Palliative and
End of Life Care
One Gloucestershire

One
Gloucestershire
Transforming Care, Transforming Communities

Gloucestershire all age, Integrated Care System Palliative and End of Life Care Strategy

2021 -
2025

ACKNOWLEDGEMENT

Gloucestershire Clinical Commissioning Group would like to acknowledge that the development of this strategy has only been made possible by the commitment and energy of all the partners listed below. In addition, the views, opinions and experiences of many Gloucestershire residents have been invaluable and have helped inform this strategy.

NHS
Gloucestershire Hospitals
NHS Foundation Trust

Gloucestershire
COUNTY COUNCIL

healthwatch
Gloucestershire

Sue Ryder
palliative, neurological and bereavement support

NHS
Gloucestershire Health and Care
NHS Foundation Trust

care UK

LONGFIELD
Community Hospice Care

GREAT OAKS
Hospice

NHS
South Western Ambulance Service
NHS Foundation Trust

CAMPDEN
HOME NURSING

Kate's
Home Nursing
A Special Kind of Palliative Care

ACTIVE IN THE LOCAL COMMUNITY
Friends of Fairford and Lechlade Communities
Formerly The League of Friends of Fairford Hospital

Cruse
Bereavement
Care

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1. EXECUTIVE SUMMARY

"End of life care is a system wide approach. A range of agencies are often involved at the end of a person's life. This will include different parts of the NHS: GPs, community services and hospitals, also care providers in the community or care homes, councils, hospices and voluntary sector organisations. Of course, there is critical involvement from the individual and their family and friends. The pattern and scope of involvement will vary for every individual, but for people to have a 'good' death all the parts need to work together."[1]

The purpose of this document is to set out the Gloucestershire's all age Integrated Care System (ICS) strategy for palliative & end-of-life care provided by Gloucestershire Health and Care Services NHS Trust (GHC), Gloucestershire Hospitals Foundation Trust, Gloucestershire County Council, hospices and other providers both statutory and voluntary.

The strategic objectives for care delivery, based on the Ambitions for Palliative & End-of-Life Care national framework, are:

1. Each person is seen as an individual.
2. Each person gets fair access to care.
3. Maximising comfort and wellbeing.
4. Care is coordinated.
5. All staff are prepared to care.
6. Each community is prepared to help.

To achieve these ambitions the ICS will need to consider Palliative and End of Life Care as everyone's business. Everyone will feel responsible for playing a positive part in delivering and achieving high-quality, personalised care and support for every individual approaching the end of their life and those important to them. A key element to achieving this approach is the partnership working between all parts of the ICS, along with other providers such as the charitable and voluntary sector.

As part of this collaborative approach, Gloucestershire ICS has identified that the Palliative and End of Life Care Strategic aim is to:-

> *"Develop a personalised approach that ensures all age coverage, listening to the voices of people with lived experience, attention to equality and health inequalities and supporting the continued implementation of the 6 ambitions for Palliative and End of Life Care."*

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[1] End of Life Care, a guide for Councils, LGA 2020

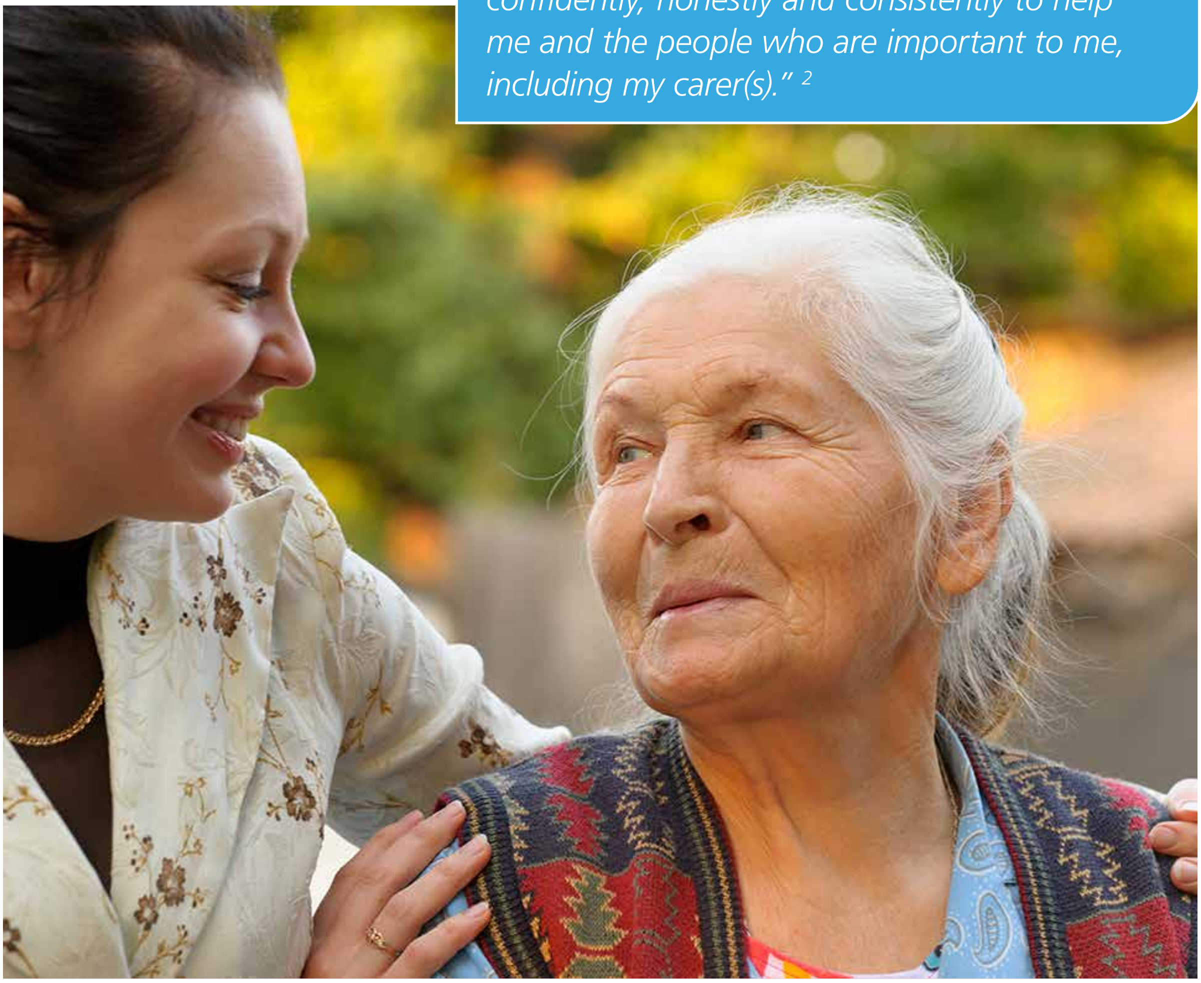
The Strategy has been informed by the Ambitions for Palliative & End-of-Life Care national framework, other national directives along with the recently refreshed Palliative and End of Life Care (P&EoLC) Needs Assessment, engagement with ICS partners, as well as feedback from family members, carers and the wider community.

Through data analysis and engagement key priorities have been identified which include:

- Early Identification of a person in their last 12 months of life
- Sharing information – development of a digital personalised care plan
- Access to 24/7 advice and support
- Enhanced pre and post bereavement support

These key priorities will be delivered through the workstreams that are identified at the end of the document. The Palliative and End of Life Care Clinical Programme Group will maintain oversight of all workstreams, and will work towards achieving the vision of good end of life care:

> *"I can make the last stage of my life as good as possible because everyone works together confidently, honestly and consistently to help me and the people who are important to me, including my carer(s)."* [2]



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[2] National Voices and the National Council for Palliative Care, Every moment counts: a narrative for person-centred coordinated care for people near the end of life, 2015

2. DEFINITIONS

The terms palliative care and end of life care are often used interchangeably, however there is a distinction between them:

2.1 Palliative care[3]

Palliative care is an approach that improves the quality of life of individuals and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of individualised care;
- offers a support system to help people live as actively as possible until death;
- offers a support system to help the family cope during the person's illness and in their own bereavement;
- uses a multidisciplinary approach to address the needs of individuals and their families;
- enhances quality of life and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, and includes those investigations needed to better understand and manage clinical complications.

