

Public Involvement & Engagement Advisory Committee

Dying Well update, Dr Lyndsey Dickinson

25th October 2023

Context



Ambitions for Palliative and End of Life Care:

A national framework for local action 2021-2026

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



Image provided by NHS England on behalf of the National Palliative and End of Life Care Partnership.

Integrated Care Strategy 2023 - 2028



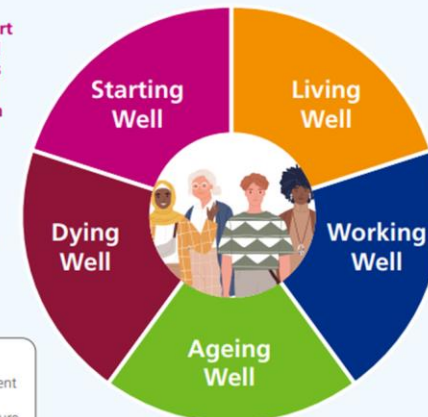
Our priorities

Our priorities reflect the different stages of life that everyone goes through.

Give our children the best start in life, supporting them and their families with problems that affect their health and wellbeing, and getting them ready to start school.

Encourage all our residents to feel comfortable in talking about planning for dying, and to be well-supported when a loved one dies.

We know that many people will be living their lives across several different parts of this life course at the same time. It is important that we make sure the connections between these are easy to navigate.



Reduce ill health and tackle inequalities across mental and physical health for people of all ages by understanding the cause of these unfair differences.

Increase ambition, aspiration and employment, with businesses supporting a healthy and stable workforce and employing people who live in the local area.

Support people to stay well in their own home, with connections to their communities and more joined up care.



How Do We Bring It All Together ?

- North West Region Clinical Network Clinical Leads Group – best clinical practice
- LSC Palliative & End of Life Care and Dying Well Transformation Strategic Leaders Group *
- LSC Transformation Programme Team
- LSC Clinical Network Group
- LSC PEOLC Education Steering Group *
- Place based Palliative & End of Life Care Steering groups *



* These groups have representatives from system partners e.g. social care, Hospices, VCFSE, Place leaders or are under review to include wider system Partners

Getting to Outstanding (GTO)

Why are we here?

- **CQC ratings GOOD-** but how do we get to outstanding in all care settings?- L&SC seized the opportunity to join national 'Getting to Outstanding' Programme
- **Health & Care Act (2022)** - places statutory responsibilities' for ICB's to commission palliative care services to meet the needs of their population
- **Palliative and End of Life Care Statutory Guidance (2022)**

"ICBs should have a clear vision of how the package of services they commission locally deliver against the Ambitions Framework and should actively seek out commissioning resources to achieve this"

Classification: Official

Publication approval reference: PAR1673



Palliative and End of Life Care

Statutory Guidance for Integrated Care Boards (ICBs)

