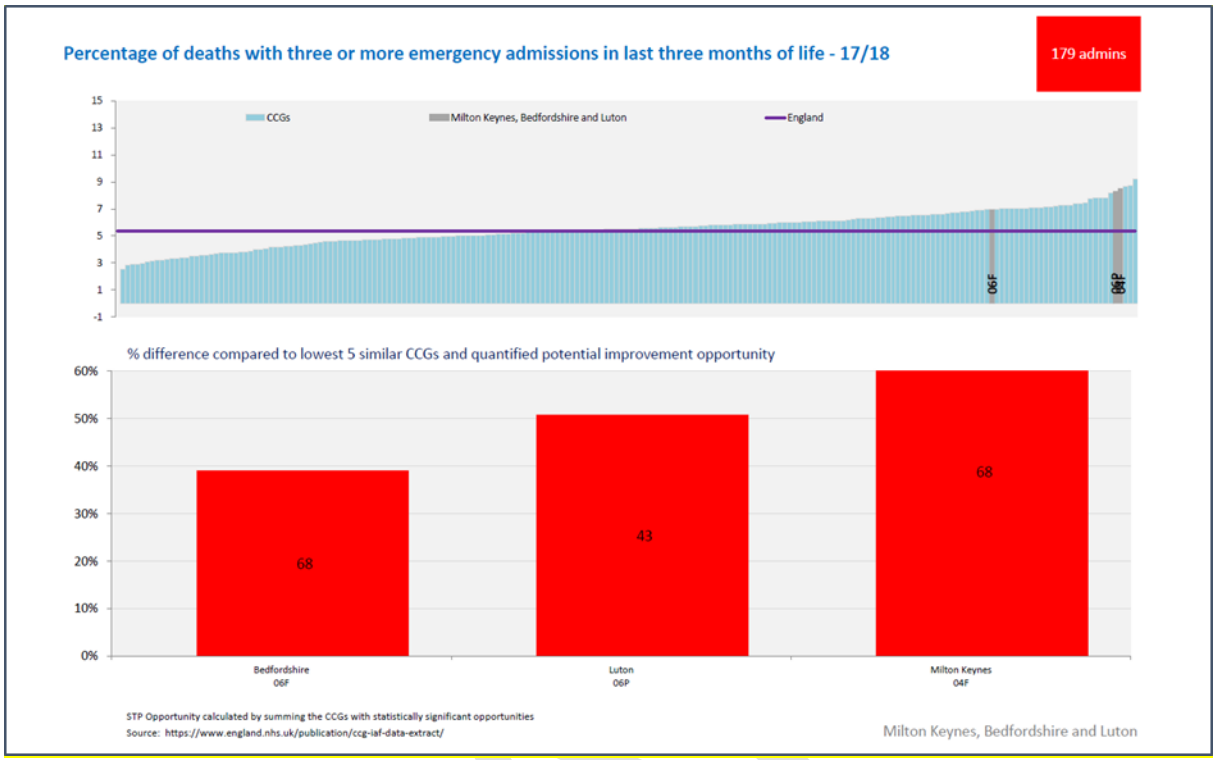


Table showing Bedfordshire Emergency Admissions by age group between 2010 and 2018.



Above tables show the percentage of deaths with 3 or more emergency admissions in the last year of life and the % difference compared to the lowest 5 similar CCGs with quantified potential improvement opportunities.

The major cause of death in Bedfordshire is circulatory disease. This is closely followed by respiratory disease and then by cancer.

Many people receive good quality care in hospitals, hospices, in their own homes and care homes. However it has been identified that one of the biggest challenges in providing end of life care is in helping people achieve their preferred place of death. National survey data suggests that many people (70%) would, given the choice, prefer to die at home, with few wishing to die in hospital.

The proportion of Bedfordshire deaths in usual place of residence is a key indicator for end-of-life care and acts as a proxy quality marker for choice and access. In Bedfordshire 46.1% of people died in their usual place of residence in 2017 which is slightly above the current national rate of 45.8%

Data from the Public Health England website reports that in Bedfordshire during 2017, 23.6% of deaths were in the patient's own home, 22.4 % in care homes and 5.8% in a hospice. However we still see a high proportion, 46% of deaths in hospital.

The table below shows a comparison of profiles of the ten most similar CCGs to Bedfordshire CCG:

	Deaths in Hospital %	Deaths at Home %
Bedfordshire	46.9%	23.6%

Mid Essex	45.3	23.4
Southern Derbyshire	44.5	22.9
East and North Hertfordshire	46.5	22.1
West Kent	43.1	22.2
Buckinghamshire	45.7	22.2
West Essex	51.2	22.0
Wiltshire	38.5	26.7
Dartford, Gravesham and Swanley	47.8	19.7
Nene	50.2	21.8
Basildon and Brentwood	51.4	23.5

Data source: fingertips/phe.org.uk/profiles/end-of-life

This local data demonstrates the requirement for an improved, more robust and proactive community end of life pathway across Bedfordshire, able to meet the needs of more complex patients as well as an increase in demand.

When comparing data for deaths in hospital across the UK, there is no one area that does this well. The table below shows comparisons of deaths in hospital within the BLMK area.

England	46%
Milton Keynes, Bedfordshire, Luton	48.1%
Bedfordshire	46.9%
Luton	49.5%
Milton Keynes	47.8%

Table shows STP EoL profiles of Hospital Deaths % Persons all ages: 2017

3.4 Multi-Agency Safeguarding and End of Life Themed Audit

The Bedford Borough Council and Central Bedfordshire Council Joint Safeguarding Board recently undertook a themed multi agency audit of Safeguarding and End of life reviewing local arrangements.

The outcome demonstrated much positive practice. Examples of this were:

- Clear evidence of engagement with family representatives by practitioners,
- Social workers liaising and working with community nurses (and vice versa) to apply joined expertise and
- Real examples of professional going above and beyond to provide support and care that people and their families need at this difficult time.

The outcome also demonstrated a need to improve in the following areas:

- Clarity of roles, responsibilities and duties of the various agencies in relation to the safeguarding process
- Increased awareness of end of life and palliative care pathways, Continuing Healthcare threshold and referrals process amongst social care and safeguarding teams. (CCG and Adult Social Care)
- Increased use of advanced care planning, by actively encouraging all adult service users to consider this whilst they are still fit and well. Encourage the use of Advanced Care Plan template produced by CCG.

These improvement areas will be included within the objectives of the delivery of this strategy.

4. PALLIATIVE AND END OF LIFE CARE IN BEDFORDSHIRE

Bedfordshire residents nearing the end of their lives access a large number of BCCG commissioned services. In the main, they access general provision and some but not all access more specialist palliative care. The services commissioned include:

4.1 Palliative Care Hub (PCH)

This service was commissioned in 2011 to provide a single point of contact through a centralized hub, for patients, families, carers, health and social care professionals requiring advice and care support. This is provided by Sue Ryder, St John's Hospice and sub contracted by East London Foundation Trust (ELFT).