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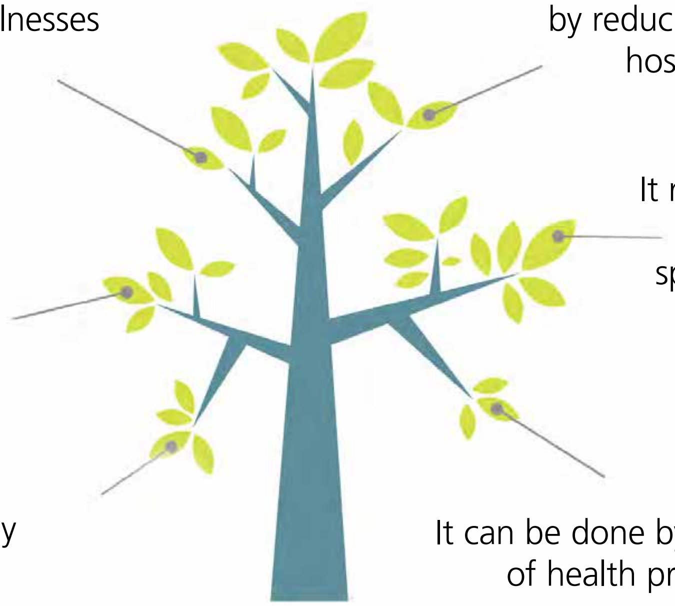
[3] Ambitions for Palliative and End of Life Care Glossary 2015 - 2020

Palliative Care can be provided by many types of health professionals and volunteers, it is described by the World Health Organisation using the below image:



It is care for patients with life-threatening illnesses & their families

It benefits health systems by reducing unnecessary hospital admissions

It relieves physical, psychosocial & spiritual suffering

It can be given in homes, health centres, hospitals and hospices

It improves quality of life

It can be done by many types of health professionals & volunteers

2.2 End of Life Care[4]

Individuals are 'approaching the end of life' when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with:

- advanced, progressive, incurable conditions
- general frailty and co-existing 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 events.

End of life care should help the person to live as well as possible until they die and to die with dignity. The people providing care should ask the person about their wishes and preferences, and take these into account as they work with the person to plan their care. They should also support their family, carers or other people who are important to the person. In General Medical Council guidance the term 'approaching the end of life' also applies to those extremely premature neonates whose prospects for survival are known to be very poor, and to people who are diagnosed as being in a persistent vegetative state (PVS) for whom a decision to withdraw treatment may lead to their death.

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[4] Ambitions for Palliative and End of Life Care Glossary 2015 - 2020

2.3 Integrating and introducing palliative care early in the illness process.

The World Health Organisation adopted a resolution on early palliative care in 2014. It states that palliative care should be considered from diagnosis onwards and integrated into care for people with any condition that means they may die in the foreseeable future[5]. Palliative care can improve the quality of life of patients and their families through timely identification of deteriorating health, holistic assessment of needs, management of pain and other problems (physical, psychosocial, and spiritual), and person centred planning of care[6].

Rather than a drastic switch from life prolonging care to palliative or hospice care towards the end of life, palliative care should adapt as a person's needs dictate through the illness course. The relative contributions of life prolonging care and comfort-based care shifts throughout the patient's illness, shifting towards palliative care which becomes more primary as curative care becomes less effective or available[7].

[5] "Strengthening of palliative care as a component of comprehensive care throughout the life course" (WHA67.19), urging national governments to carry out actions to develop palliative care, 2014

[6] Palliative care from diagnosis to death, BMJ, 2017

[7] Rethinking care towards the end of life- Salzburg Global Seminar 2016

Early Identification:

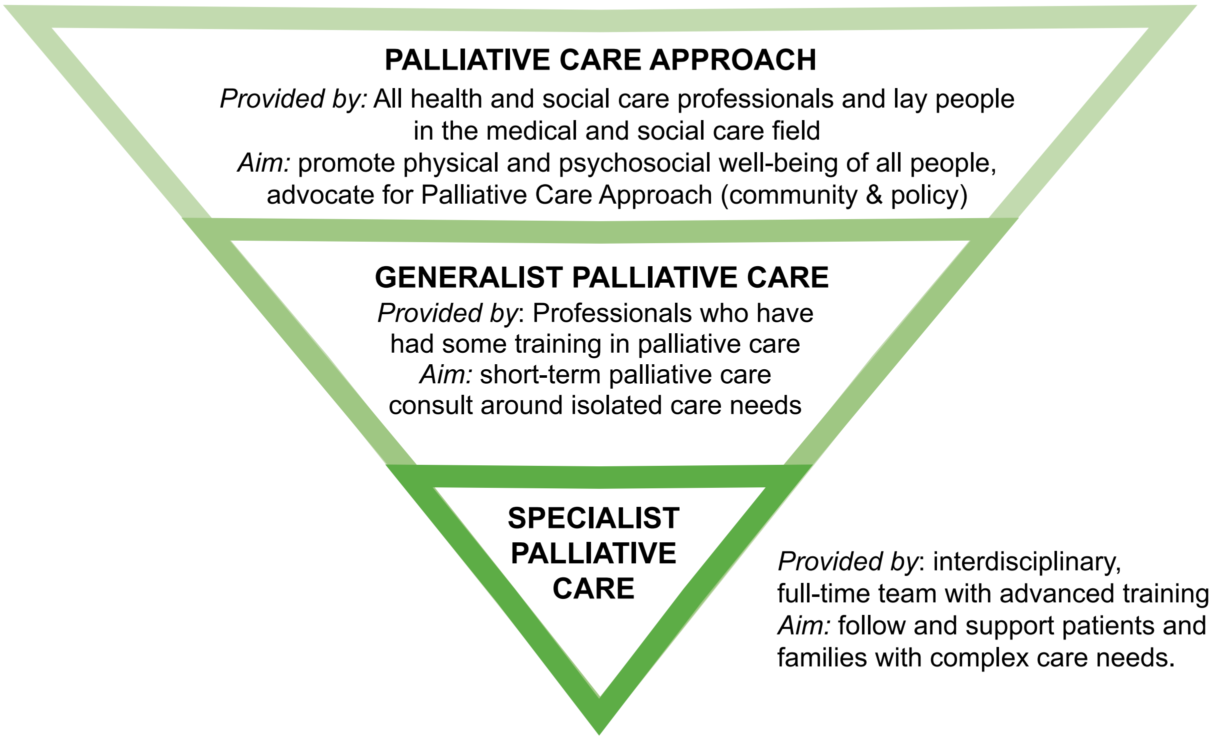
There are a number of advantages to early identification, both to the individual and their family and also to the health care system.

Improved recognition and optimised out-of-hospital services could translate into significant NHS savings,[8] using a population health management approach and other tools such as the Supportive and Palliative Care Indicators Tool SPICT to help predict and identify patients approaching the end of life has the potential to lead to more anticipatory, crisis-preventing care of patients in their last year of life. Being able to anticipate those likely to die in the coming year with any condition in any setting, is more likely to ensure greater provision of patient-centred equitable care.

In addition to cost-savings and better use of resources, early recognition leads to better patient outcomes. There has been much focus on enabling greater choices for people nearing the end of life, particularly in relation to place of care, and preferred place of death. Earlier identification enables a more proactive, less crisis-led approach, helping create the space leading to smoother planning of care in anticipation of later decline and a higher likely hood that the individual will die in their place of preference[9]

2.4 Levels of palliative care[10]:

There is a recognised need to move away from palliative care solely as a specilisation and toward a multi-tiered or multi-leveled definition. The below image illustrates a possible framing of this structure.



PALLIATIVE CARE APPROACH

Provided by: All health and social care professionals and lay people in the medical and social care field

Aim: promote physical and psychosocial well-being of all people, advocate for Palliative Care Approach (community & policy)

GENERALIST PALLIATIVE CARE

Provided by: Professionals who have had some training in palliative care

Aim: short-term palliative care consult around isolated care needs

SPECIALIST PALLIATIVE CARE

Provided by: interdisciplinary, full-time team with advanced training

Aim: follow and support patients and families with complex care needs.

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[8] Hughes-Hallett T, Craft A, Davies C (2011) Palliative care funding review. Funding the right care and support for everyone. (Secretary of State for Health).

[9] Keri Thomas and Sir Muir Gray, Population based person centred end of life care: time to rethink 2018

[10] Rethinking care towards the end of life-Salzburg Global Seminar 2016

2.5 Specialist palliative care is provided by multi-disciplinary teams that include Palliative Medicine and will be needed for the minority of people with life-limiting illness. This multidisciplinary approach may include for example, consultants, nurse specialists, specialist social workers and experts in psychological care along with Occupational Therapists, Physiotherapists, Counsellors and Complementary therapy. Specialist services include some hospices, hospital inpatient advisory teams, out-patient services, home care, day care and bereavement services.

2.6 Generalist palliative care is provided by general health and social care services, including GPs, district and other general community nursing teams, hospital staff, care home staff, social care staff, carers and others. General services will provide routine/standard care for people at the end of their lives.

2.7 Third and community sector providers In Gloucestershire provide hospice care, counselling, information, helplines, forums and local groups to support people, and their carers to manage end of life issues.

3. VISION

National Voices, the National Council for Palliative Care and NHS England have produced a clear description of the National Palliative and End of Life Care partnership's vision of good end of life care:

> *"I can make the last stage of my life as good as possible because everyone works together confidently, honestly and consistently to help me and the people who are important to me, including my carer(s)."* [11]

The Partnership's ambition, and one Gloucestershire Clinical Commissioning Group (CCG) shares, is to make this experience a consistent reality for all.

Delivery of this vision requires a joined up Integrated Care System (ICS) approach, and includes a range of Palliative and End of Life Care services which includes specialist and generalist provision and services delivered by third sector and community organisations.