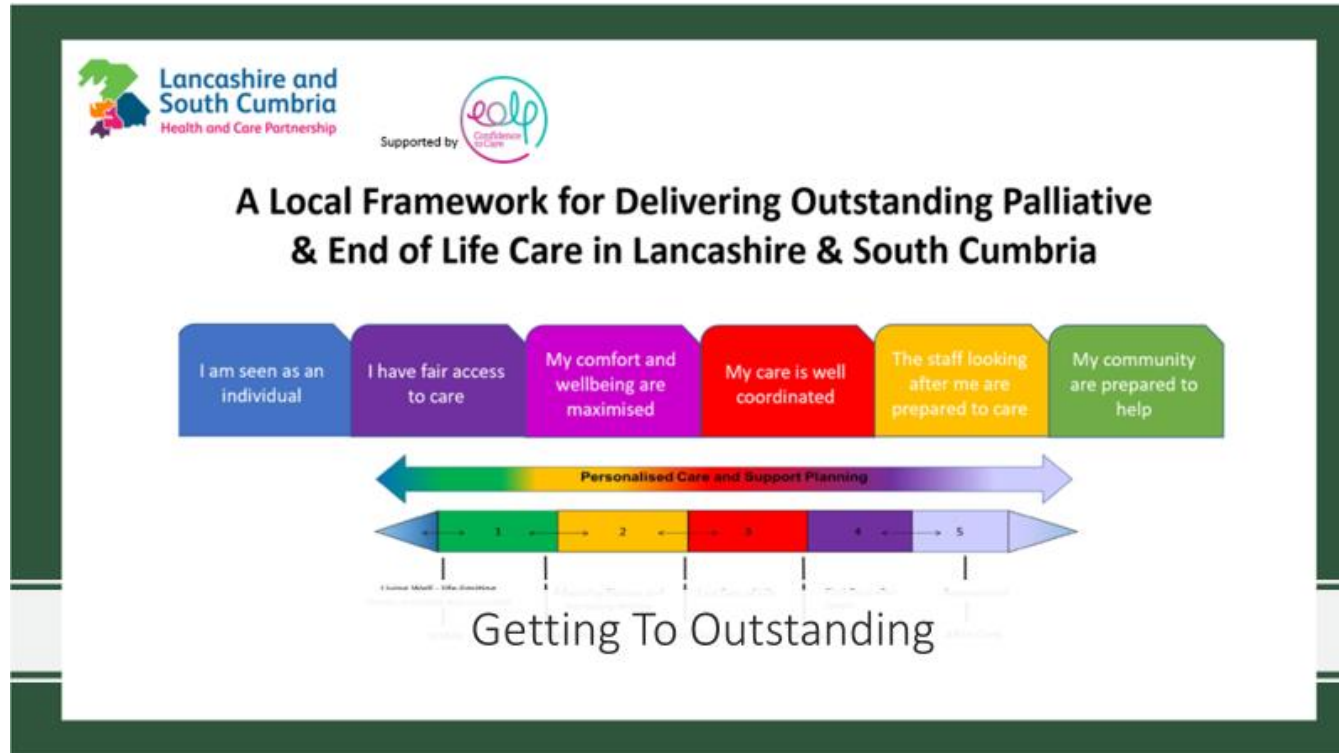
20 July 2022

Getting to Outstanding - the goal...

- 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 & the AMBITIONS framework** to frame the journey
- The ICS will use the defined outstanding patient journey as a **specification for the provision and commissioning of PEOLC across Lancashire & South Cumbria**
- Place Based / Integrated Commissioning Partnerships will **benchmark services against the defined outstanding journey**
- The AMBITIONS **self –assessment tool** will be adapted to support the review

Place self-assessment and baselining

against the framework involving ALL system partners, facilitated by Marie Curie staff



[LSC Integrated Care Board :: Palliative and end of life care \(icb.nhs.uk\)](https://www.icb.nhs.uk)

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

National Ambition 6: Each community is prepared to help

What the citizens of Lancashire and South Cumbria say this means for them

- "I feel like my community cares about me and my family."
- "This is a great ambition to work towards. Supporting each other and everyone involved in the end-of-life care. Honest and open conversations can be difficult but having people you can approach in the community would be great."
- "Encouraging people in communities to talk about death, to plan and to prepare. Involving funeral directors and others in the community who are often involved around death and dying (clerics, publicans etc.)"
- "Death is the only experience we will all share so encouraging planning, talking about and knowing about our loved ones wishes can reduce so much anguish and anxiety for all."