The hub holds and maintains a centrally held end of life care register for Bedfordshire, populated using active caseloads of palliative and end of life care patients held by the generalist and specialist palliative care community nursing teams and General Practitioners.

The hub is coordinated by clinicians and Palliative Care Support workers with knowledge in specialist palliative care to enable calls to be triaged and the most appropriate response provided.

Palliative Care Support Workers (PSWs) provide a 24/7 rapid response to requests in all care settings as required with the aim to reduce the risk of crises occurring to patients, their families and carers. Along with this, PSWs attend scheduled visits and night sitting to provide care for patients to give respite to relatives/carers. Care to patients is provided in their normal place of residence.

4.2 Hospices

There are four hospices serving Bedfordshire residents. These include: Garden House Hospice, Willen Hospice, Keech Hospice and St John's (Sue Ryder Care).

They provide holistic care supporting the emotional, psychological and spiritual needs of patients diagnosed with life limiting or terminal illnesses. They offer a wide range of services including inpatient care, hospice at home support, respite care and day hospice services. Local hospices offer services supporting people with lymphedema and pain management, art and music therapy, physiotherapy and carer support. They also provide additional bereavement support to relatives following the death of their loved one. They have a community development agenda to support people to achieve their preferred place of care in the last 6-12 months of life.

Keech Hospice delivers a South Bedfordshire Palliative Support Worker service. PSWs respond to patients and their family in the event of a crisis and also provide planned visits. The PSWs work very closely with the Specialist Palliative nurses and Community nurses in South Bedfordshire.

In addition Bedford Daycare service is commissioned to provide a number of educational programs to support service users who have a progressive, incurable disease for whom death is foreseeable. It also oversees support delivered to carers and bereavement support.

4.3 East London Foundation Trust Community Health Services

ELFT community health services fulfil a key role in end of life care. Community nurses provide clinical care in the community in people's homes and are often with patients during the dying phase. The unplanned care team (formerly known as Rapid Intervention Team) provide a rapid response over a period of 72 hours to prevent hospital admissions. Specialist Palliative Care Nurses take a pivotal role in the planning and co-ordination of end of life care and provide specialist palliative support to patients and professionals in the last stages of life including in nursing homes

In addition, ELFT community health services includes more specialist services which support people during the end stages of long term conditions For example, specialist Parkinson's nurses, specialist Rare Neuro conditions nurses, therapists and more. Community health services ensure service users only have to tell their story once, establishing trust and therapeutic alliance, improving outcomes by ensuring responses and interventions.

4.4 General Practitioners / Primary Care

Caring for people nearing the end of their lives is part of the core business of general practice. The GP and primary care team occupy a central role in the delivery of end of life care in the community. The 2015 Royal College of General Practitioners (RCGP) and Marie Curie national survey confirmed that 97% of GPs surveyed felt that general practice plays a pivotal role in the delivery of care to people approaching end of life and their families. This role is greatly valued by patients and remains pivotal to the effective provision of all other care. Care of the dying is an essential part of the health service, and challenges general practice to respond with the best that the profession has to offer – clinical expertise, considered professionalism, personalised care and human compassion.

GPs actively identify patients for the Gold Standard Framework (GSF) list from the chronic disease registers and arrange meetings to discuss coordinating care for those patients. RCGP and Marie Curie have collaborated to develop the Daffodil Standards to assist and further improve on Quality Indicators related to early identification of patients, coordinated care with documented plans which can be shared electronically, support for carers and systems to receive and act on patient and staff feedback (see RCGP website for detail).http://www.goldstandardsframework.org.uk/cd-content/uploads/files/General%20Files/Prognostic%20Indicator%20Guidance%20October%202011.pdf

A retrospective End of Life Care Audit is being undertaken by Bedfordshire GPs. This audit will identify challenges and form the basis of improvement goals for both GPs and the new Primary Care Networks as a whole.

The first annual review of this strategy will reflect the findings and improvement plans.

4.5 Continuing Healthcare Fast Track

Bedfordshire CCG has been working in partnership with stakeholders on a pilot to increase the quality of care to patients and their families who are eligible for Fast Track continuing health care in their homes.

Fast Track continuing health care provision for people who are rapidly deteriorating and may be entering the terminal phase is traditionally purchased through domiciliary care providers. A successful pilot is in progress trialling the purchase of care from Sue Ryder (sub contracted by ELFT Community Health Services), integrated within our Bedfordshire system

delivering specialist end of life services across Bedfordshire. Due to its success, plans are in place for this service to become business as usual after the pilot period. In addition, the aim is to remove the requirement for referral to CHC for domiciliary care fast tracks.

4.6 Independent Voluntary services

A multitude of independent services support people and their families during this time.

5. BEDFORDSHIRE CCG VISION FOR PALLIATIVE AND END OF LIFE CARE

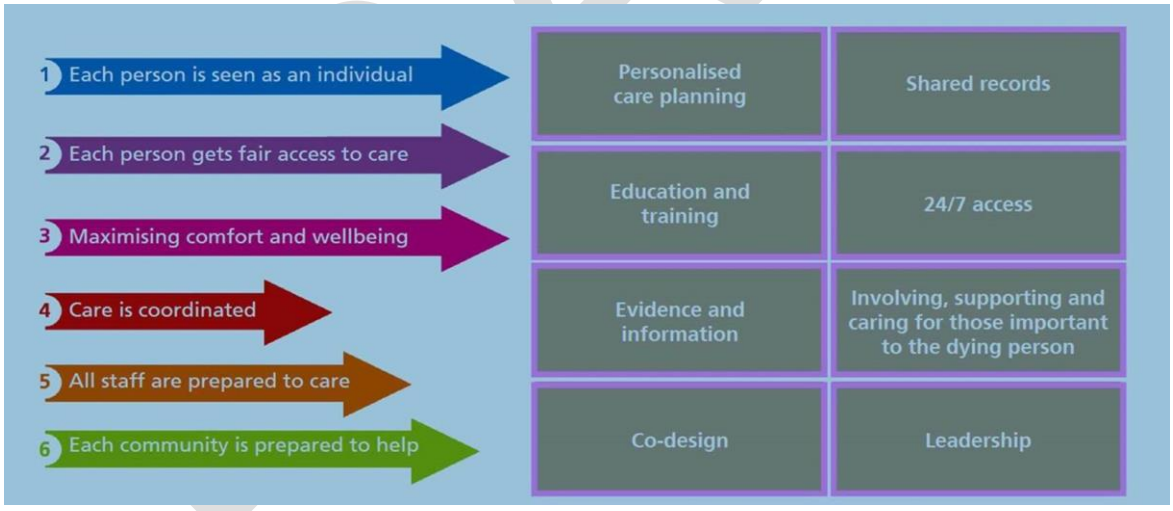
Bedfordshire CCG vision is that all patients at end of life, together with those closest to them, are able to express their needs and wishes, and that as far as clinically appropriate and practically possible, these needs and wishes are met.

We are committed to enabling people to live well and die well in the place of their choice.