The ICS collaborative in September 2020 identified Gloucestershire's Palliative and End of Life Care Strategic aim is to:-

> *"Develop a personalised approach that ensures all age coverage, listening to the voices of people with lived experience, attention to equality and health inequalities and supporting the continued implementation of the 6 ambitions for Palliative and End of Life Care."*

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[11] National Voices and the National Council for Palliative Care, Every moment counts: a narrative for person-centred coordinated care for people near the end of life, 2015

4. NATIONAL CONTEXT AND DRIVERS – ALL AGE

The recent White Paper (February 2021) "Integration and Innovation: working together to improve health and social care for all"[12] focuses on:

- a new model of collaboration, partnership and integration
- reducing bureaucracy
- an increased focus on quality and safety
- the adoption of a population health management approach
- the value of a coterminous boundary with local authorities whilst recognising the importance of "place".[13]

Several national policies and priorities have helped to inform and shape this strategy in Gloucestershire. The 6 ambitions for Palliative and End of Life Care developed in 2015 (and relaunched essentially unchanged in 2021) remain the framework for local action. In addition to the 6 ambitions the NHS Long term plan also emphasises the importance of personalisation to improve end of life care, a consequence of which would be the reduction in avoidable emergency admissions and more people being able to die in a place they have chosen.

National Ambitions

National Palliative and End of Life Care Partnership

NHS England

Six ambitions to bring that vision about

01 Each person is seen as an individual

02 Each person gets fair access to care

03 Maximising comfort and wellbeing

04 Care is coordinated

05 All staff are prepared to care

06 Each community is prepared to help

"I can make the last stage of my life as good as possible because everyone works together confidently, honestly and consistently to help me and the people who are important to me, including my carer(s)."

National Palliative and End of Life Care Partnership
www.endoflifecareambitions.org.uk

www.england.nhs.uk

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[12] https://www.gov.uk/government/publications/working-together-to-improve-health-and-social-care-for-all/integration-and-innovation-working-together-to-improve-health-and-social-care-for-all-html-version (accessed 27.04.2021)

[13] https://www.gov.uk/government/publications/working-together-to-improve-health-and-social-care-for-all/integration-and-innovation-working-together-to-improve-health-and-social-care-for-all-html-version (accessed 27.04.2021)

4.1 The 6 ambitions for Palliative and End of Life Care:

1 Each person is seen as an individual

I, and the people important to me, have opportunities to have honest, informed and timely conversations and to know that I might die soon. I am asked what matters most to me. Those who care for me know that and work with me to do what's possible.

2 Each person gets fair access to care

I live in a society where I get good end of life care regardless of who I am, where I live or the circumstances of my life.

3 Maximising comfort and wellbeing

My care is regularly reviewed and every effort is made for me to have the support, care and treatment that might be needed to help me to be as comfortable and as free from distress as possible.

4 Care is coordinated

I get the right help at the right time from the right people. I have a team around me who know my needs and my plans and work together to help me achieve them. I can always reach someone who will listen and respond at any time of the day or night.

5 All staff are prepared to care

Wherever I am, health and care staff bring empathy, skills and expertise and give me competent, confident and compassionate care.

6 Each community is prepared to help

I live in a community where everybody recognises that we all have a role to play in supporting each other in times of crisis and loss. People are ready, willing and confident to have conversations about living and dying well and to support each other in emotional and practical ways.

4.2 Six national Palliative and End of Life care Priorities:

Building on the 6 ambitions are the recently announced NHSE/I Palliative and End of Life Care national priorities as set out in their draft 5 year delivery plan (2020-2025). While these priorities are currently being consulted on they are unlikely to alter significantly. These overarching priorities can be seen as operational and system enablers to support the delivery of the 6 ambitions. They will be considered in conjunction with the 6 ambitions when identifying local priorities in Gloucestershire.

1. Clinical Excellence	***2. Digital***	***3. Commissioning, contracting and finance***
Support and enable the provision of outstanding clinical care based on best available evidence to ensure personalised palliative and personalised care for all ages in all settings	Establish a clear digital blueprint for the, definition, development and implementation of information standards for P&EoLC in England	Explore, make recommendations and support development of commissioning and contracting arrangements, to increase choice, flexibility and control to people and ensure optimal use of funding
4. Patient Experience	***5. Stakeholder Engagement & Communications***	***6. Workforce***
Identify mechanisms to systematically embed the requirement and ability to understand and learn from patient experience into the commissioning and delivery of PEoLC services	Oversee the development and delivery of a strategic approach to communications and engagement across the national programme, and into the regions	Support the development of a world class PEoLC workforce that is confident, capable and responsive to the needs of the individual.

Alongside these 6 Priorities are 3 critical considerations, an all age approach, listening to the voices of people with lived experience and attention to equality and health inequality.

4.3 National Institute for Health and Care Excellence (NICE) Quality Standards for Adults and Children

4.3.1 Adult Standard - QS13

This quality standard covers care for adults (aged 18 and over) who are approaching the end of their life. This includes people who are likely to die within 12 months, people with advanced, progressive, incurable conditions and people with life-threatening acute conditions. It also covers support for their families and carers. It includes care provided by health and social care staff in all settings. It describes high-quality care in priority areas for improvement.

The NICE quality standards for end of life care are being reviewed, with updated draft quality standards out to consultation, statements out for consultation include:

Statement 1 Adults who are likely to be approaching the end of their life are identified using locally developed systems. [2011, updated 2021]

Statement 2 Adults approaching the end of their life have opportunities to discuss advance care planning. [New 2021]

Statement 3 Carers providing end of life care to people at home are supported to access local services that can provide assistance. [New 2021]

Statement 4 Adults approaching the end of their life receive care that is coordinated between health and social care practitioners within and across different services and organisations. [2011, updated 2021]

Statement 5 Adults approaching the end of their life have access to support 24 hours a day, 7 days a week. [2011, updated 2021]

For further information regarding NICE quality standards for people approaching their end of life please see the appendix.

In 2016, NICE published a guideline End of Life Care for Infants, Children and Young People: Planning and Management Guideline (2016) followed by a Quality Standard in 2017 which aims to improve the planning and management of end of life and palliative care for infants, children and young people (aged 0–17 years) with life-limiting and life-threatening conditions.

Statement 1 Infants, children and young people with a life-limiting condition and their parents or carers are involved in developing an advance care plan.

Statement 2 Infants, children and young people with a life-limiting condition have a named medical specialist who leads and coordinates their care.

Statement 3 Infants, children and young people with a life-limiting condition and their parents or carers are given information about emotional and psychological support, including how to access it.

Statement 4 Infants, children and young people with a life-limiting condition are cared for by a multidisciplinary team that includes members of the specialist paediatric palliative care team.

Statement 5 Parents or carers of infants, children and young people approaching the end of life are offered support for grief and loss when their child is nearing the end of their life and after their death.

Statement 6 Infants, children and young people approaching the end of life and being cared for at home have 24-hour access to both children's nursing care and advice from a consultant in paediatric palliative care.

4.4 The Care Act

The Care Act 2014 sets the legal framework for councils with social care responsibilities to support individuals nearing the end of their lives along with their families and carers. There is no specific guidance in the Care Act relating to end of life care, although the principles underpinning good end of life care run through the Act. The act also enshrines the personalised approach. Councils have the following responsibilities towards individuals and their families under the Act.

> *"10.1 Care and support should put people in control of their care, with the support that they need to enhance their wellbeing and improve their connections to family, friends and community.*
>
> *10.2 The person must be genuinely involved and influential throughout the planning process and should be given every opportunity to take joint ownership of the development of the plan with the council if they wish, and the council agrees."*

Specific activities that Councils are responsible for in relation to Palliative and End of Life Care include:

- Councils have responsibilities to undertake Needs Assessments: Councils must undertake an assessment for any adult with an appearance of need for care and support, regardless of whether the council thinks the individual has eligible needs or of their financial situation.
- Councils and their partners in the provision of housing and adaptations may also have responsibilities to people at the end of their lives.
- A person's wish to die at home may need involvement from another council with housing responsibilities, or a Housing Association.
- The legislation also places a duty on councils in relation to market development, with duties on councils to facilitate a diverse, sustainable high-quality market for their whole local population, including those who pay for their own care and to promote efficient and effective operation of the adult care and support market as a whole.
- Many people die at home or in care homes, care in both settings is substantially commissioned by councils. The duty in the Care Act extends to services, which the Local Authority does not directly commission, therefore it is important for councils to be assured that their commissioned and market engagement are, for example, helping to deliver the 6 key aims of the Ambitions Partnership. Particularly important is whether care staff and managers are trained in end of life care and connected to local networks.

5.0 LOCAL CONTEXT

5.1 Findings from the Palliative and End of Life Care needs analysis

In 2020/21 the Palliative and End of Life Care Needs Assessment for the county was refreshed. In line with NHSE/I recommendations this needs assessment focused on the end of life care for all age groups and considered the whole spectrum of services delivered by health, social care and (where possible) voluntary and community sector agencies. It included:

- A review of the available epidemiological information relating to end of life care.
- Mapping existing services.
- Modelling of future need.
- Identification of priorities for further development.

The needs assessment was conducted during the early phases of the Covid-19 pandemic (March – September 2020) and took into consideration the short term impact of the pandemic on future need. Longer term impact is yet to be determined.

Key findings from the Needs Assessment are shared below, for a more comprehensive understanding this strategy document should be read in conjunction with the full Gloucestershire Palliative and End of Life Care Needs Assessment 2020.

