

HEALTH AND WELLBEING BOARD



TO:	Health and Wellbeing Board
FROM:	Philippa Cross, Associate Director Place Development and Integration, Blackburn with Darwen
DATE:	Tuesday, 5 March 2024

SUBJECT: Dying Well Update

1. PURPOSE

To provide and update of what is happening across Lancashire and South Cumbria and Blackburn with Darwen regarding the 'Palliative and End Of Life Care (PEOLC) and Dying Well' work programme. The report also provides the Health and Wellbeing Board with an overview of key emerging priorities for Blackburn with Darwen in regards to improving palliative and end of life care, following a recent "Getting to Outstanding" review.

2. RECOMMENDATIONS FOR THE HEALTH & WELLBEING BOARD

The Health and Wellbeing Board are recommended to:

- Note the updated provided in regards to the development of plans to improve end of life care in Blackburn with Darwen and across the wider Lancashire and South Cumbria footprint
- Agree to the establishment of a BwD Dying Well Steering Group to collaboratively refine the improvement plan for palliative and end of life care and oversee its delivery.

2. BACKGROUND

It is broadly recognised that opportunities to support people to die in their preferred place of death, with appropriate early identification of end of life and high-quality advance care planning are significant. The potential for improved patient experience and system wide efficiencies could be realised with more integrated working and transformation to service provision. There is one opportunity to get it right for people when they die and to support their loved ones, carers, and family in the journey of death and bereavement.

National context

The Health and Social Care Act 2022 places statutory responsibilities for Integrated Care Board's to commission palliative care services to meet the needs of their population. Alongside this the new Care Quality Commission inspection framework requires adult social services directorates to show how they are supporting people at the end of their life to have comfortable, dignified and pain-free deaths.

The national "Ambitions for Palliative and End of Life Care framework for local action 2021 – 26" around set out six very clear ambitions.

1. Each person is seen as an individual
2. Each person gets fair access to care
3. Maximising comfort and wellbeing

4. Care is co-ordinated
5. All staff are prepared to care
6. Each community is prepared to help

Lancashire and South Cumbria context

The Lancashire and South Cumbria Integrated Care Partnership Strategy sets out clear system level ambitions for end of life care which include:

- The citizens of Lancashire & South Cumbria to be supported to live well before dying in peace and with dignity in the setting of their choice.
- Equitable access to end of life care for the citizens of Lancashire and South Cumbria.
- End of life care to be of high quality and person centred.
- End of life care in Lancashire and South Cumbria to reflect national best practice; fulfil the priorities set out in the NHS long term plan and achieve the ambitions within the ICB joint forward plan.

The Lancashire and South Cumbria (LSC) Integrated Care Board (ICB) has committed to the following actions in order to achieve these ambitions:

- We will define what the commissioning of an outstanding PEOLC patient journey looks like from the point of identification, through to death and bereavement;
- We will utilise the North-West model for life limiting conditions and the national ambitions framework to frame the journey
- The Integrated Care System as a whole, will then use the defined outstanding patient journey as a specification for the provision and commissioning of PEOLC across Lancashire and South Cumbria
- Place Based Partnerships will benchmark services against the defined outstanding journey
- The AMBITIONS self –assessment tool will be adapted to support the review.

The ICB have worked with the LSC PEOLC clinical network, part of the Northwest Coast clinical networks to transform the local approach to PEOLC to reflect the National Ambitions Framework and NHS Long Term Plan commitments and subsequently developed a “Getting to Outstanding” (GTO) framework. All the place-based partnerships (PBPs) in LSC were then requested to complete a baseline review against the GTO framework, in order to help them understand where key improvements in support for patients and their families could be made. It should be noted that the first phase of this framework was to consider care and support for adults, and the second phase, which is currently being developed by the ICB, is to look at care and support for children and young people.

Blackburn with Darwen context

In Blackburn with Darwen we know that:

- More people die in hospital than in any other place and this is higher than the England average
- There are significantly less people dying in care homes compared to the North West and England average
- Fewer people are identified as being at end of life in primary care, than in Lancashire and South Cumbria and in England as a whole

The JSNA highlights specifically that:

- a greater proportion of the borough’s residents die in hospital compared to England, and a lower proportion die in care homes
- a greater proportion of people aged 85 and over die in hospital compared to England (44.1% compared to 38.8%)
- For residents aged 65 to 84, the proportion who die in a hospital is 56.9% compared to 47.9% nationally.