Our strategy supports the earlier recognition of those who are going to die within the next 12 months, enhances the co-coordination of services and promotes quality care. It also covers the support of family friends and carers during bereavement.

To realise this vision, Bedfordshire CCG have adopted the six ambitions and eight foundations set out in the "*Ambitions for Palliative and End of Life Care: A National Framework for local action 2015-2020*" produced by the National Palliative and End of Life Care Partnership.

This national framework sets out six 'ambitions' or principles for how care for those nearing death should be delivered at local level and eight principles which are the foundations to build and realise the ambitions:



These foundations are the pre-conditions for delivering the rapid and focused improvement that the CCG seeks.

Responsibility for implementing the ambitions of the new framework spans the commissioner and provider spectrum, putting onus not just on CCGs, but on providers, NHS England, Public Health England, local councils, and third sector organisations to take action, monitor progress and influence change.

Acknowledging this, Bedfordshire's End of Life Care Strategy sets out our aspirations for the coming years. We are also committed, in an environment where resources are constrained, to make best use of those available and to deliver value for money. This includes seeking

the best experience possible for both patient and carers in the palliative period. As far as the patient's clinical condition allows, the aim is to deliver real choice for patients and meet their wishes, where possible, in the last phase of their life.

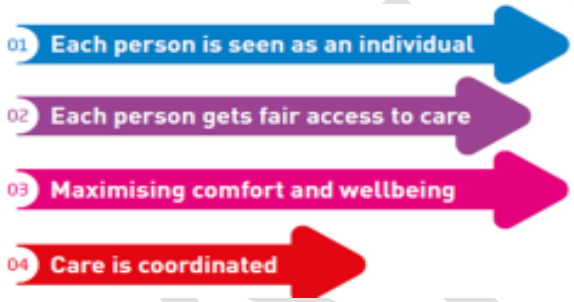
By working together to implement this strategy we are confident that we can continue to make a really positive difference to improving end of life care in Bedfordshire.

6. PRIORITY AREAS

Using feedback following engagement through workshops, service user audits, analysis of performance reporting and more, Bedfordshire CCG has identified the following priority areas. These areas are in line with both national strategy and also direction of travel from an STP perspective (see section 10 for more information on STP EoL).

6.1 Personalised Care Planning

Linked to the following National Ambitions:



NICE Guidance states that services should carry out comprehensive holistic assessments with people identified as approaching the end of life, in response to their changing needs and preferences, which include the opportunity to discuss, develop and review a personalised care plan for current and future support and treatment.

As such people approaching end of life should be offered full assessments to ensure they are getting the best care and support for their circumstances. During these assessments, they have the opportunity to discuss their needs (for example, physical, psychological, social, spiritual and cultural needs) and preferences.

Palliative and end of life care plans are often instigated when the person is identified as being in the last year of life, however the point at which and way in which people are identified can vary greatly depending on the conditions the person has. In 2013 a study found that *"75% of patients with cancer had been identified formally for palliative care compared with 20% of non-cancer patients"* indicating that for some conditions, people are not being identified at all. The same study found that for all conditions, palliative care often was introduced too late and that for some people it was only in their last few weeks of life that they were identified as end of life stage.

Research suggests that people who have been identified for palliative and end of life care and who have a personalised care plan, either for the last year of life or through an advance care plan are more likely to achieve their preferred place of death.

The Bedfordshire Luton and Milton Keynes (BLMK) Integrated Care System (ICS) is a demonstrator site for personalisation and as such this will be a focus in Bedfordshire.

As part of advanced care planning and personalisation, we must not lose sight of the national guidance around the Mental Capacity Act (MCA). The MCA nice guidance published

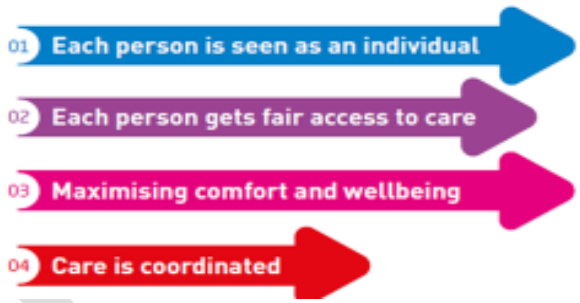
October 2018 https://www.nice.org.uk/guidance/ng108 sets out the role of practitioners in relation to the Act and the need to ensure practice encompasses the five statutory principles. In addition, the Social Care Institute for Excellence (SCIE) MCA directory https://www.scie.org.uk/mca-directory/ is a further resource.
Bedfordshire has seen an increase in the number of people on the end of life register, suggesting improvements have been made in identifying people approaching end of life. However, recent post death audits demonstrated that 70 % of people who died in hospital had not previously been identified as being end of life. Data gathered from a Baseline review of End of life admissions to hospital, showed that around 32% of patients were known to the Palliative Care Hub, but of those, only 17% were known to have advanced care plan. To ensure patients receive quality and personalised end of life care, three components are required:

i. Early identification of end of life
ii. Advance Care Plan discussions
iii. A system for sharing care plans across care settings in a co-ordinated way

Case studies have shown that where these three components are achieved patients and their families feel supported and good palliative and end of life care is delivered which can have a lasting impact on how families and carers grieve. Bedfordshire CCG aims to achieve these through the implementation of this strategy and the subsequent action plans derived from it.

6.2 Early Identification

Linked to the following National Conditions:



If people are to receive the appropriate support and care in their last stage of life, early identification of them being at that stage is required. The Gold Standards Framework (GSF) supports GPs to identify end of life patients, assess and record their needs and plan their care appropriately. Those identified under the framework are placed on the end of life care register. It is estimated that approximately 1% of patients within a practice should be on the register. For Bedfordshire CCG this is approximately 4270 people a year.

By identifying who is in their last year of life the appropriate conversations and care planning can take place leading to a higher quality of end of life care, fewer inappropriate hospital admissions and a good death in their preferred place of death. In Bedfordshire, all GPs have the GSF tool to identify their patients. Once identified and recorded on the GSF register, patients' needs are reviewed on a regular basis. One of the ways this is done is through monthly GSF meetings which involve GPs, community nurses, specialist palliative care community nurse and other specialist roles.

The Quality and Outcomes Framework (QOF) target is for practices to hold these meetings as a minimum every 3 months. However, given the number of patients that may need to be

discussed and the rapid deterioration that some patients will experience, the CCG expects this to be a monthly discussion.

The recent publication of the NHS Long Term Plan highlights that proactive personalised end of life care remains a key part of the new QOF GP Contract for 2019/20. It states that practices will need to demonstrate: early identification, well planned and coordinated care, and identification and support for family / carers and include an increased proportion of people on the supportive care register.