Palliative and End of Life Care in Gloucestershire

Increase in need

By 2040 the ONS projects that Gloucestershire's under 65 population will increase by **1%** (3,354) and the over 65 population by **42%** (59,547). Planning services to meet the needs of the rising older population and those that will care for them is increasingly important

Increase in the number of carers

The number of carers aged **65 years old** and over is predicted to rise by **24%** by 2030 with the greatest increase predicted for **80-84 year olds (53.35%).**

Long Term conditions

The average person at the age of **47 years** living in the most deprived quintile has at least 1 LTC, the same is true of someone living in the least deprived quintile when thay are **60 years old**

Reducing Inequality

14 of the top **20** most deprived areas in the County are in Gloucester City. Gloucester has the lowest life expectancy of **78 years** for males and **83 years** for females, and the highest inequality gap of 7 and 5 years for males and females respectively

▼ 5%

Dying in hospital

The proportion of deaths in Gloucestershire occuring in hospital has reduced by **5%** since 2016 to **38%**

Dying in usual place of residence

In 2019/20 **82.9%** of people with dementia in Gloucestershire died in their usual place of residence (an increase of **4%** since 2016). only **14%** of people with dementia died in hospital a decrease of **5.5%** since the last report

Advance Care Planning

On average of only **42%** of people who are on the end of life care register are coded as having an advance care plan recorded

Key priorities:

Early identification

Continue to improve and promote the need for early identification

Joining up our data

Development of an ICS dashboard and a digital personalised care plan that can be shared

Access to 24/7 advice and support

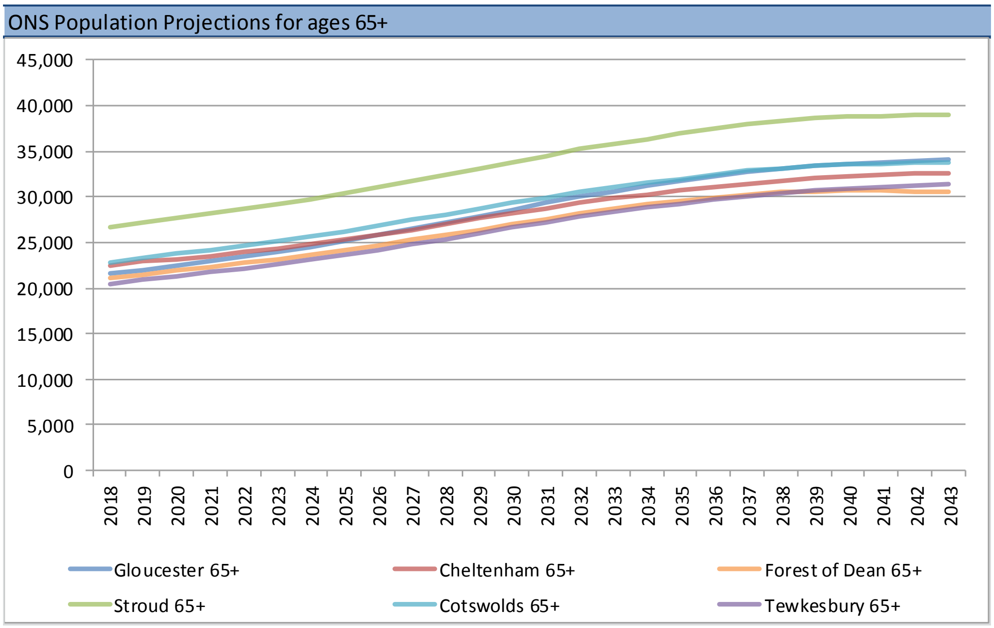
Scope and develop a **24/7** palliative and end of life care support and advice offer

Enhance pre and post bereavement support

Develop consistent pre and post bereavement support across Gloucestershire

5.1.1 Demographic insights

- The single most important indicator of end of life care need is the annual incidence of deaths. From 2016-2019 Gloucestershire had an average of 6,521 deaths per year. In 2020 the number of deaths was 7,235. This increase is due to the impact of Covid-19. The effects of the pandemic will be discussed in the report.
- The number of 'expected deaths', where end of life care needs can be identified and planned for, is circa 4,890 per annum in Gloucestershire in 2020.
- A higher proportion of older people live in Stroud, the Cotswolds and Cheltenham compared to the rest of the county, these areas have the highest numbers of expected deaths annually which may translate into higher levels of end of life care need in those localities.
- There is a significant increase in numbers of children and young people surviving for longer with Life Limiting Conditions. Significantly, morbidity is increasing, and death is occurring later in childhood or as young adults.
- By 2030 the Office of National Statistics projects that Gloucestershire's under 65 population will have increased by 1% (3,410) and the over 65 population by 24% (33,289) compared to 2018 data. By 2040 the ONS projects that Gloucestershire's under 65 population will have increased by 1% (3,354) and the over 65 population by 42% (59,547) compared to 2018 figures. Planning services to meet the needs of the rising older population and those that will care for them is increasingly important.

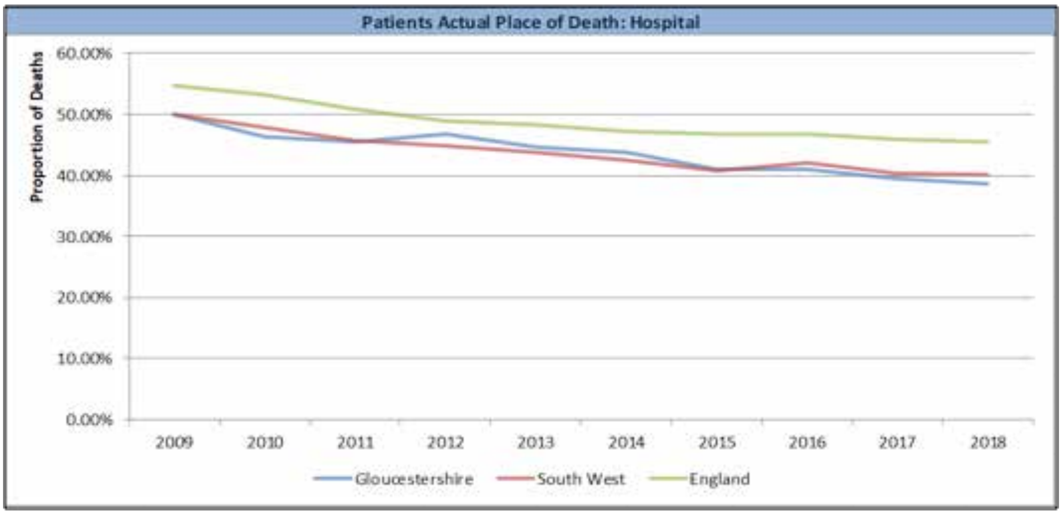


- 14 of the top 20 most deprived areas in the County are in Gloucester city including all of the top 5. Gloucester has the lowest life expectancy of 78 years for males and 83 years for females, and the highest inequality gap of 7 and 5 years for males and females respectively. Higher levels of deprivation correlate strongly with lower life expectancy. This correlation needs to be considered when planning access to end of life care services. needs to be considered when planning access to end of life care services.

- People living in more deprived areas develop Long Term Conditions (LTCs) at a younger age; the average person at the age of 47 years living in the most deprived quintile (Q1) has at least 1 LTC – the same is true of someone living in the least deprived quintile (Q5) when they are 60 years old.
- People living alone require more community and primary care end of life support if they wish to die at home and are more at risk of dying in hospital. The proportion of the population living alone is similar across the localities in Gloucestershire although Cheltenham has a slightly higher proportion of 85 years + population living alone localities in Gloucestershire although Cheltenham has a slightly higher proportion of 85 years + population living alone.

5.1.2 People's needs and preferences

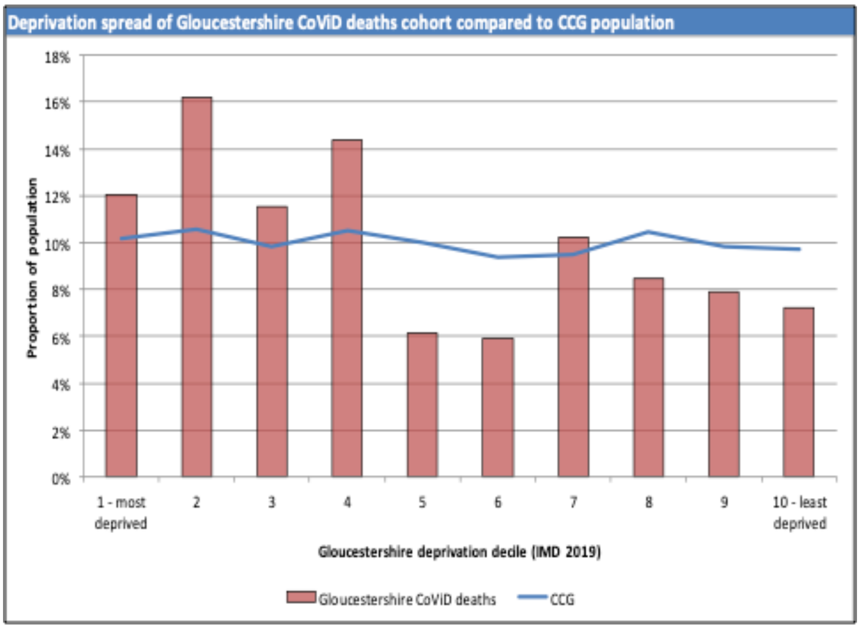
The proportion of Gloucestershire deaths occurring in hospital in 2019/20 was 38%, compared to 45% in England and 40% in the South West. The proportion of deaths in Gloucestershire occurring in hospital has reduced by 5% since 2016.