The Blackburn with Darwen Health and Wellbeing Strategy confirms that dying well is a key ambition for through borough, the strategy sets out key commitments for delivery, which are intended to address health inequalities, these are:

- Engage with communities to inform our approach to end of life planning and bereavement support considering the differing requirements of our communities and how we can best we can support these.
- Normalise conversations around end of life and planning for end of life by raising awareness of talking about dying with the public through community campaigns.
- Develop and deliver our local approach to end of life planning for our residents and build capacity through a network of End of Life Champions.
- Support people to complete advance and emergency care plans with their loved ones and the professionals who are supporting them.
- Working with our partners across Lancashire and South Cumbria to gain a full understanding of bereavement support availability and capacity across and ensure that our residents have improved access to this support.
- Develop and implement a Bereavement Improvement Plan to develop knowledge, skills and confidence with our communities

The Getting to Outstanding review was undertaken in Blackburn with Darwen from September – November 2023 and involved focus groups and discussion sessions with a wide range of stakeholders from across the NHS, local authority, VCFSE and hospice sector. Improvement planning against the review findings remains underway at the time of writing, but the key emerging actions are summarised within this report for the benefit of the Health and Wellbeing Board.

In support of the GTO review, the PBP commissioned Healthwatch Blackburn with Darwen, to undertake resident insight work over the summer of 2023 in order to understand residents views and experiences of end of life care. This work was the first of its kind in LSC and has subsequently informed not only the BwD improvement planning, but also the wider LSC planning. The full report is attached at Appendix A for the information of the Health and Wellbeing Board.

This report now sets out key issues and findings in relation to palliative and end of life care in BwD, and outlines proposed next steps.

3. RATIONALE

The work outlined in this report supports the Health and Wellbeing Board's strategic priority around dying well where all residents are encouraged to feel comfortable in talking about planning for dying, and to be well supported when a loved one dies. The aim of the Health and Wellbeing Strategy is to ensure that the adults, children and young people of Blackburn with Darwen to live well, before dying with peace and dignity, in the place where they would like to die, supported by the people important to them.

It should be noted that, at this present time, the main contents of this report focus on care and support for adults, work to identify key improvement actions for children and young people will be undertaken during 2024, in line with the ICB's current phased approach to the Getting to Outstanding reviews.

4. KEY ISSUES

Healthwatch Blackburn with Darwen carried out six focus groups across the borough in Summer and Autumn 2023 with residents from a range of ages and ethnic backgrounds. The focus groups were framed around four key areas of: -

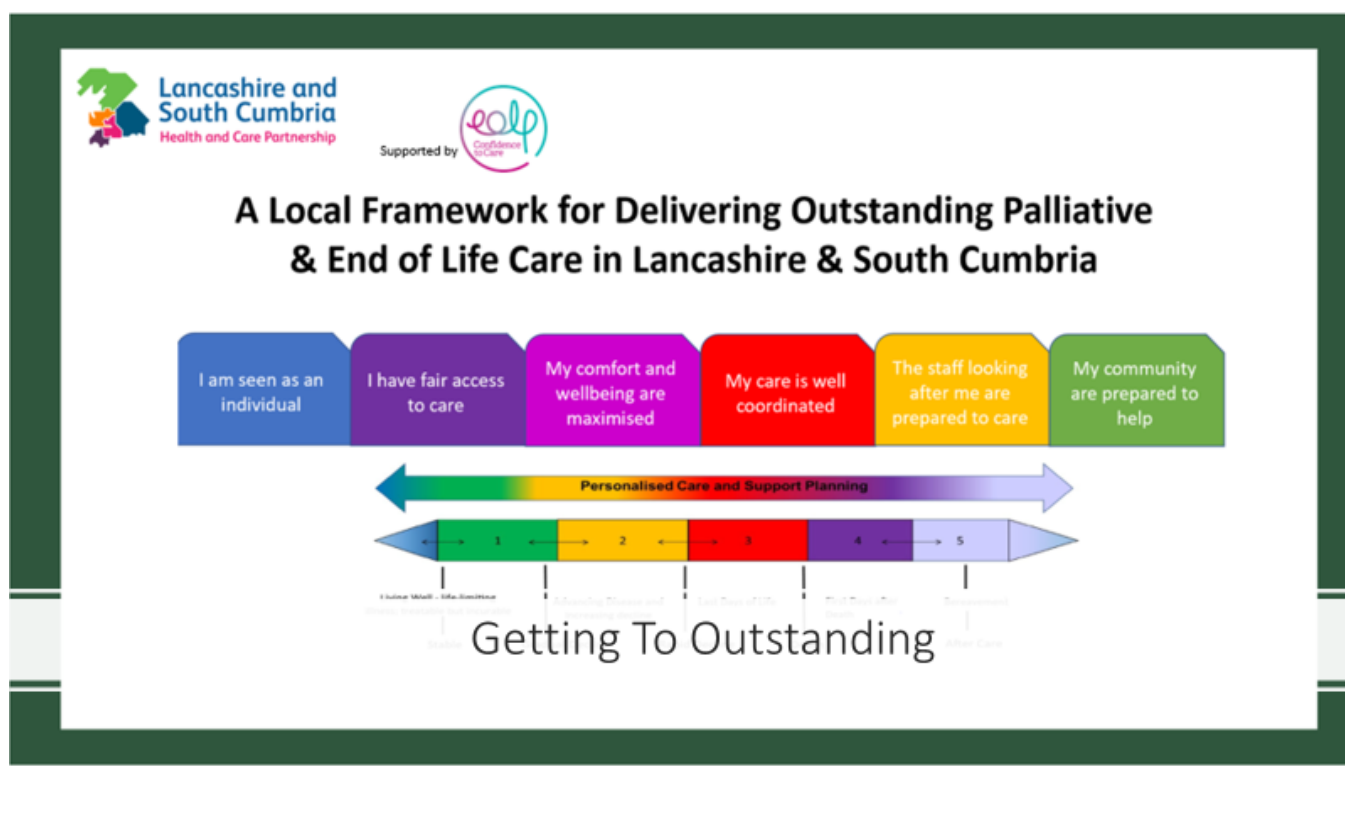
- The individual's needs and wishes
- Family and carers needs and wishes
- Involvement of Health and Care Professionals at the end of life
- Talking about dying within our community