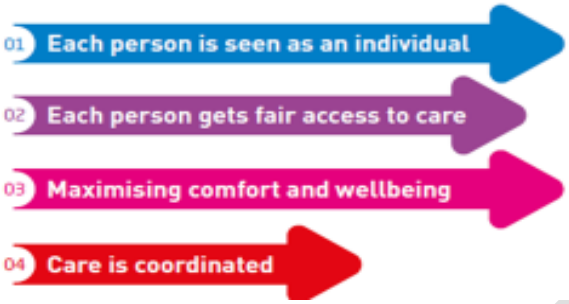
The Daffodil Standards developed by the RCGP and Marie Curie supports this QOF outcome.
The local audit indicated that a high proportion of people who were admitted to hospital and died within 48 hours had not been previously identified as being end of life. As such, early identification of people at end of life is a high priority area for improvement across all commissioned services in the Bedfordshire system.

6.2.1 Objectives for this element are:

Every patient 'approaching end of life' must be on their general practice's Gold Standards Framework (GSF) Register (with the exception of those who have life-threatening acute conditions caused by sudden catastrophic events).
End of Life patients must be identified early using best practice tools such as The GSF Proactive Identification Guidance.
Each general practice must hold at least one meeting a month to discuss the needs of patients known to be 'approaching the end of life' and must complete a proforma to evidence this. This meeting should also factor in patients discussed at multi-disciplinary meetings with long term and chronic conditions to ensure patients that transition to 'approaching the end of life' are identified in a timely way.
Ensure everyone approaching the end of life is offered full assessments to ensure they are getting the best care and support for their circumstances
Undertake an audit across the system to ascertain what the full assessment encompasses and through the EoL improvement group, develop a single version to be adopted across Bedfordshire.
Monitor the numbers of full assessments undertaken to determine an increase.
Undertake an audit of training across services in Bedfordshire to understand what opportunities there are to increase training.
The outcome of the audit will be developed into a Bedfordshire-wide training strategy and rolled out across Bedfordshire to ensure a consistent approach to training to support the workforce in the identification of end of life.
All organisations caring for people at end of life, elderly, frail will be expected to undertake a minimum level of regular training for end of life.
GP practices evaluate the current quality of their end of life care and identify areas for improvement – including a retrospective death audit (Q1003).
GP practices identify quality improvement activities and set improvement goals to improve performance Q1003.
Participate in a minimum of 2 GP network peer review meetings each year (Q1004)
GP practices complete the QI monitoring template in relation to this indicator (Q1003 + Q1004).

6.3 Advance Care Plan

Linked to the following National Conditions:



The NICE Quality Standard for end of life care states that people approaching their end of life should be *"offered comprehensive holistic assessments in response to their changing needs and preferences, with the opportunity to discuss, develop and review a personalised care plan for current and future support and treatment."*

Although the emphasis is on those approaching their end of life, conversations with people with long term conditions regarding their preferences and plans should begin prior to being identified as end of life through advance care plans. For some conditions e.g. dementia, the last year of life may be too late for the individual to make decisions as they lack capacity. Whilst it would be ideal for discussions to take place as early as possible following diagnosis, it is recognised that there are cases where disease progression is advanced. In such circumstances, the responsibility may fall to a family member or carer. This added responsibility can be difficult to cope with and so having an advance care plan will help to relieve some of the pressures and stress from carers and families.

Advanced Care Planning is a process of discussion between an individual and their care providers irrespective of discipline. The difference between ACP and planning more generally is that the process of ACP is to make clear a person's wishes and will usually take place in the context of an anticipated deterioration in the individual's condition in the future, with attendant loss of capacity to make decisions and/or ability to communicate wishes to others.

With the individual's agreement, discussions should be:

- documented (In a format that can be shared with key teams using the Bedfordshire ACP booklet/template)
- Regularly reviewed
- Communicated to key persons involved in their care via SystmOne.

If the individual wishes, their family and friends may be included.

- Examples of what an ACP discussion might include are:
    - the individual's concerns
    - values or personal goals for care that are important to them
    - their understanding about their illness and prognosis
    - particular preferences for types of care or treatment that may be beneficial in the future and the availability of these
    - preferred place of care / death

In 2017, the Bedfordshire End of Life Care Improvement Group developed a Bedfordshire-wide Advanced Care Plan. Since its development, there has been an increased focus on ensuring this is used and as such, Bedfordshire has seen an increase in the number of ACP

discussions. The Bedfordshire ACP document is a paper version and clinicians upload details of people's preferences onto SystmOne which enables the safe sharing across health professionals caring for individuals.

Quality improvement case studies 2019/20 NHSE noted that people who had their plan in a format which could be shared with key teams, were able to have the information shared both in and out of hours. The recent local audit undertaken demonstrated that a high proportion of people had not had an ACP discussion.

It is not uncommon for many people who are in their last year of life to have multiple and complex conditions. The increase in conditions can lead to an increase in the number of people involved in an individual's care and so it is vital that care is co-ordinated.

Bedfordshire CCG recognises that more needs to be done to ensure a greater number of people are offered the opportunity to express their wishes and feelings.

It should be recognised that advance care planning is an ongoing, interactional process to support shared decision making and individual choice. It should not be a one-off conversation and should be regularly revisited while the person is receiving support. It is important to emphasise that end of life care planning is not limited to the plans that are developed for a person who is in the last few days of life. Rather end of life planning should start early on and can be seen as the preparation for worsening of a person's symptoms or condition so that they can have the care they want in all circumstances.

Those involved in the person's care, should have an awareness of the support services available to help them make decisions about their future. There will be the need to have the single ACP document available in different formats e.g. Easy Read and dementia friendly, with people given a choice about how much or little they wish to complete.

We recognise that as with all other areas of health and social care, provision needs to be made for co-ordination between children's and adult services. These should be developed in line with NICE guideline [NG43] Published date: February 2016 - Transition from children's to adults' services for young people using health or social care services.

Joint Strategic Needs Assessments should be used to develop services especially with regards to groups who have traditionally been hard to reach or those known as having trimorbidity. This cohort may require specialist support to enable them to access personalised care that supports their needs and wishes.

The Faculty for Homeless and inclusion health specifically look at how this can be achieved and there are a number practical guidance documents which support staff to improve their interactions and outcomes with these groups.

https://www.hospiceuk.org/docs/default-source/Policy-and-Campaigns/briefings-and-consultations-documents-and-files/care_committed_to_me_web.pdf?sfvrsn=0

https://www.mariecurie.org.uk/professionals/palliative-care-knowledge-zone/equality-diversity/homeless-people#support

https://endoflifecaresubstanceuse.files.wordpress.com/2019/05/good-practice-guidance-supporting-people-with-substance-problems-at-the-end-of-life.pdf

6.3.1 The objectives for this element are:

Everyone with a long-term condition or life-limiting condition must be offered the chance to have an Advance Care Plan and a record of this discussion and whether they decided to have an ACP must be documented in their notes. (Use of EPaCCS recording system during 2020/21 – see section 6.4 re plans for EPaCCS).
Increased training for ACP to be rolled out to all health and social care staff across Bedfordshire to ensure professionals feel confident to have discussions.
The End of Life Improvement Group will re-visit the Bedfordshire ACP document to decide whether any area of it requires updating in line with the recommendations contained within this strategy prior to re-printing.