- People are more likely to die in hospital if they have circulatory or respiratory diseases, 46.5% and 58.6% respectively died in hospital in 2019/20. This is well above the average for Gloucestershire of 38%. However the proportion has reduced since 2016 by 3.9% for respiratory conditions and 3% for circulatory conditions.
- In 2019/20 82.9% of people with dementia in Gloucestershire died in their usual place of residence (an increase of 4% since 2016). Only 14% of people with dementia died in hospital a decrease of 5.5% since the last report.
- On average only 42% of people who are on the end of life care register are coded as having an advance care plan recorded.
- A preferred place of death is only recorded on average in 8% of deaths. When considering place of death for the cohort with a recorded preference we find that 77% of those people died in their place of preference.
- In 2016 there was no data available to determine whether people with disabilities including learning disability have equitable access to Palliative and End of Life Care services. Data is now available from the Learning Disabilities Mortality Review (LeDeR 2020). The report demonstrates improvements in services, 56% (18 deaths) had an active end of life plan in place (compared to 46% nationally). However there is still a gap in our understanding of the extent to which fair access is or is not achieved for all inequality groups.

5.1.3 Impact of Covid-19

- Deaths largely reflect the national picture in terms of rising above the 5-year average during the first wave, falling below for the following weeks and rising again due to reasons other than Covid-19.
- Between March and August 2020 patients living in deprivation deciles 1-4 accounted for 54% of deaths attributed to Covid-19 in Gloucestershire; the proportion of the CCG population in these areas is 41%.



- Black and Minority Ethnic (BAME) patients accounted for 1.9% of deaths attributed to Covid-19 in Gloucestershire; the proportion of the CCG BAME population is 5.8%. The national over representation of BAME deaths is not reflected in Gloucestershire – this could be because the Gloucestershire BAME population is on average 12 years younger than the White population and age is the strongest risk factor.
- Of deaths registered up to 7th August 2020 the majority (93%, 538) of deaths occurred in a care home (47%, 273) or hospital (46%, 265). The location of deaths varies across Districts significantly; this could be due to the number of care homes in each district.
- The impact on carers' mental health is significant - Carers UK's survey into the experiences of over 5,000 current and former carers found that 70% of carers are providing more care due to the Covid-19[14].
- Our data suggests that 36% of Covid-19 deaths in Gloucestershire were of patients with Dementia, whilst the ONS study predicted 25%.
- There was a high prevalence of LTC's which allows us to understand the local risk groups e.g. 37% prevalence of dementia.
- Long term impact of Covid-19 on future Palliative and End of Life Care needs are still to be fully understood.

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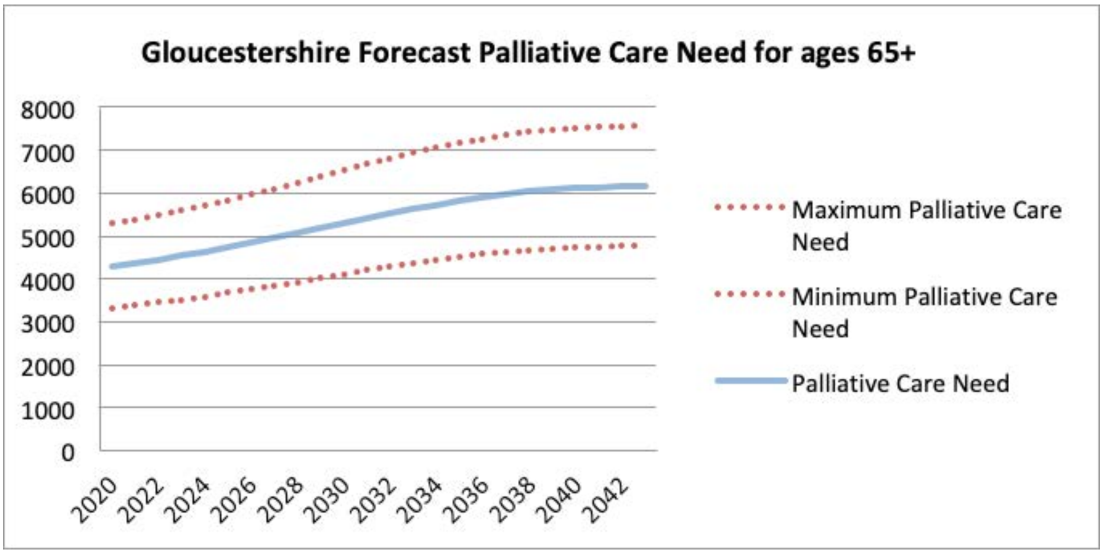
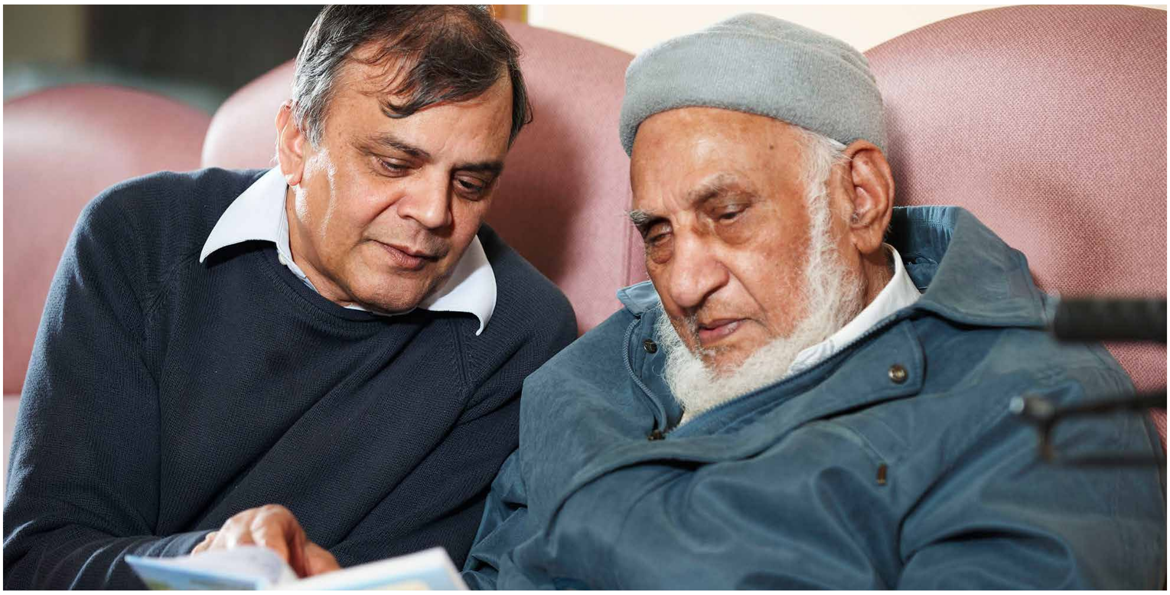
[14] Carers UK, Caring behind closed doors, 2020

5.1.4 Modelling future need:

- We see the biggest increase in Palliative and End of Life Care need is with those aged over 65yrs, from 4,298 in 2020 to 4,746 in 2025, rising to 6,145 in 2042.



- Modelling undertaken as part of the Palliative and End of Life Care Needs Assessment shows that the requirement for bereavement services in the context of the pandemic will increase by 311 beyond previously anticipated levels. Bereavement capacity was already struggling to meet demand in the county even prior to the pandemic.
- If the proportion of carers in the population stays the same, the number of carers aged 65 years old and over is predicted to rise from 20,157 in 2020 to 25,077 in 2030, a rise of 24.4%, with the greatest increase predicted for 80-84 year-olds (53.35%).



5.1.5 Recommendations at a glance

Below are examples of the next steps identified from the Needs Assessment 2020 to work towards achieving the 6 ambitions for Palliative and End of Life Care.

