



**Report of:** Leeds Palliative Care Network

**Report to:** Leeds Health and Wellbeing Board

**Date:** 29 April 2021

**Subject:** Leeds Palliative and End of Life Care Strategy for Adults 2021-26

Are specific geographical areas affected? If relevant, name(s) of area(s):	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No
Are there implications for equality and diversity and cohesion and integration?	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No
Is the decision eligible for call-In?	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No
Does the report contain confidential or exempt information? If relevant, access to information procedure rule number: Appendix number:	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No

### Summary of main issues

- ***“How we care for the dying is an indicator of how we care for all sick and vulnerable people.”*** (*Ambitions for Palliative and End of Life Care: A national framework for local action 2015-20*)
- The development of the *Palliative and End of Life Care Strategy for Adults 2021-26* (see Appendix) was supported by the Leeds Health and Wellbeing Board in Sept 2019 as essential to achieving the ambition of the Leeds Health and Wellbeing Strategy to be the Best City for Health and Wellbeing, our citywide priority of ‘The best care, in the right place, at the right time’ and being an Age Friendly City.
- This report provides an overview of the *Palliative and End of Life Care Strategy for Adults 2021-26* to be retrospectively agreed by the Health and Wellbeing Board following its previous circulation to members.
- The importance of palliative and end of life care continues to grow and be recognised across Leeds and beyond. We are all aware of the projected growth in demand for palliative care over the coming years and the challenges posed by the increasing complexity and diversity of people’s needs, the challenges of workforce capacity and capability and the multiple demands placed on the healthcare, social care and voluntary sectors.
- The unprecedented impact of the Covid-19 pandemic has delayed the development of this strategy, but also shone further light onto the inequalities, needs and care for people and their families near to and at the end of life. Despite the challenges, we continue to use this experience to further understand and improve the care needs of people who are dying and will be reflected in our annual action plans.

## Recommendations

The Health and Wellbeing Board is asked to:

- Retrospectively note the Leeds Palliative and End of Life Care Strategy for Adults 2021-26.

### 1 Purpose of this report

- 1.1 The purpose of this report is to present the new *Leeds Palliative and End of Life Care Strategy for Adults 2021-26* for the Health and Wellbeing Board (HWB) to retrospectively note.

### 2 Background information

- 2.1 ***“How we care for the dying is an indicator of how we care for all sick and vulnerable people.”*** (*Ambitions for Palliative and End of Life Care: A national framework for local action 2015-20*)
- 2.2 The development of the *Palliative and End of Life Care Strategy for Adults 2021-26* (see Appendix) was supported by the Leeds Health and Wellbeing Board in 2019 as essential to achieving the ambition of the Leeds Health and Wellbeing Strategy to be the Best City for Health and Wellbeing, our citywide priority of ‘The best care, in the right place, at the right time’ and being an Age Friendly City.
- 2.3 The importance of palliative and end of life care continues to grow and be recognised across Leeds and beyond. There are approximately 6,850 deaths per year in Leeds. By 2040 the number of annual deaths is projected to rise by 25%, with the greatest rise in those over 85. In Leeds this will be up to an additional 1,700 people dying per year. The demand for palliative and end of life care may rise by 40% as those requiring care have increasingly complex needs and require support for longer.
- 2.4 Over the last 10 years, the percentage of people dying in hospital has decreased from 56% to 45.4%, and the percentage of those dying at home, in a hospice or a care home has increased. However there are still people dying in hospital when this was not their preferred place of death, and despite increases in recorded advanced care planning conversations, there is still much more to do in order to tackle inequalities and to increase the numbers of people experiencing a good death and having their wishes met at the end of life.
- 2.5 The unprecedented impact of the Covid-19 pandemic has delayed the development of this strategy, but also shone further light onto the inequalities, needs and care for people and their families near to and at the end of life.
- 2.6 In order to meet future demand and to tackle inequalities in provision, the Leeds Palliative Care Network have worked across the health and care system to develop the *Leeds Palliative and End of Life Care Strategy for Adults 2021-2026*. Embracing a Team Leeds approach, this was developed through the Strategy Advisory Group, which included senior representation from all partner organisations in the city who guided, informed and influenced its future strategic developments and a wide-ranging engagement programme including:

- Two large stakeholder events (involving 60 people from 21 health and social care organisations).
- Leeds Health and Wellbeing Board in Sept 2019 and via email in early 2021.
- Consultation with Peoples' Voices Group.

2.7 Following the strategic steer from the Health and Wellbeing Board in Sept 2019 and feedback from the People's Voices Group a number of changes were made to the Strategy including:

- The outcomes were changed to ensure that they were clear and easy to understand.
- Focus on tackling health inequalities was strengthened.
- Greater focus on improving access to advanced care planning for underrepresented groups (including people from deprived areas and some BAME backgrounds) and on improving their chances of achieving their preferred place of death.