6.3.2 Dementia and Advanced Care Planning

Linked to the following National Conditions:

In Bedfordshire, it is estimated that more than 4000 members of the population are living with dementia. Dementia is one of the top 5 underlying causes of death and one in three people over the age of 65 die with dementia.

However, research indicates that many people with dementia are not supported to make the right choices in their end of life care. They receive poorer end of life care, particularly palliative care and have less access to hospice care.

Advanced care planning has been identified as both a national and a local priority and it is particularly important that people with dementia have the opportunity to engage in end of life care discussions in the early stages of their illness, whilst they have the mental capacity and ability to make their wishes known and be in agreement with the planned future care.

6.3.3 Long Term Conditions and Advanced Care Planning

Linked to the following National Conditions:

The major cause of death in Bedfordshire is circulatory disease. This is closely followed by respiratory disease and then by cancer.

People can live for many years with diseases such as Chronic Obstruction Pulmonary Disease (COPD) and treatment can help control symptoms. The recent audit indicates that there were high proportions of people at end of life with no Advanced Care Plans, it also indicated high proportions of people with COPD and respiratory problems.

Despite the high morbidity and mortality associated with severe COPD, national research shows that many patients receive inadequate palliative care. There are several reasons for this. First, patient – clinician communication about palliative and end of life care is infrequent. Secondly, the uncertainty of predicting prognosis for patients with COPD makes communications about end of life more difficult. As such discussions regarding end of life between patient and clinicians are unlikely to occur or occur too late.

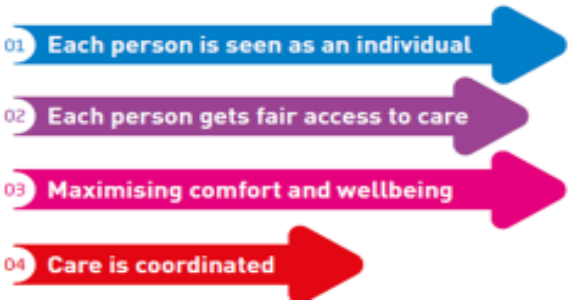
Whilst no one wants to focus on death, it is important for this cohort to plan for end life needs. Advanced care planning has been identified as a local priority and it is particularly important that people with COPD to have the opportunity to engage in end of life care discussions in the early stages of their illness.

6.3.4 The objectives for this element are:

Everyone who is diagnosed as being in the early stages of dementia must be offered the chance to have an Advance Care Plan and a record of this discussion and whether they decided to have an ACP must be documented in their notes.
Increased training in awareness for the need for ACPs undertaken in the early stages of dementia to be rolled out across all health and social care staff across Bedfordshire.
To see an increased number of people living with dementia access palliative and end of life care.
Organisations providing palliative and end of life care should seek to work together with professional experts in the relative field to ensure services are developed to deliver the highest standard of care for all, including dementia.
Increased training in awareness for the need for ACPs undertaken for service users suffering LTCs such as respiratory diseases and COPD.

6.4 A System for Sharing Care Plans across Care Settings in Coordinated Way

Linked to the following National Conditions:



It is easy for people to find themselves repeating their needs multiple times and a lack of coordination of care can be frustrating for individuals, their families and their carer's. There is little point in having a well-constructed and detailed care plan if it is not visible to all involved in the person's care.

Statement 8 of the NICE Quality Standard for end of life care specifies that *"people approaching the end of life receive consistent care that is coordinated effectively across all relevant settings and services at any time of day or night, and delivered by practitioners who are aware of the person's current medical condition, care plan and preferences."*

The implementation of an Electronic Palliative Care Co-ordination System (EPaCCS) across Bedfordshire will enable both health and social care practitioners to be aware of the latest

treatment plan for those in their care. They will also be able to view the individual's wishes regarding their care and preferred place of death. A review of end of life care by the National End of Life Care Intelligence Network (NELCIN) found that "*people who have an EPaCCS record are more likely to die in their preferred place of death*".

At a recent workshop, the Bedfordshire, Luton and Milton Keynes (BLMK) Palliative and End of Life Care improvement network identified communication as being a key area of improvement. The STP priority 2 Board has agreed the concept of a BLMK roll out of the EPaCCs.

A business case has been approved for the roll out of EPaCCS across Bedfordshire. The recommendation is for this to be undertaken in a phased approach. Although the EPaCCS system will provide a mechanism for coordinating information electronically, the monthly GSF meetings mentioned in section 4.4 will be vital in ensuring that care is co-ordinated and reviewed to continue to meet the needs and preferences of the individual.

EPACS is a web-based electronic register, based on sharing care summaries and plans alongside patients' electronic records, patient portals, real-time extractions from the SystmOne records of participating organisations, etc. They aim to provide up-to-date key information about patients in the last year of their life in GP practices, emergency services (111 and 999), GP out of hours services, accident and emergency departments, ambulance services, hospitals, community nursing teams, specialist palliative care services, hospices and care homes. EPaCCS aims to improve communication and coordination and ensure that all those involved in a patient's care are aware of their wishes, preferences and advance care plan. They are expected, and to an extent have been demonstrated, to enable more patients to die at their preferred place and reduce unnecessary hospital admissions and ambulance journeys, inappropriate interventions, use of unscheduled care and repeated 'difficult conversations'. EPaCCS also supply detailed outcome metrics and enable continuous quality improvement in local end of life care services.

As well as the above benefits, it achieves the following:

- Shares Advanced Care Plans in a much more systematic way as it records each of the elements of the ACP electronically
- Capable of producing reports to demonstrate ACPs completed and tracks where ACPs are not completed in order to prompt timely completion.
- Includes a carer's section which will flag up to social care whether a carers assessment is required. This can prevent carer breakdown and as such prevent avoided admissions to hospital.
- Drives an improvement in data quality, therefore reducing variation across the Bedfordshire system.
- Would support the Continuing Healthcare Department in defining individuals who are rapidly deteriorating, reducing inappropriate referrals.
- For services that are not on SystmOne, the EPACS system facilitates special notes and enhanced summary records, ensuring information is shared consistently.

6.4.1 The objectives for this element are:

Every patient on the GSF register must be offered the opportunity to have an Electronic Palliative Care Co-ordination System record (EPaCCs) and where they consent this must be created.
MDTs / GSF / HIU reviews already take place across Bedfordshire. As part of the NHS Long Term Plan, revisit this area reducing any variation across Bedfordshire

and ensuring that care is coordinated and reviewed to continue to meet the needs and preferences of the individual.

6.5 Education and Training

The following National Ambitions are linked to this:

A motivated, appropriately skilled, compassionate workforce is integral to delivering end of life care that meets the needs of patients and their relatives. For this to be achieved the following issues need to be considered:

Workforce development ensures that health and social care staff are competent and feel confident when defining and providing end-of-life care, and is also the driving force behind service improvements and shifting behavioural change in end of life care. However, the 'One Chance to Get It Right' report identified that some staff do not have the appropriate knowledge and skills to deliver high-quality end-of-life care. In addition, the national audit of acute hospitals found that training in care of the dying was mandated for doctors in only 19% of acute hospital trusts and for nurses in only 28%.