Ambition 1:	Ambition 2:	Ambition 3:
Each person is seen as an individual	**Each person gets fair access to care**	**Maximising comfort and wellbeing**
Implement projects to support early identification Continue to rollout and embed personalised care plans Roll out and embed advance care planning and ReSPECT v3 Further develop Gloucestershire's offer of pre and post bereavement support Further develop an ICS approach to shared decision-making	Routinely use population health management data to support identification of individuals in the last 12 months of life Use identified and agreed baselines and outcome measures to identify areas for development and embed a system of continuous learning and improvement Map services to identify gaps for all groups to better understand inequalities in access including those with a non-cancer diagnosis Develop an expert user group made up of people with lived experience to lead on the identification of priorities based on evidence gathered Gain a better understanding of diversity, cultural differences and BAME communities within Gloucestershire to improve the support offered to individuals, families and carers Develop strategic relationships with the various partnership boards to better understand and address issues	Develop a clear process for case reviews of deaths in Gloucestershire ICS adopting a culture of no blame and learning Scope and develop a 24/7 P&EoLC support and advice offer that is both practitioner and public facing Develop clear referral pathways for access to spiritual care to support the individual, families and carers at EOL across all providers within the ICS

Ambition 4:	Ambition 5:	Ambition 6:
Care is Co-ordinated	**All Staff are prepared to care**	**Each Community is prepared to help**
Review the progress of JUYI (Joining Up Your Information- Gloucestershire's Shared Care Record) and consider further options for developing a digital solutions to sharing patient information Further develop and embed an ICS approach to shared decision-making Develop a P&EoLC ICS dashboard in order to better establish baselines, understand the impact across the ICS and monitor progress moving forward	Develop and implement an ICS P&EoLC training and education strategy to include national competency frameworks (Royal College of Paediatrics and Child Heath, Royal College of Nursing) along with the Royal College of General Practitioners toolkit and identify and support competency/skills gaps across the ICS Support service reviews and proposals for improvement where required Support the development of transition arrangements between Children's and Adult's Services	Develop and strengthen relationships with community and third sector providers to further the aim of normalising end of life, death, bereavement and grief Develop and implement a public facing communication and engagement strategy to better understand the views and preferences of the population of Gloucestershire

https://www.rcgp.org.uk/clinical-and-research/resources/toolkits/palliative-and-end-of-life-care-toolkit.aspx

6.0 FEEDBACK FROM PATIENTS, FAMILIES & CARERS

6.1 Carers survey

In April 2020 Carers UK published the report "Caring Behind Closed Doors"[15]. This report looks at the profound impact the Covid-19 crisis is having on carers' lives. Carers UK's survey into the experiences of over 5,000 current and former carers found that:

- 70% of carers are providing more care due to the Covid-19 outbreak.
- Over a third (35%) of carers are providing more care as a result of local services reducing or closing.
- Carers are, on average, providing 10 additional hours of care a week.
- 69% of all carers are providing more help with emotional support, motivation, or keeping an eye/ checking in on the person they care for.

In November 2020 Gloucestershire County Council published a locally focused report, Supporting Carers beyond Covid-19.[16] For the purposes of the report the focus was the results of the local carer's survey that was live in August and September 2020. The response level was good, with 273 carers responding. The report also drew on the following reports:

- Caring Behind Closed Doors – Carers UK
- GP Patient survey – analysis of responses from carers in Gloucestershire
- Healthwatch Gloucestershire carers in Covid-19 focus groups
- Healthwatch Gloucestershire – carers of people with mental health issues report
- #shareyourstory – carers' responses
- Gloucestershire Carers Hub daily log of carers' concerns during lockdown

The two main purposes for the report were:

1. To amplify the voices of carers in Gloucestershire. *We will share carer's stories, experiences and concerns with people all across the health and social care system, as well as the voluntary and private sectors.*
2. To ensure actions taken in 2021 reflect what carers need and want. Included in the report is a 'You said, we will' section, so people can see how carers are responded to directly.

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[15] Carers UK, Caring behind closed doors, 2020

[16] Gloucestershire County Council, Supporting Carers beyond Covid-19, 2020

The overarching themes from the report found that:

- Many carers mental health is being affected by the current situation. Many are feeling anxious and stressed.
- Many carers are very worried about Covid-19 and do not want to put themselves or the person they care for at risk of the virus.
- Respite is still crucial for carers.
- Some carers are feeling abandoned by healthcare professionals.
- Many carers do not know where to go for help and support.

Carers said:

- I am looking forward to more time outside, getting back into nature, gardening and exercise.
- I want more social activity with friends and family
- I sometimes struggle with these activities due to the health of my cared for, someone to look after my cared for and my own health
- I would like a GP carer co-ordinator, a well-being event and carer bubbles/ peer support groups to support me
- I would like more support for IT training and advice on how to use technology

6.2 End of Life Survey

Shaped around the 6 ambitions a public facing survey was developed as part of dying matters engagement week. This survey ran from May 2021 to July 2021. In total there were 334 responses to the survey, with 127 responses from people whose loved one was a Gloucestershire resident. The data below includes only responses from those people whose loved one was resident in Gloucestershire. The responses asked people to consider care they and their loved one received in the last 3 years.

Responses reflected the general trend of a move towards people dying at home, with 40% of people saying their loved one died at home, 39% in hospital, 15% in a care home and 7% dying in a hospice.

Highlights from the survey responses are below, for a full survey results please see the appendix.

Positive findings from the survey

- When asked if the Health and care staff caring for your loved one were understanding and compassionate 76% of people either strongly agreed or agreed with the statement, with 14% either disagreeing or strongly disagreeing.
- When asked if the person close to the respondent was listened to and supported by those that cared for them: 73% of people either strongly agreed or agreed with the statement, with 17% either disagreeing or strongly disagreeing.
- When asked if all involved knew who the care staff were and why they were there 65% either strongly agreed or agreed, with 24% either disagreeing or strongly disagreeing.
- When asked if the person close to them had the support care and treatment that they needed to help them to be comfortable and as free from distress as possible 70% of people either strongly agreed or agreed with the statement, with only 21% either disagreeing or strongly disagreeing.
- When asked if health and care staff caring for your loved one were skilled and competent 76% of people either strongly agreed or agreed with the statement, with only 13% either disagreeing or strongly disagreeing.
- Only 14% of people surveyed accessed bereavement support, however out of those that did 88% either strongly agreed or agreed with the statement that the information or support I received really made a difference to me.

Areas for development

- When asked if the person close to the respondent had recorded their wishes on a plan that was shared with healthcare professionals: 45% of people either strongly agreed or agreed with the statement, however 33% either disagreed or strongly disagreed and a further 20% didn’t know.
- When asked if the person close to me had a plan and medication in place just in case they needed them 55% of people either strongly agreed or agreed with the statement, however 29% either disagreed or strongly disagreed.
- When asked if the person close to me was able to access equipment that helped them to remain at home 55% of people either strongly agreed or agreed with the statement, however 29% either disagreed or strongly disagreed.

Next steps

- Where areas for development have been identified these will be fed into the relevant work stream.
- Further work will be undertaken to identify specific trends or issues within the comments section of the survey.
- 88% of respondents were White British, further work will be done to understand the experiences of ethnic minority groups.
- It is proposed that this survey is run each year around Dying Matters Week, not only to promote further conversations around death and dying but to also understand if the public identify any progress being made against the 6 ambitions.

6.3 Clinical audits

6.3.1 National Audit of Care at the End of Life (NACEL)

This national audit reviewed the quality of care provided to adults and to those important to them who died in Gloucestershire Hospitals NHS Foundation Trust in Spring 2019. Comparison was made with other Trusts in England and Wales. The audit required data to be uploaded and generated outputs. These included combined summary scores aligning to the 5 Priorities of Care from 'One Chance to Get it Right.'[1] The 2019 round comprised 3 key elements:

- Organisational audit
- Case note review
- Quality survey of bereaved relatives

Results and commentary

36 of a possible 40 sets of notes were reviewed. The response rate to the quality survey of bereaved relatives was 22%, similar to nationally. As demonstrated on the infographic (appendix F), with the exception of 'recognising the possibility of imminent death' and 'workforce' which are discussed below, the Trust results compare similarly and frequently favourably to the national picture.

The care of dying patients in GHFT is supported by the Gloucestershire wide 'Shared Care Plan' document which helps to enable a personalised care plan for individuals to be agreed with them and those important to them and for the delivery of this care to be documented.

The summary scores were particularly influenced by the very positive feedback provided by bereaved relatives.
This included: with respect to their information needs, involvement in decisions about the persons care and also the care environment. Three quarters of respondents rated the care and support provided to the dying person as outstanding or excellent (national comparison approx. two thirds) and two thirds rated the care and support provided to them as outstanding or excellent (national comparison approx. half).

This is the second round of this National Audit. While the audit aims to *improve the quality of health and social care services through the use of relevant, benchmarking* due to methodological changes most summary scores cannot be compared between the two rounds. The 'recognition of the possibility of imminent death' domains which are shown on the infographic can be compared as these do not comprise summary scores. In the first round GHFT was aligned with the national average but in this round, it has scored less well. This is being addressed in a number of ways including re-calculating for a further cohort of patients, revisiting the identification and management of dying including in mandatory training and other education sessions and developing ways to additionally support clinicians in identifying and managing patients who are 'sick enough to die.'

The GHFT score for workforce reflects that at the time of the audit the Trust did not have End of Life Care included in induction or mandatory training or a face to face specialist palliative care service seven days/week. There is currently an End of Life module included in mandatory training. Whilst two thirds of Trusts similarly do not have a face to face service at weekends this was a component of Priority 5 of One Chance to Get it Right[17]. Currently advice to professionals is always available by telephone.

The Trust was enrolled to participate in the third round of the audit during Spring / Summer 2020. This was postponed due to Covid-19 with and will take place in 2021.

See the Needs Assessment for full Gloucestershire Hospitals NHS Foundation Trust NACEL infographic.