2.8 It should be noted that, the scope of this Strategy includes adults (aged 18+) with advanced progressive life-limiting disease and /or who are dying (last phase of life) and in its delivery will focus on transition from children's to adult services to develop seamless pathways and services.

2.9 Due to the more specialised nature of the care provided and the smaller number of providers for children and young, Leeds is working on this regionally through the Yorkshire and Humber Palliative Care Network and the West Yorkshire & Harrogate Integrated Care System's Children, Young People and Families Programme, which has a dedicated work stream on Palliative and End of Life Care. It aims to ensure that 'Children who have a life limiting condition will have the right care and support in the right place with support for their families through the life course and at end of life'.

2.10 The *Palliative and End of Life Care Strategy for Adults 2021-26* has been endorsed by the Strategy Advisory Group, Leeds Palliative Care Network Executives, NHS Leeds CCG Executive Management Team, Leeds City Council Adults & Health and by members of the Leeds Health and Wellbeing Board following its previous circulation in early 2021. It builds upon and replaces the Leeds End of Life Care Commissioning Strategy for Adults 2014-19.

### **3 Main issues**

3.1 This Strategy sets out our vision that: *"People will die well in their place of choice; carers and the bereaved will be well supported."*

3.2 It will help us meet national standards, address local priorities for improving end of life care for adults in Leeds and tackle inequalities over the next five years. It takes account of the *Health Needs Data Update – End of Life Care Services for Adults in Leeds 2019*, feedback from the public, patients, health and care providers, family carers and the bereaved and its action plans will be responsive to the impact of the Covid-19 pandemic.

3.3 The Strategy details seven key outcomes that we will deliver as Team Leeds, their progress to date and how they will be delivered:

***People in Leeds who need palliative and /or end of life care will:***

1. Be seen and treated as individuals who are encouraged to make and share advance care plans and to be involved in decisions regarding their care
2. Have their needs and conditions recognised quickly and be given fair access to services regardless of their background or characteristics
3. Be supported to live well as long as possible, taking account of their expressed wishes and maximising their comfort and wellbeing
4. Receive care that is well-coordinated
5. Have their care provided by people who are well trained to do so and who have access to the necessary resources
6. Be assured that their family, carers, and those close to them are well supported during and after their care, and that they are kept involved and informed throughout
7. Be part of communities that talk about death and dying, and that are ready, willing and able to provide the support needed.

3.4 These outcomes will be underpinned by a set of agreed principles that end of life care services in Leeds will:

- Meet the current and projected needs of the local population
- Involve those using our services in their development and evaluation
- Be delivered in a variety of settings so that people can use the service of their choice
- Be easy to access 24 hours a day, 7 days a week
- Be accessible to everyone who could benefit from them, working to identify health inequalities and putting in place measures to significantly reduce these
- Have low, or no, waiting times and no unnecessary waiting
- Be developed in line with people's needs, including locations and timings of services
- Encourage and empower people to be actively involved in planning their own end of life care and support them to make choices
- Treat all people and carers with dignity and respect
- Offer treatment and care that is evidence-based and consistent across services
- Be cost effective.

3.5 The Strategy also has four key Enablers which will be crucial to success. These are:

**Understanding population needs:** Leeds is very fortunate to have an Academic Unit of Palliative Care (AUPC), a partnership between St Gemma's Hospice and the University of Leeds, School of Medicine, in addition to resources such as the Leeds Data Model and established collaborations with organisational business intelligence and informatics teams. Working across the system, by analysing population data, patient outcomes, research, clinical audit and feedback from patients and carers, we will increase our understanding of our city's palliative care needs and will use this understanding to further develop services and to tackle health inequalities.

**Medicines management:** We want to make sure that medication issues are not a barrier to people receiving the best care and management of their symptoms, wherever they are being cared for. Together, our work on medicines management will help ensure that the right drugs are available at the right time in the right quantities across care settings and help to reduce unnecessary waste.

**Use of technology to improve care:** Taking maximum advantage of digital solutions and innovations will be core to delivering our strategy. In Leeds, we have made significant progress in a number of areas, particularly around the uptake of digital advance care planning tools, shared electronic patient records and electronic prescribing. The LPCN has established key relationships with digital partners within Leeds and across the region in order drive further development and improvement.

**Workforce:** Our health and social care workforce is our most important resource. An extensive range of staff roles with a wide variety of skills and specialisms are involved in caring for dying people. Working with the Strategic Workforce Board, we want to ensure they have the skills, confidence and resilience they need to deliver holistic, compassionate care for dying people and their families, regardless of where they are cared for.

3.6 Following publication of this strategy, the Leeds Palliative Care Network will refresh the work programmes that they are currently delivering in order to ensure that they are aligned with the priorities and outcomes that we have set out. Each work stream will develop a plan identifying short, medium and long term actions which will help to deliver the seven outcomes that we are aiming for.