National Common Core Competences and Principles for End of Life Care were developed by 'Skills for Care and Skills for Health' in partnership with the Department of Health and the NHS End of Life Care Programme, in addition to core principles relating to end of life care.

https://www.skillsforcare.org.uk/Learning-development/ongoing-learning-and-development/end-of-life-care/End-of-life-care.aspx

The purpose of this was to support workforce development, training and education across the health and social care system.

The Common Core Competences (underpinned by values and knowledge) are:

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

Bedfordshire CCG is keen to develop with stakeholders a Palliative and End of Life Care Education Programme which seeks to train all staff involved in providing palliative and end of life care.

Priorities for this area also include the learning areas from the multi-agency safeguarding and end of life audit.

6.5.1 **The objectives for this element are**:

Development of the commissioned workforce to have common core competencies with a rolling training and education programme
Clarity of roles, responsibilities and duties of the various agencies in relation to the safeguarding process.
Increased awareness of end of life and palliative care pathways, Continuing Healthcare threshold and referrals process amongst social care and safeguarding teams. (CCG and Adult Social Care).

7. Difficult Conversations

The following National Ambitions are linked to this:

Death and dying are not easy conversations to have and the reluctance to talk about these issues increases the likelihood of people's preferences not being discussed or met. It also increases the likelihood of people not being aware of all the options available to them when it comes to their care.

The significant value of a conversation between clinicians, the individual and their next of kin to provide a full understanding of prognosis and expected level of deterioration must not be underestimated. Research demonstrates that where this has happened, families have felt supported in terms of planning for end of life.

The national VOICES survey found that *"more than 5 out of 6 bereaved people (86%) understood the information provided by health care professionals, but 1 out of 6 (16%) said they did not have time to ask questions to health care professionals".*

In order to have an informed conversation with a person and their families and carers about their preferences and wishes, time needs to be given to allow information to be processed and it should not be a one off event. Dealing with death and dying can be difficult to process mentally and so conversations need to be revisited with information and resources readily available for individuals to digest in their own time.

The CCG website includes information covering issues that affect people who are dying and their families and carers. It is recognised that there are a number of other leaflets and websites that provide useful and reliable information and the CCG will work with its providers to ensure there is a central location where this information is held.

https://www.ageuk.org.uk/globalassets/age-uk/documents/booklets/talking_about_death_booklet_final_version.pdf

Having a single point to direct people to where they can access reliable and up to date information on a number of topics from "making a will" to "what happens to my pets when I die" will support people to develop a clear understanding of the decisions and choices they will need to make regarding their palliative and end of life care.

Quality of life and a peaceful, pain-free death are often cited as the preferences of those receiving palliative and end of life care and it the responsibility of those supporting individuals to develop their care plans to manage the expectations and provide a realistic approach to what can be achieved.

Raising awareness and promoting palliative and end of life care needs to be part of all aspects of health and social care and not the sole responsibility of those providing the services. Public Health England has developed a toolkit to support the implementation of Compassionate Communities Charter. A compassionate community is one that:

- *"Has local health policies that recognise compassion as an ethical imperative*
- *Meets the special needs of its aged, those living with life threatening illnesses, and those living with loss*
- *Has a strong commitment to social and cultural differences*
- *Involves grief and palliative care services in local government policy and planning*
- *Offers its inhabitants access to wider variety of supportive experiences, interactions and communication*
- *Promotes and celebrates reconciliation with indigenous peoples and memory of other important community losses*
- *Provides easy access to grief and palliative care services"*

Implementing the Compassionate Communities *"encourages communities to support people and their families who are dying or living with loss. It aims to enable all of us to live well within our communities to the very end of our lives.* Other expected outcomes include:

- *"Death, dying and bereavement would cease to be taboo subjects and would become more normalised within society*
- *People's expectations of death and dying would change, as would how death is managed*
- *Palliative care would re-orientate, supporting health and social care staff to work with the community in providing care to those at the end of life, and their loved ones"*

One of the biggest barriers to people receiving palliative and end of life care is having the conversation about death and dying. Only by encouraging these conversations and changing perceptions to death and dying will the wishes and preferences of the individual be met.

There is an increasing concern nationally regarding social-isolation in older generations and consideration needs to be given to those who may not have family or carers to support them.

In Bedfordshire, Keech Hospice Care has initiated Compassionate Communities. The ambition is that this is developed further across all areas of Bedfordshire and embedded.

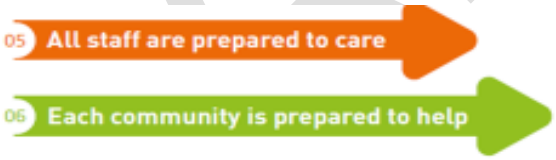
7.1 The objectives for this element are:

Organisations providing palliative and end of life care should work together to ensure that everyone approaching end of life, and their families/carers have a face to face, honest, sensitive and informed discussions about dying, death and bereavement. This should be with members of their care team and should allow the individual, their family/carers to take part in shared decision making about their care, with the outcomes recorded, shared and regularly reviewed.
The CCG will work with its providers to ensure there is a central location where information covering issues that affect people who are dying and their families and carers is held.
Commissioned services will ensure people are signposted and provided with information covering issues that affect people who are dying and their families and carers.

Everyone and their families/carers should be supported to make decisions about their priorities for the remainder of their life, as early as possible, including managing expectations.
Learning and education for professionals to develop the necessary skills to have difficult conversations will be included within the development of a training plan for health and social care professionals across Bedfordshire.
Development of leaflets regarding provision of services across Bedfordshire and how to access.
Organisations providing palliative and end of life care will use every opportunity to promote their service supported by the CCG.
Increasing Compassionate Communities across Bedfordshire.
To undertake an audit of end of life training being delivered across Bedfordshire CCG commissioned services. Understand where there are any gaps, develop a joined up approach to training in line with the training needs outlined in this strategy, seek to fill any gaps in training.
Champion and support training and education initiatives to improve the skills of the workforce across the system in the effective and compassionate delivery of palliative and end of life care including symptom management, advanced communication skills and referral to other services.
Palliative and end of life care must be integral to training curricula for all staff groups and organisations that employ people who work in palliative and end of life care.

8. **Working environments**

The following National Ambitions are linked to this:



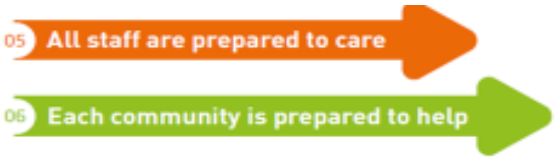
The "*Ambitions for Palliative Care"* Report acknowledged that "*to give care day in and day out requires organisational and professional environments in all settings that ensure psychological safety, support and resilience.*" Providing end-of-life care is emotionally and physically demanding and employers must support their workforce so that resilience is fostered, as well as being aware of the effects of burnout and how to prevent it.

8.1 The objectives for this element are:

Ensure that all health and social care staff are trained in delivering high quality end of life care and have access to clinical supervision, where appropriate to support them.
Promote psychological support for health and social care staff working in environments where death happens frequently.