The following recommendations were made based on feedback from residents:

- Importance of flexible advanced care planning - there was an overall lack of awareness around advanced care planning. Residents also felt that professionals should respect individual's decisions to change these plans and be flexible in the support they provide at end of life.
- Respect for individuals' wishes – this was particularly important for Muslim residents who felt that hospital professionals should listen rather than do what they think is best.
- Funeral planning – greater support for individuals and families to plan financially for end of life would be beneficial including joint promotion between the voluntary sector and local law firms of free wills month.
- Bereavement Support – the need for better awareness and wider provision of bereavement support that is person centred as well as a need for 'anticipatory' bereavement support.
- Education for young people on death and coping with bereavement – education on bereavement should be included in PHSE lessons in both primary and secondary schools to help young people talk freely about it. Wellbeing champions in schools could also offer peer to peer support. Young people also wanted suicide awareness training in schools.
- Role of GP and other professionals in starting the conversation early – GPs should initiate conversations about end of life. Also the wider involvement of professionals should include organisations such as the Council's social prescribers, the Hospice and voluntary sector organisations.

Getting to outstanding review in Blackburn with Darwen

The GTO approach is structured to allow local systems to "score" themselves against a range of criteria aligned to the six national ambitions for Palliative and End of Life Care.



Level	Locality Level Descriptor
Level 0	Not at all ready to achieve/ anticipate barriers to achievement
Level 1	Desire to achieve this ambition but there are currently no plans in place
Level 2	Plans are in place towards achieving this ambition
Level 3	Limited achievement across one or two organisations within Place only
Level 4	Partially achieving e.g. across most, but not all care settings within Place
Level 5	Fully achieving e.g. across all care settings at Place, with supporting evidence available
Level 6	Fully embedded at Place including regular outcome monitoring and review

Marie Curie UK were engaged by the ICB to support place-based partnerships in undertaking their Getting to Outstanding reviews. In Blackburn with Darwen the review was undertaken in a manner that aimed to ensure as many stakeholders were able to input as possible. The approach included:

- Self-assessment against getting to outstanding ambitions undertaken internally
- Ambitions 1, 3 and 4 identified for broader stakeholder input and a “deep dive” review
- On-line survey to wider partnership group
- Smaller focus groups completed with Intermediate Care Allocation Team (ICAT); District nurses and East Lancashire hospice; BwD Council; Care sector; ELHT Specialist Palliative Care and bereavement support leads
- Workshop 1 – testing what we’ve heard, identifying key priorities to action plan against
- Workshop 2 – action planning
- Cross-referencing of Healthwatch insight and recommendations as a proxy for patient/resident voice

A range of key actions were identified through this process including:

- Early identification and advance care planning needs to be undertaken more consistently – there is an opportunity to explore the role of wider workforce e.g. social care and VCFSE in supporting identification
- More focus needed on Gold Standard Framework reviews and INT meetings to ensure people’s care is co-ordinated – support early identification in general practice
- Increase bereavement support including anticipatory support to prepare people for grief – opportunity to raise awareness of wider support that is available, including wellbeing support for people who don’t need formal therapy
- Record sharing is still difficult – supporting the planned role out of “My Wishes” will help put people in control of their own information and allow them to chose who to share with
- Improve relationships with care homes and offer more support including training on care planning
- Carers identification and support – people don’t recognise themselves as being “carers” they are “just” loved ones – opportunity to support better identification and referral for carers assessment with social care
- Massive opportunities with our young people – normalise conversations – explore including in local schools
- Opportunity to learn from our communities and stop over medicalising everything
- Seize opportunities to work with faith sector and strengthen their role

Work is underway, with partners to establish a detailed action plan, with milestones and key impact metrics against these key improvement areas.