3.7 Progress against delivery will be monitored by the Leeds Palliative Care Strategy Oversight Group which is attended by senior colleagues from provider organisations from across the city, and is chaired by the NHS Leeds Clinical Commissioning Group. It will also be summarised in the LPCN's annual report. The action plans will be kept up to date and will develop as the local and national context shifts over the next five years and be responsive to the impact from the Covid-19 pandemic.

## **4 Health and Wellbeing Board governance**

### **4.1 Consultation, engagement and hearing citizen voice**

4.1.1 A range of engagements have occurred throughout the development of the Strategy. From a professional perspective these have included two system-wide stakeholder events and regular updates through the Leeds Palliative Care Network. The views of carers have been incorporated into the strategy through involvement of Carers Leeds in the Strategy Advisory Group and by incorporating recommendations from the annual bereaved carers survey. The views of citizens have been gathered through feedback from the People's Voices Group and through the 'What matters to people living with frailty, older people at end of life and their carers?: Engagement Report' published in 2018.

4.1.2 Citizen voice will also be central to the delivery of the Strategy, with a key underpinning principle being to encourage and empower people (and the loved ones) to be actively involved in planning their own end of life care and supporting them to make active choices..

### **4.2 Equality and diversity / cohesion and integration**

4.2.3 One of the key aims of the strategy is to increase end of life care planning amongst underrepresented groups (in particular people from some BAME backgrounds and from some more deprived areas), and to ensure that there is equality of opportunity in accessing a full range of services at the end of life. This will increase the chances that all groups within society have of achieving their wishes at the end of life and help to tackle existing inequalities.

### **4.3 Resources and value for money**

4.3.1 Delivery of the key outcomes in the strategy will enable more patients to be cared for closer to home, providing a better experience for patients and families, and delivering care in a more efficient way for the system. Where investment is required to deliver the priorities and actions identified, the LPCN will work with providers to consider a range of options including reallocating funds, seeking funding through national and local grants, and securing further CCG / statutory investment through discussion with commissioners. Where seeking to identify funding for developments the LPCN will ensure alignment with the seven key outcomes set out earlier.

### **4.4 Legal Implications, access to information and call In**

4.4.1 There are no legal, access to information or call in implications from this report.

### **4.5 Risk management**

4.5.1 Risks from the Strategy will be managed through the Leeds Palliative Care Strategy Oversight Group and escalated to the Leeds Palliative Care Network.

## **5 Conclusions**

- 5.1 It is our aspiration that Leeds is a great place to live out our final years, months and weeks of life, to have great confidence in our care and comfort, and to have the assurance we will die with dignity and peace. The *Palliative and End of Life Care Strategy for Adults 2021-26* is central to our ambition to being the Best City for Health and Wellbeing and Age Friendly Leeds and in our response and recovery from the Covid-19 pandemic.

## **6 Recommendations**

The Health and Wellbeing Board is asked to:

- Retrospectively note the Leeds Palliative and End of Life Care Strategy for Adults 2021-26.

## **7 Background documents**

- 7.1 None.

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### How does this help reduce health inequalities in Leeds?

One of the key aims of the strategy is to increase end of life care planning amongst underrepresented groups, and to ensure that there is equality of opportunity in accessing a full range of services at the end of life. This will increase the chances that all groups within society have of achieving their wishes at the end of life and help to tackle existing inequalities.

### How does this help create a high quality health and care system?

The strategy, produced by partners across the city, promotes integration of services and joint working between professionals regardless of their organisational background. The strategy sets out clear aims to develop the Leeds health and care workforce and to widen access to training in advanced care planning and 'better conversations'. It also sets out how specialist end of life care input will be made available to patients with a wider range of conditions (e.g. in addition to cancer), and how this advice will enable a wider range of specialists to provide better end of life care and support to their patients. This collaboration across organisations and specialties will help to ensure that "**People will die well in their place of choice; carers and the bereaved will be well supported**": a key aim set out in the Leeds Health and Care Plan.

### How does this help to have a financially sustainable health and care system?

Delivery of the key outcomes in the strategy will enable more patients to be cared for closer to home, providing a better experience for patients and families, and delivering care in a more efficient way for the system

### Future challenges or opportunities

Future funding of the hospice sector is a particular challenge, particularly in light of the reduction in fundraising and the closure of charity shops during the pandemic. Similarly, the impact of Covid on future staffing may also prove to be a particular challenge in the medium to long term

### Priorities of the Leeds Health and Wellbeing Strategy 2016-21

A Child Friendly City and the best start in life	
An Age Friendly City where people age well	X
Strong, engaged and well-connected communities	X
Housing and the environment enable all people of Leeds to be healthy	
A strong economy with quality, local jobs	
Get more people, more physically active, more often	
Maximise the benefits of information and technology	X
A stronger focus on prevention	
Support self-care, with more people managing their own conditions	
Promote mental and physical health equally	
A valued, well trained and supported workforce	X
The best care, in the right place, at the right time	X