9. Support Services Available 24/7

The following National Ambitions are linked to this:



The support people and their relatives have is key to achieving a good outcome in palliative and end of life care. Furthermore, research suggests that access to good and early palliative care can improve outcomes for life expectancy as well as improve the quality of life. Patients approaching the end of their life must also be helped to achieve maximal independence and social participation in accordance with their preferences.

The '*Ambitions for Palliative Care'* highlighted the need for services to be available 24/7. Currently, Bedfordshire offers an end of life 24/7 single point of access for people, their relatives and professionals. In addition, Bedfordshire has a night-sitting respite service for carers provided by Sue Ryder for people who require this. Sue Ryder also offers a seven days a week continuing health care fast track service to people who are rapidly deteriorating.

The recent end of life audit showed that high proportions of patients were being admitted to hospital out of hours. As such, there are improvements required to enhance out-of-hours service provision to ensure palliative and end of life patients receive the right care are the right time without bouncing into hospital out of hours if not appropriate.

9.1 The objectives for this element are:

Organisations providing palliative and end of life care should work together to ensure that pathways are developed across organisations including robust communication mechanisms to ensure a joined up approach.
All people in need of palliative and end of life care should have access to support 7 days a week to address their medical, nursing and social needs and preferences.
All patients and their family/carers must be informed of the function of the Palliative Care Hub to help them in times of needing urgent support including out of hours.
Good end of life care includes bereavement support.

10. CO-DESIGN

NHS organisations and local councils developed shared proposals to improve health and care, working in 44 areas covering all of England.

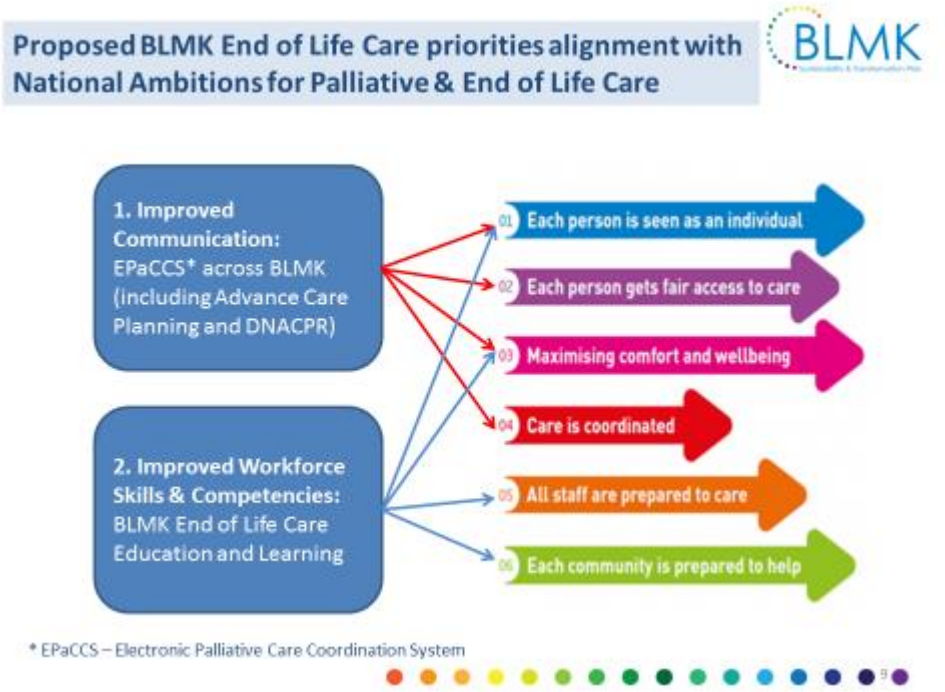
Known as sustainability and transformation partnerships (STPs), STPs were created to bring local health and care leaders together to plan around the long-term needs of local communities. They were drawn up by senior figures from different parts of the local health and care system, following discussion with staff, patients and others in the communities they serve.

A number of these partnerships have now grown into integrated care systems (ICS) and it is expected that by April 2021 every STP will become one. Last year, the Bedfordshire, Luton and Milton Keynes (BLMK) ICS approved a BLMK wide Palliative and End of Life Improvement Network. The network meets regularly and its commissioning intention is to:

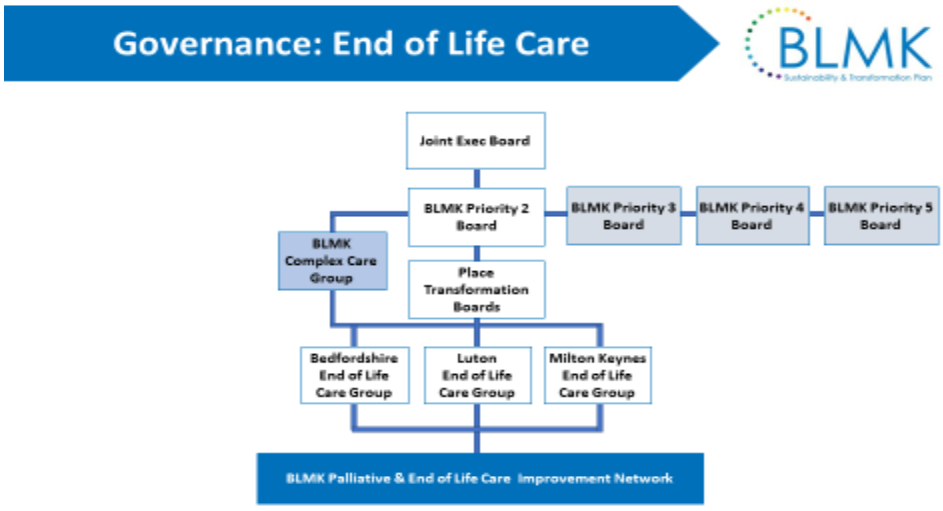
'Scope provision of end of life and palliative care provision across BLMK to ensure parity of access and consider if there are opportunities around economies of scale'.

Co-designing is at the heart of this and at its first network, a series of workshops were facilitated to understand what the priorities for 2019/20 should be. The slide below shows the two main priorities and how these align to the National Ambitions document.

Furthermore, this Bedfordshire strategy aligns to the BLMK priorities and as such the National Ambitions document.



To ensure accountability of delivery, the network has agreed the following governance for end of life improvements across BLMK.



11. IMPLEMENTING THE STRATEGY AND NEXT STEPS

Bedfordshire CCG is committed to improving the quality of experience for those in need of palliative or end of life care and supporting their carers and families.

Following the agreement of this strategy, further work will be taken to develop an implementation plan with commissioned services in order to achieve the vision and objectives identified throughout the strategy.

Given the spectrum of conditions for which palliative and end of life care is relevant, it is recognised that this strategy will need to link into other programmes across the CCG e.g. Stroke, respiratory and dementia.

11.1 Measuring Success

The implementation plan will contain outcome measures which will be used to monitor and evaluate the impact of the delivery of the strategy against the identified objectives.