As some health and care providers deliver support for residents across Blackburn with Darwen and East Lancashire, specifically East Lancashire Hospitals Trust, North West Ambulance Service and East Lancashire/Pendleside Hospice, the GTO review has been developed in tandem with the East Lancashire locality team. A joint action planning session, with professionals from across both places, is schedule for 27 February, this will allow the opportunity to identify actions that can be delivered once across Blackburn with Darwen and East Lancashire; actions that are important to both that can be recommended to the ICB/LSC system for delivery and those actions which need

to be delivered, uniquely, in each place. Following this session the BwD improvement plan will then be finalised and socialised with all stakeholders.

Dying Well Steering Group

Following the development and finalisation of the BwD improvement plan, it will be necessary to ensure that all partners are taking action to deliver relevant actions and that progress and impacts are monitored. It is therefore proposed that a BwD Dying Well Steering Group be established to collaboratively refine the improvement plan and oversee its delivery. The Steering Group would hold the following remit:

- Assure the HWBB against the delivery of actions detailed within the Health and Wellbeing Strategy and the impact for people
- Assure the ICB against the delivery of actions detailed within the GTO improvement plan
- Advise the PBP Board of key actions that need to be delivered and seek commitment to delivery
- Alert the PBP to any barriers/delays to delivery and secure actions to mitigate these
- Assure themselves that any actions identified for delivery by the ICB or wider system are delivered effectively for the people of BwD and escalate as necessary should these actions not be delivered

Next steps

Following discussion with the HWBB, the steps to complete the improvement plan for palliative and end of life care in BwD will be undertaken. This will involve collaboration with partners with BwD and wider across the East Lancashire and ICB footprint, in order to ensure those actions that can be delivered once across the system are owned and that those actions relevant to BwD are clear and understood.

If supported, a Dying Well Steering Group will be established with membership drawn from local organisations as relevant to drive the delivery of the improvement plan.

An progress report will be provided back to the HWBB in due course.

6. POLICY IMPLICATIONS

There are no changes to local policy required as a result of this report.

The actions and approaches outlined within this paper support the Council and the ICB to deliver on the national requirements to provide people with effective care and support as they approach the end of their life.

As the Getting to Outstanding improvement plan is finalised, any changes to local policy or processes that are identified will be subsequently discussed with the Council, ICB and any other relevant organisations, with changes being enacted through organisational governance as required.

7. FINANCIAL IMPLICATIONS

There are no financial implications resulting from this report. As the Getting to Outstanding improvement plan is finalised, work will be undertaken to identify any costs required to deliver improvement actions, these will be subsequently discussed with the LSC ICB and any other relevant organisations. However, it is recognised that given the financial constraints on the health and care system, most of the actions will be no cost and will likely require changes to existing processes or use of existing capacity, rather than additional investment.

8. LEGAL IMPLICATIONS

There are no legal implications resulting from this report.

9. RESOURCE IMPLICATIONS

Organisations are recommended to support their workforce to increase their skill knowledge and confidence to deliver high quality end of life care. This will include increasing the number of staff and volunteers across Blackburn with Darwen who have completed training in palliative and end of life care, personalised care and support planning and whom report improved confidence, knowledge and skills.

10. EQUALITY AND HEALTH IMPLICATIONS

The Healthwatch insight work identified that different members of our community experience death and dying in different ways and as such actions that are developed through the Getting to Outstanding review will need to be developed in a culturally sensitive, inclusive way, in order to ensure that right interventions are developed for different communities, different health inclusion groups and for people with different conditions, such as dementia. It is anticipated that further engagement and co-production work will be required in order to tailor actions accordingly, this will be a key piece of work for the Dying Well Steering Group to develop.

An EIA toolkit has not been completed at this time as no definitive actions are proposed. Once actions have been fully identified the appropriate EIAs will be undertaken.

11. CONSULTATIONS

Various stakeholders were engaged in the Getting to Outstanding review process, including representatives from all health and care organisations, VCFSE and hospice sector. Local residents were engaged for their views through the Healthwatch insight work.

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DATE:	22.02.24
BACKGROUND PAPER:	n/a