National Ambition 6: Each community is prepared to help

Lancashire and South Cumbria commitments towards making this happen

- We will build end of life care capacity by developing and nourishing compassionate communities
- We will support the public to have more informed and confident discussions around dying, death and bereavement
- We will ensure practical support, information and training on end of life matters is accessible and relevant to those that need it by working closer with families, neighbours and the community
- We will coordinate the recruitment, connecting and training of volunteers so that their contribution and value can be best utilised
- We will ensure that people know what support they can access from their community

Enablers

- Compassionate communities - awareness and promotion with the public, dedicated approach and resources to building and maximising the use of community assets, volunteer led models of end of life care and bereavement support.
- **Public conversations and future life planning** - e.g. ongoing public engagement around future life planning, platforms and resources to support members of the public to think about, talk about, record, and share what is important to them.
- Public health campaigns - e.g., local approaches to National Dying Matters and National Grief Week where all organisations, members of the public and businesses are encouraged to participate, social media is used to communicate public health messages far and wide, joint working with population health and public health to support messaging e.g. organ donation.
- **Public/patient representatives** - active engagement within palliative and end of life strategic and operational groups across the locality.
- Social prescribing - e.g. social prescribers are trained to be knowledgeable, skilled, and confident to recognise and signpost to palliative and end of life care support and services.
- **Informal caregivers** - carers of people with palliative and end of life care needs are recognised, education and support packages are available, they have access to bereavement support, collaborations with VCFSE sector.
- **VCFSE groups - active and frequent engagement with the VCFSE** sector to plan, implement and evaluate palliative, end of life care and bereavement services including services to carers.

The ICP Strategy- Dying Well



Our Themes	Talking - Encourage our residents to feel comfortable with talking about death and dying	Planning - Advance care planning enables individuals to make plans about their future health care and provide direction to healthcare professionals when a person is not in a position to make and/or communicate their own healthcare choices.	Supporting bereavement - Outstanding support for people who have lost a loved one, their families and carers with an approach that meets their individual needs.
Our Key Actions	<ul style="list-style-type: none"> Compassionate conversations – helping people understand how important it is to think about death, talk about death and plan for it. Make sure more people are supported to have end of life conversations Support a consistent approach to understanding when people are coming towards the end of their life, regardless of where they live or their needs. 	<ul style="list-style-type: none"> Help health and care professionals to support planning for people near the end of life, including what to do in an emergency. Support partners with end-of-life care conversations and plans, and bereavement support in our communities. Make sure there is more support and training for advance care plans, including training volunteers 	<ul style="list-style-type: none"> Bereavement services are easy to find in our places and everyone can access the same levels of support across Lancashire and South Cumbria. Create Bereavement Improvement Plans to develop knowledge, skills and confidence within our communities
Projects that may support	<p>Compassionate Communities EARLY identification programme Catching the Conversations Last Days Matter</p>	<p>North West Anticipatory Clinical Management Planning inc DNACPR guidance MyWishes EPaCCS - Electronic Palliative Care Coordination Systems</p> <p>Training and Education Programme inc:</p> <ul style="list-style-type: none"> MayFly Advance Care Planning Communication Skills Training <ul style="list-style-type: none"> Advance Communication Skills Training - supporting more challenging conversations <ul style="list-style-type: none"> Carers Check In Lancaster University International Observatory End of Life Care <ul style="list-style-type: none"> End of Life e-learning for All 	<p>Place based bereavement groups Compassionate communities Bringing partners together. Bereavement Services Directory (needs resource to keep updated)</p>

Supporting all staff across the partnerships to better understand the end of life: Training opportunities

What we use to help us identify and inform...

EARLY - a tool used in Primary Care to provide a consistent approach across LSC to identify people who are probably in the last 12 months of life, regardless of where they live, their medical condition or diagnosis.

Once identified people can be offered support and signposted to services delivered by Partners across their Place. This may include advance care planning discussions, 'what matters', 'what if' and 'my wishes' conversations.

Data dashboard - To enable equity of access to end of life care which is of high quality and sustaining delivery of end of life care.

National Audit of Care at the End of Life (NACEL) - a national comparative audit of the quality and outcomes of care experienced by the dying person and those important to them during the last admission leading to death in acute hospitals, community hospitals and mental health inpatient providers in England, Wales and Northern Ireland.