Key outcomes will include:

- An increase in the percentage of people achieving their preferred place of care and preferred place of death
- All those identified as in need of palliative and end of life care will be offered the opportunity to have an advance care plan
- An operational EPaCCS system across all providers
- A reduction in unnecessary hospital admissions for those receiving end of life care

The success against the achievement of these outcomes will be regularly monitored, evaluated and reported using national and local quantitative and qualitative information and data. Updates will be provided through the Bedfordshire End of Life Improvement Group.

12. APPENDIX ONE: DEFINITIONS

Palliative Care
Palliative care aims to improve the quality of life for people with life-limiting illnesses, by controlling pain and other symptoms. It also helps those receiving care, families and carers deal with emotional, spiritual or practical issues arising from the illness.

People suffering from an incurable progressive illness may require palliative care - for example, those with heart failure, advanced respiratory disease, dementia, the end stages of progressive neurological diseases or cancer. People of all ages can benefit from palliative care at all stages of their illness.

Approaching the End of Life
People who are likely to die within the next 12 months are 'approaching the end of life'. This also takes into account people whose death is likely to be imminent in the next few days or hours. The General Medical Council (GMC) defines people 'approaching the end of life' as being those with:

- advanced, progressive, incurable conditions
- general frailty and coexisting conditions that mean they are expected to die within 12 months
- existing conditions if they are at risk of dying from a sudden acute crisis in their condition
- life-threatening acute conditions caused by sudden catastrophic events8

Within this context, any palliative care received within the last 12 months of life is regarded as end of life care.

End of Life Care
According to the Department of Health (2008) End of life care is care which "*helps 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*".

13. APPENDIX TWO: OVERVIEW OF OBJECTIVES BY PRIORITY AREA

Early Identification

Every patient 'approaching end of life must be on their General Practice's Gold Standards Framework (GSF) Register (with the exception of those who have life-threatening acute conditions caused by sudden catastrophic events).
End of Life patients must be identified early using best practice tools such as The GSF Proactive Identification Guidance
Each general practice must hold at least one meeting a month to discuss the needs of patients known to be 'approaching the end of life' and must complete a proforma to evidence this. This meeting should also factor in patients discussed at multi-disciplinary meetings with long term and chronic conditions to ensure patients that transition to 'approaching the end of life' are identified in a timely way.
Ensure everyone approaching the end of life is offered full assessments to ensure they are getting the best care and support for their circumstances.
Undertake an audit across the system to ascertain what the full assessment encompasses and through the EoL improvement group, develop a single version to be adopted across Bedfordshire.
Monitor the numbers of full assessments undertaken to determine an increase.
Undertake an audit of training across services in Bedfordshire to understand what opportunities there are to increase training.
The outcome of the audit will be developed into a Bedfordshire wide training strategy and rolled out across Bedfordshire to ensure a consistent approach to training to support the workforce in the identification of end of life.
All organisations caring for people at end of life, elderly, frail will be expected to undertake a minimum level of regular training for end of life.
GP Practices evaluate the current quality of their end of life care and identify areas for improvement –including a retrospective death audit (Q1003).
GP practices identify quality improvement activities and set improvement goals to improve performance Q1003.
Participate in a minimum of 2 GP network peer review meetings each year (Q1004)
GP Practices Complete the QI monitoring template in relation to this indicator (Q1003 + Q1004).

Advanced Care Planning

Everyone with a long-term condition or life-limiting condition must be offered the chance to have an Advance Care Plan and a record of this discussion and whether they decided to have an ACP must be documented in their notes. (Use of EPaCCS recording system during 2020/21 – see section 6.4 re plans for EPaCCS).
Increased training for ACP to be rolled out to all health and social care staff across Bedfordshire to ensure professionals feel confident to have discussions.
The End of Life Improvement Group will re-visit the Bedfordshire ACP document to decide whether any area of it requires updating in line with the recommendations contained within this strategy prior to re-printing.

Dementia and Advanced Care Planning

Everyone who is diagnosed as being in the early stages of dementia must be offered the chance to have an Advance Care Plan and a record of this discussion and whether they decided to have an ACP must be documented in their notes.

Increased training in awareness for the need for ACPs undertaken in the early stages of dementia to be rolled out across all health and social care staff across Bedfordshire.
To see an increased number of people living with dementia access palliative and end of life care.
Organisations providing palliative and end of life care should seek to work together with professional experts in the relative field to ensure services are developed to deliver the highest standard of care for all, including dementia.

System for Sharing Care Plans

Every patient on the GSF register must be offered the opportunity to have an Electronic Palliative Care Co-ordination System record (EPaCCs) and where they consent this must be created.
MDTs / GSF / HIUs already take place across Bedfordshire. As part of the NHS Long Term Plan, revisit this area reducing any variation across Bedfordshire and ensuring that care is coordinated and reviewed to continue to meet the needs and preferences of the individual.

Education and Training

Development of the commissioned workforce to have common core competencies with a rolling training and education programme.

Difficult Conversations

Organisations providing palliative and end of life care should work together to ensure that everyone approaching end of life, and their families/carers have a face to face, honest, sensitive and informed discussions about dying, death and bereavement. This should be with members of their care team and should allow the individual, their family/carers to take part in shared decision making about their care, with the outcomes recorded, shared and regularly reviewed.
The CCG will work with its providers to ensure there is a central location where information covering issues that affect people who are dying and their families and carers is held.
Commissioned services will ensure people are signposted and provided with information covering issues that affect people who are dying and their families and carer's.
Everyone and their families/carers should be supported to make decisions about their priorities for the remainder of their life, as early as possible, including managing expectations.
Learning and education for professionals to develop the necessary skills to have difficult conversations will be included within the development of a training plan for health and social care professionals across Bedfordshire.
Development of leaflets regarding provision of services across Bedfordshire and how to access.
Organisations providing palliative and end of life care will use every opportunity to promote their service supported by the CCG.
Increasing Compassionate Communities across Bedfordshire.
To undertake an audit of end of life training being delivered across Bedfordshire CCG commissioned services. Understand where there are any gaps, develop a

joined up approach to training in line with the training needs outlined in this strategy, and seek to fill any gaps in training.
Champion and support training and education initiatives to improve the skills of the workforce across the system in the effective and compassionate delivery of palliative and end of life care including symptom management, advanced communication skills and referral to other services.
Palliative and end of life care must be integral to training curricula for all staff groups and organisations that employ people who work in palliative and end of life care.

Working Environment

Ensure that all health and social care staff are trained in delivering high quality end of life care and have access to clinical supervision, where appropriate to support them.
Promote psychological support for health and social care staff working in environments where death happens frequently.

Support Services Available 24/7

Organisations providing palliative and end of life care should work together to ensure that pathways are developed across organisations including robust communication mechanisms to ensure a joined up approach.
All people in need of palliative and end of life care should have access to support 7 days a week to address their medical, nursing and social needs and preferences.
All patients and their family/carers must be informed of the function of the Palliative Care Hub to help them in times of needing urgent support including out of hours.
Good end of life care includes bereavement support.