The NACEL audit was also undertaken in 2019 for the then Gloucestershire Care Services (GCS). This service has since merged with 2gether NHS Foundation Trust forming Gloucestershire Health and Care Service NHS Foundation Trust (GHC). This audit purely focuses on physical health services and is based on the findings of 23 case note reviews. The audit found that in terms of individual care planning the trust performed well with 87% of people having an individualised plan of care, compared to 71% of people nationally. However, in the areas of communication with the dying person and family/ carers GCS fell slightly below the England average. However, families and others' experience of care in terms of quality well exceeded the UK average. See the Needs Assessment for full NACEL info graphic.

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[17] Leadership Alliance for the Care of Dying People, One Chance to get it right Improving people's experiences of care in the last few days and hours of life 2014

7. FINDINGS FROM THE PALLIATIVE AND END OF LIFE CARE COLLABORATIVE

A system wide Palliative and End of Life Care collaborative event took place in September/October 2020. The Collaborative was attended by upwards of 70 stakeholders from across the ICS. Prior to the event a survey of stakeholders indicated that the 6 ambitions were generally thought to be well implemented at a service level. However, there was recognition more could be done to join up across the county. Through the interactive event workshops these system needs were further discussed and clarified, taking into consideration the variety of services and partners involved across the Palliative and End of Life Care system. The events enabled internal and external partners across the ICS to review, refresh and reset Gloucestershire's system-wide transformation approach to Palliative and End of Life Care. Throughout the sessions local priorities in the context of national drivers were identified.

This resulted in the co-production of the following need areas/ local priorities:

A. Professionals confident in responding to the changing needs and wishes of people as they reach the end of life and communicating well with system colleagues;

B. Understanding the individual and their family (including their unique presentations and needs, and consideration for personal context e.g. culture, ethnicity, learning disability);

C. Shared knowledge of the full range of services and community assets in the county (so that people can be supported to access the right care at the right time for them);

D. Shared Care Plans to enable timely responses and good documentation of wishes (including digital solutions);

E. Smooth and supported transitions between children's and adult Palliative and End of Life Care services;

F. A sustainable finance model to enable high quality Palliative and End of Life Care to meet the needs of our local communities. There is potential to use different commissioning models, such as integrated care provider contracts to promote a sustainable, systems approach.

G. A 24/7 coordination hub (for public and professionals) enabling a consistent approach to access advice and coordination of relevant services.

These outputs along with the findings of the Needs Assessment have been combined to shape the Palliative and End of Life Care strategy.

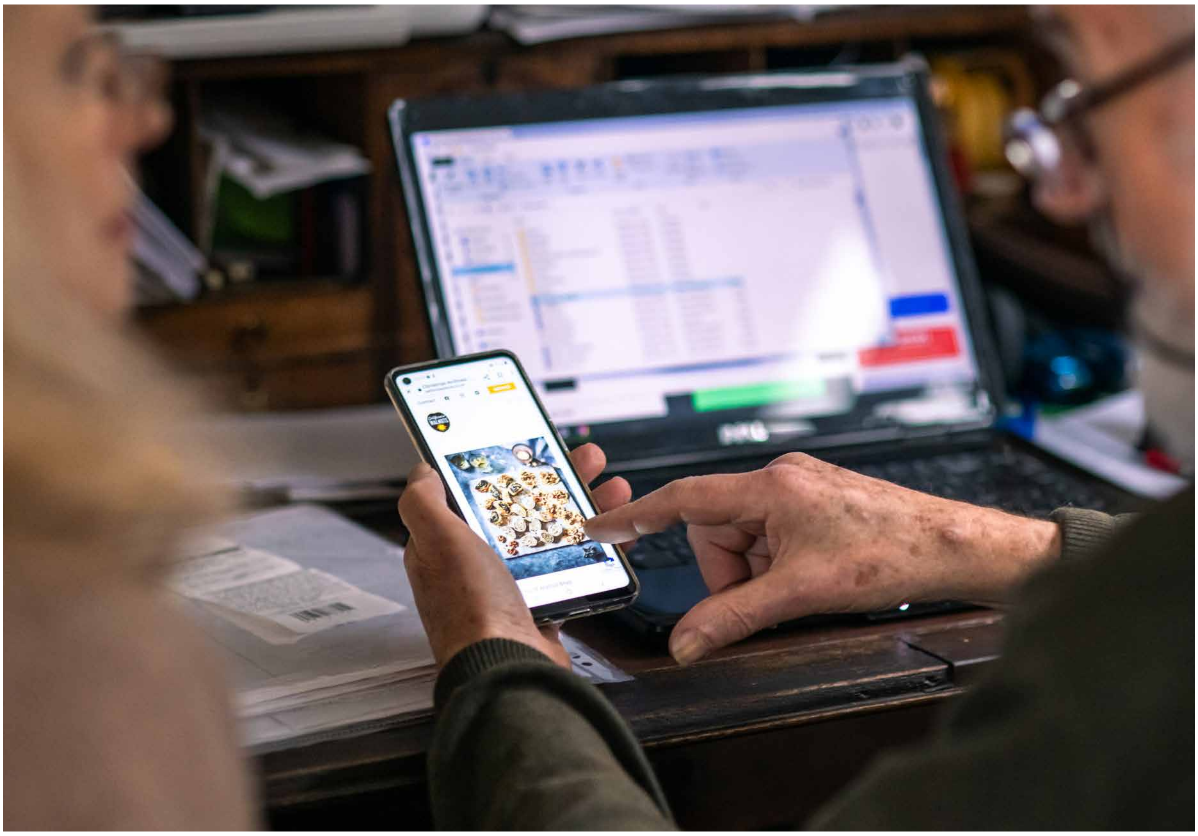
7.1 Ambitions and local priorities

The ICS collaborative in September 2020 identified Gloucestershire's Palliative and End of Life Care strategic aim is to:-

> *"Develop a personalised approach that ensures all age coverage, listening to the voices of people with lived experience, attention to equality and health inequalities and supporting the continued implementation of the 6 ambitions for Palliative and End of Life Care."*

National Ambition	Local Priorities
Each person is seen as an individual *"I, and the people important to me, have opportunities to have honest, informed and timely conversations and to know that I might die soon. I am asked what matters most to me. Those who care for me know that and work with me to do what's possible."*	**Understanding of the Individual & their family** including their unique presentations and needs, and consideration for personal context e.g. culture, ethnicity or learning disability Taking a personalised approach to each individual recognising all their needs Providing personalised bereavement support appropriate for all Understanding of the individual's rights and needs for advocacy
Each person gets fair access to care. *"I live in a society where I get good end of life care regardless of who I am, where I live or the circumstances of my life"*	**Shared knowledge** of the **full range of services** and community assets in the county so that patients can be supported to access the right care at the right time for them Consider specific needs, e.g. children & young adults, mental health, learning disabilities, autism, dementia Embedding equalities value base in all education and training Mapping provision in each locality Promoting awareness of available services and support Tailoring services to meet the needs of the local population
Maximising comfort and wellbeing. *"My care is regularly reviewed and every effort is made for me to have the support, care and treatment that might be needed to help me to be as comfortable and as free from distress as possible"*	**Shared Care Plans** to enable timely responses & good communication of wishes (including digital solutions) Increased identification in the last 12 months of life A 24/7 coordination hub (for public and professionals) enabling a consistent approach to access advice and coordination of relevant services advice Development of a rapid discharge pathway from GHFT (home to die)

🟥	***Care is coordinated.*** *“I get the right help at the right time from the right people. I have a team around me who know my needs and my plans and work together to help me achieve them. I can always reach someone who will listen and respond at any time of the day or night”*	Smooth & supported **transitions between Children’s and Adult** Palliative and End of Life Care Services Developing shared all age (digital) care plans Encouraging a shared ownership of the digital offer Implementing shared decision making via the shared care plan Encouraging engagement and shared understanding across the system, including 3rd sector provision Ensuring policy, procedures and tools are in place to support effective transitions Produce timely and appropriate planning for transition phase Supporting and managing expectations of parents and carers through transition Share commissioning intentions between adults and children’s commissioners
🟧	***All staff are prepared to care.*** *“Wherever I am, health and care staff bring empathy, skills and expertise and give me competent, confident and compassionate care*	Professionals confident in responding to the **changing needs & wishes** of people as they reach the end of life and also then **communicating** well with system colleagues Promoting confidence by meeting education, training and competency needs of staff Communicating with a shared language culture and understanding across the system Ensuring staff have connected communications regarding patient’s needs (care plans) Giving staff confidence to identify recognise and communicate with and on behalf of an individual in their last year of life Providing consistent approach and standards of quality in Palliative and End of Life Care Engendering trust in others judgements/
🟩	***Each community is prepared to help.*** *“I live in a community where everybody recognises that we all have a role to play in supporting each other in times of crisis and loss. People are ready, willing and confident to have conversations about living and dying well and to support each other in emotional and practical ways*	Promoting a cultural shift to encourage more conversations around end of life – making end of life everyone’s business Valuing all community assets



7.2 Local enablers

Sustainable funding model

In addition to these local priorities a sustainable funding model to allow high quality EoLC to meet the needs of our local communities was also identified as a key enabler to facilitating the successful delivery of these priorities.