So what...?

Training & Education

Coordinated by LSC Education Strategy Group

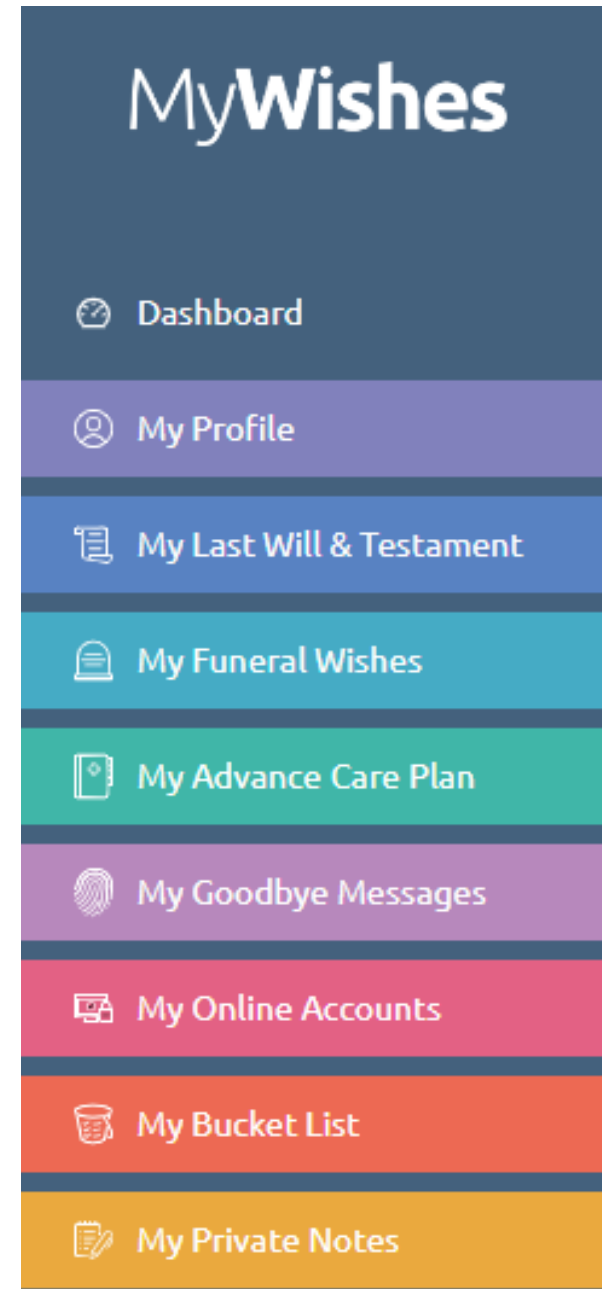
To support the workforce to have the skill knowledge and confidence to deliver high quality end of life care.

This includes increasing the number of staff and volunteers across our Partnership who have completed training in palliative and end of life care personalised care and support planning and report improved confidence, knowledge, and skills

- Advance Communication Skills Training
- Mayfly
- Catching the Conversations
- Last Days Matter
- Carers Check In
- Lancaster University International Observatory End of Life Care
- <https://www.acpsupport.co.uk/>
- End of life E-Learning for all staff – built by partners across LSC

www.mywishes.co.uk/

- A public health approach to future care planning
- A localised version is currently being built for L&SC
- Provides our residents with a tool where they can:
 - Document what is important to them
 - Write a will
 - Share funeral plans
 - Plan their digital legacy
 - Share their wishes about healthcare
- Once complete residents will be able to share relevant information into their healthcare record
- Dedicated care home platform being created so that residents can be supported to complete this.



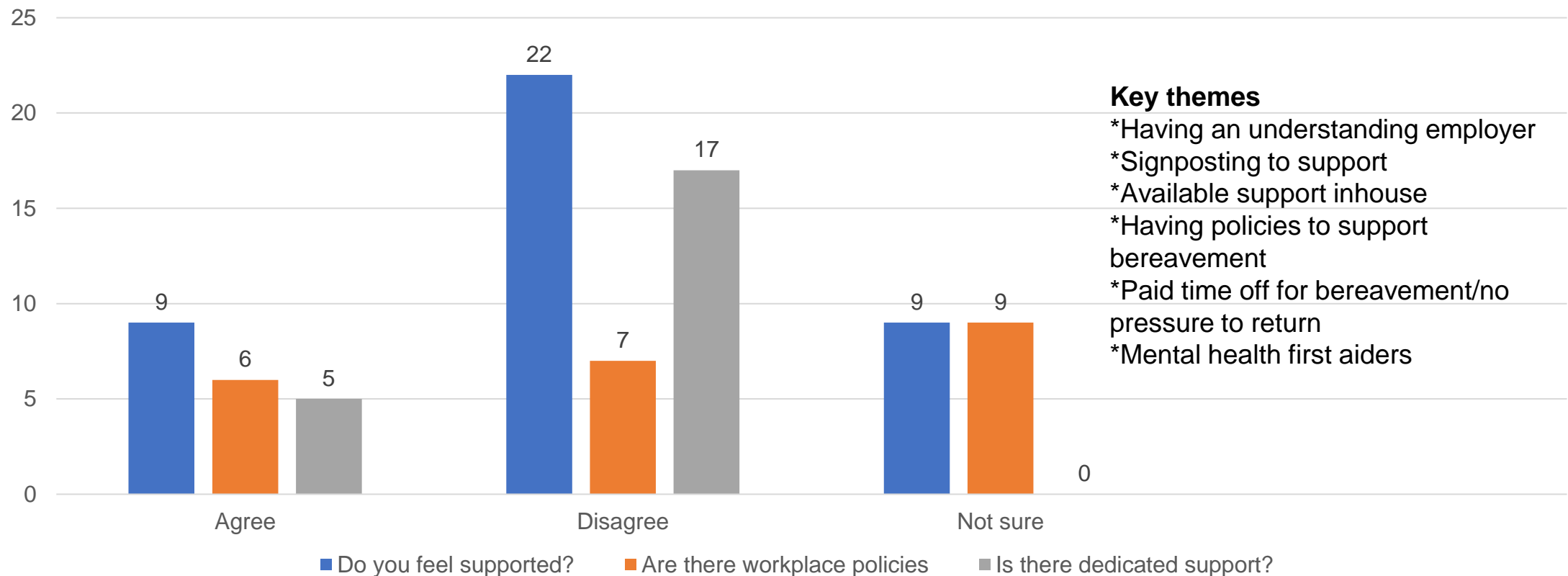
Lived experience stories to the Integrated Care Board – End of Life Care (March 2023)

The image shows a YouTube video player. At the top left is the YouTube logo with a hamburger menu icon. A search bar is located at the top center. The video frame shows a woman with glasses, wearing a dark blue dress and a heart-shaped necklace, sitting on a brown leather sofa in a living room. To her left is a wooden side table with a lamp and a cup. The video player controls at the bottom show a play button, a progress bar at 0:00 / 4:37, and icons for volume, closed captions, settings, full screen, and share. Below the video, the title 'Christine Thornton EoL' is displayed, followed by 'Unlisted'. The channel name 'Lancashire and South Cumbria ICB' is shown with a subscriber count of 75. A 'Subscribe' button is visible, along with icons for likes (0), dislikes, share, save, and a more options menu.

<https://youtu.be/4uMbxgxBu00>

Dying matters week : bereavement in the workplace

If bereaved have you felt supported in the workplace ?



Key themes

- *Having an understanding employer
- *Signposting to support
- *Available support inhouse
- *Having policies to support bereavement
- *Paid time off for bereavement/no pressure to return
- *Mental health first aiders

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