Digital Transformation

There is no Electronic Palliative Care Co-ordination System (EPaCCS) in Gloucestershire, instead the county has developed JUYI, the Gloucestershire Shared Care Record. This has been implemented in a number of settings across primary care, acute, community and mental health services. In addition, the Summary Care Record with additional information is available across the health community and is the ambulance service's preferred method to access patient information. Work is ongoing to increase the information available and the numbers of users accessing both systems.

The wider digital strategy for Gloucestershire ICS includes delivery of additional digital care planning capabilities covering a number of clinical pathways and including functionality relating to an individual's ability to view and contribute.

8.0 INTERDEPENDENCIES

There are several other strategies and workstreams that are currently being developed that will have an impact on the effective delivery of the Palliative and End of Life Care strategy, these include:

- **Ageing Well Programme**

This programme is integral improving out of hospital care, and to give people more control over their health and more personalised care when they need it. the national Ageing Well Programme's 4 main priorities are:

  - Urgent Community Response
  - Enhanced Health in Care Homes Framework
  - Anticipatory Care/Community Teams
  - Digital

- **One Gloucestershire Frailty Strategy**
- **One Gloucestershire Dementia Strategy**
- **Fast Track Continuing Health Care Strategy & delivery**
- **Equipment Review**
- **Service Specification for Domiciliary Care for the current Gloucestershire Health & Social Care Framework 2020-4**
- **Review Contract for Residential and Nursing Care**
  - Gloucestershire County Council are in the process of reviewing their current contract for residential and nursing care. Following a period of engagement with the provider market and other stakeholders, it is intended to put a new contract in place within the next two years. It is envisaged that this new contract would contain provisions around palliative and end of life care, including requirements for providers to follow national and local guidelines and for the training of their staff.

9.0 MEASURES AND INDICATORS

To demonstrate the delivery of high quality end-of-life care, taking into consideration the local priorities the identified indicators of success are:

Baseline & targets

- Increase in earlier identification of patients who will benefit from end-of-life care.
- Increased engagement with advance care planning and achievement of documented wishes and preferences.
- Improvement in identification of a person's preferred place of care when dying.
- Increase in the percentage of people dying in their preferred setting.
- Reduced unnecessary hospital admissions.
- Increased positive feedback from bereaved relatives and those identified as important to the patient.
- Reduction in end-of-life care related complaints.
- Development and implementation of a framework for education and training to ensure an appropriately skilled workforce, with confirmation that all relevant health care professionals have undertaken training in end-of-life care where it is role specific.

An ICS dashboard will be developed to monitor these established baselines and progress made towards the work stream outcomes outlined in this strategy.

10.0 GOVERNANCE

Members from across the ICS along with third sector and community organisations will have their own governance and reporting structures.

ICS Board

Consists of members from all of the partner organisations & NHSE/I.

Provides strategy & acts as a partnership to oversee performance across the whole ICS & provides a final decision/escalation point

ICS Executive

Consists of members from all of the partner organisations.

To ensure delivery of strategic priorities by relevant organisational boards and provide a central decision making point and escalation point for organisational boards

ICS Clinical Programme Board (CPB)

To maintain oversight of all clinical programme groups

P&EoLC CPG

consists of members from all partner organisations

To work towards co-developing and delivering an all-age PEoLC strategy;

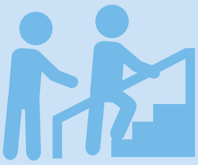
To Develop integrated, system-wide, evidence-based PEoLC services with an embedded personalised care approach

Workstream/ programme groups

consists of specific and relevant members from across partner organisations

To work towards the delivery of specific outcomes identified against each workstream

11. OUR STRATEGIC AIMS AND WORK STREAM OBJECTIVES:

Workstream	Outcome	Measures
Each person is seen as an individual		
Review and improve support to carers along with the consistency of bereavement support across the county for all 	People will have timely and appropriate access to: • Carers support • Pre and post bereavement support • Holistic spiritual needs and grief support for carers including in advance of bereavement Where and when they require it	• Cruse bereavement data - ‘timely’ access (wait times) ‘Appropriate’ access – equality data • Bereavement activity delivered via providers- number of people supported & equality measures • Number of bereaved carers supported through the carers service • NACEL audit • Annual public engagement survey
Review of access to equipment 	People have timely access to equipment they need to help to support them to remain at home should they wish to	• To be identified
Maximising comfort and well being		
Early Identification of people approaching their last 12 months of life 	People will receive a more personalised and proactive approach to end of life care planning, increasing the likelihood of people dying in their place of preference and avoiding a crisis response	• Number of people on palliative care register by GP practice & condition (Benchmark figure available) • Number of people uniquely identified by their risk stratification • Number of Just in case boxes prescribed
Scoping and development of a 24/7 hub **This maps against the Trust’s goal for scoping 7/7provision working for SPCT Specialist Palliative Care Team**		

Each person gets fair access to care

Identifying and reducing inequalities in access and delivery of services 	People will receive the same standard of care regardless of who they are, where they live or the circumstances of their life	• Identify a qualitative baseline for all ‘inequality groups’ Current quantitative measures available: • Some ethnicity data • Deprivation • LeDeR report • Geography/ isolation • Qualitative feedback from ‘inequality groups’

Each community is prepared to help

Communication and engagement with communities 	People and communities are encouraged to think of dying as a normal part of life and are aware of the full range of support available to them	• Number of responses to the annual public engagement survey • Number of people participating using the engagement platform & other engagement activities • Number and range of organisations engaged with to promote key messages

Each person is seen as an individual

Advance Care Planning, ReSPECT & Personalised care planning **This maps against Trust initiatives including REsPECT** 	People and professionals are supported to have early conversations about death and dying and decision making for their future care	• Number of people with advance care plan • Number of people with a ReSPECT form in place • People dying in their place of preference

Care is co-ordinated

Transition from Children's to Adult's palliative care services	People and professionals are supported to have early conversations about death and dying and decision making for their future care	- Number of CYACP ReSPECT forms in place

Care is co-ordinated

Review of commissioning approaches	People will experience high quality, joined up, efficient P&EoLC that meets the needs of local communities	Delivery of a report reviewing commissioning approaches including future recommendations for sustainable funding

All staff are prepared to care

Work force development Maps against Trust education goals, Trust development plan also highlights need to support staff beyond training them if they are to deliver excellent EOL care	People will experience a workforce that is confident, capable and responsive to their individual needs	● Baseline of current training and education across the system ● Numbers of staff attending relevant training across the system for their grade

Maximising comfort and well being

Scoping and development of a 24/7 hub **Maps against Trust goal for scoping 7/7 working for SPCT**	People and practitioners will have consistent & timely access to EoL advice, guidance and support	To be confirmed once funding for the approach is identified and agreed
Development of a rapid home to die pathway. This maps against Trust objective 	People are better supported to die in their place of choice	To be confirmed once the pathway is agreed

Care is co-ordinated

Digital transformation 	People's data and information is held securely on a digital platform that is accessible to all relevant parties, enabling more joined up care across providers	To be confirmed once funding for the approach is identified and agreed

To support monitoring of the above

Development of ICS P&EoLC dashboard	To support monitoring of the above	

12. APPENDIX

Current statements are:

Statement 1 People approaching the end of life are identified in a timely way.

Statement 2 People approaching the end of life and their families and carers are communicated with, and offered information, in an accessible and sensitive way in response to their needs and preferences.

Statement 3 People approaching the end of life are 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.

Statement 4 People approaching the end of life have their physical and specific psychological needs safely, effectively and appropriately met at any time of day or night, including access to medicines and equipment.

Statement 5 People approaching the end of life are offered timely personalised support for their social, practical and emotional needs, which is appropriate to their preferences, and maximises independence and social participation for as long as possible.

Statement 6 People approaching the end of life are offered spiritual and religious support appropriate to their needs and preferences.

Statement 7 Families and carers of people approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, and holistic support appropriate to their current needs and preferences.

Statement 8 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.

Statement 9 People approaching the end of life who experience a crisis at any time of day or night receive prompt, safe and effective urgent care appropriate to their needs and preferences.

Statement 10 People approaching the end of life who may benefit from specialist palliative care, are offered this care in a timely way appropriate to their needs and preferences, at any time of day or night.

Statement 11 This statement has been removed and replaced by NICE's quality standard on care of dying adults in the last days of life. For more details see update information.

Statement 12 The body of a person who has died is cared for in a culturally sensitive and dignified manner.

Statement 13 Families and carers of people who have died receive timely verification and certification of the death.

Statement 14 People closely affected by a death are communicated with in a sensitive way and are offered immediate and ongoing bereavement, emotional and spiritual support appropriate to their needs and preferences.

Statement 15 Health and social care workers have the knowledge, skills and attitudes necessary to be competent to provide high-quality care and support for people approaching the end of life and their families and carers.

Statement 16 Generalist and specialist services providing care for people approaching the end of life and their families and carers have a multidisciplinary workforce sufficient in number and skill mix to provide high-quality care and support.

Palliative and
End of Life Care
One Gloucestershire

If you would like to comment on the content of the strategy or have a question in relation to this document please contact Gloucestershire CCG using this email address:

glccg.endoflifeteam@nhs.net