

Palliative and End of Life Care Strategy 2022-2025

Children, young people and adults



*Best Care
Healthy Communities*

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Introduction



Palliative and end of life care is one of the core services provided by Birmingham Community Healthcare NHSFT, with care delivered to children, young people and adults. To ensure we continually provide high quality care that is both inclusive and responsive, it is crucial that we understand:

- **How best we can meet the needs of all the communities we serve across Birmingham and ensure the care we provide is culturally sensitive**
- **What our priorities must be for palliative and end of life care if we are to meet the needs of our population and address inequalities across all age ranges**

Our strategy builds on our progress over the past three years; (**appendix 1**) with priorities aligned to the refreshed National Framework: 'Ambitions for Palliative and End of Life Care' (2021-2026) and influenced by other national and local strategic drivers including:

- **Birmingham Community Healthcare NHS Foundation Trust 'Healthy Communities Strategy; Promoting health equity' (2021)**
- **Together for Short Lives Core Care Pathways (2015)**
- **Together for Short Lives Transition pathway 'Stepping up' (2015) - enabling a good transition to adulthood for young people with life limiting and life threatening conditions**
- **Birmingham Community Healthcare NHS Foundation Trust 'Mortality Policy: Identifying, Reporting, Investigating and Learning from deaths in care' (2021)**
- **Birmingham Community Healthcare NHS Foundation Trust Professional Nursing Strategy (2021-2024)**

A key part of our work to inform the strategy priorities has been through engagement with our communities; capturing feedback and experience through a series of one to one interviews and a short survey which asked people to consider:

- **what really matters to them at the end of life, either to themselves or their loved ones**
- **barriers faced when accessing end of life services**
- **where they would go to access information about healthcare services for a person who is at the end of life**



The main themes identified from this engagement work are summarised in **figure 1** and reflected in each of our priorities. Quotes from the feedback received are also included throughout this document, aligned to the six national ambitions.

Figure 1



Our vision:

Our vision over the next three years reflects that of the national ambitions framework:

'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 carers'

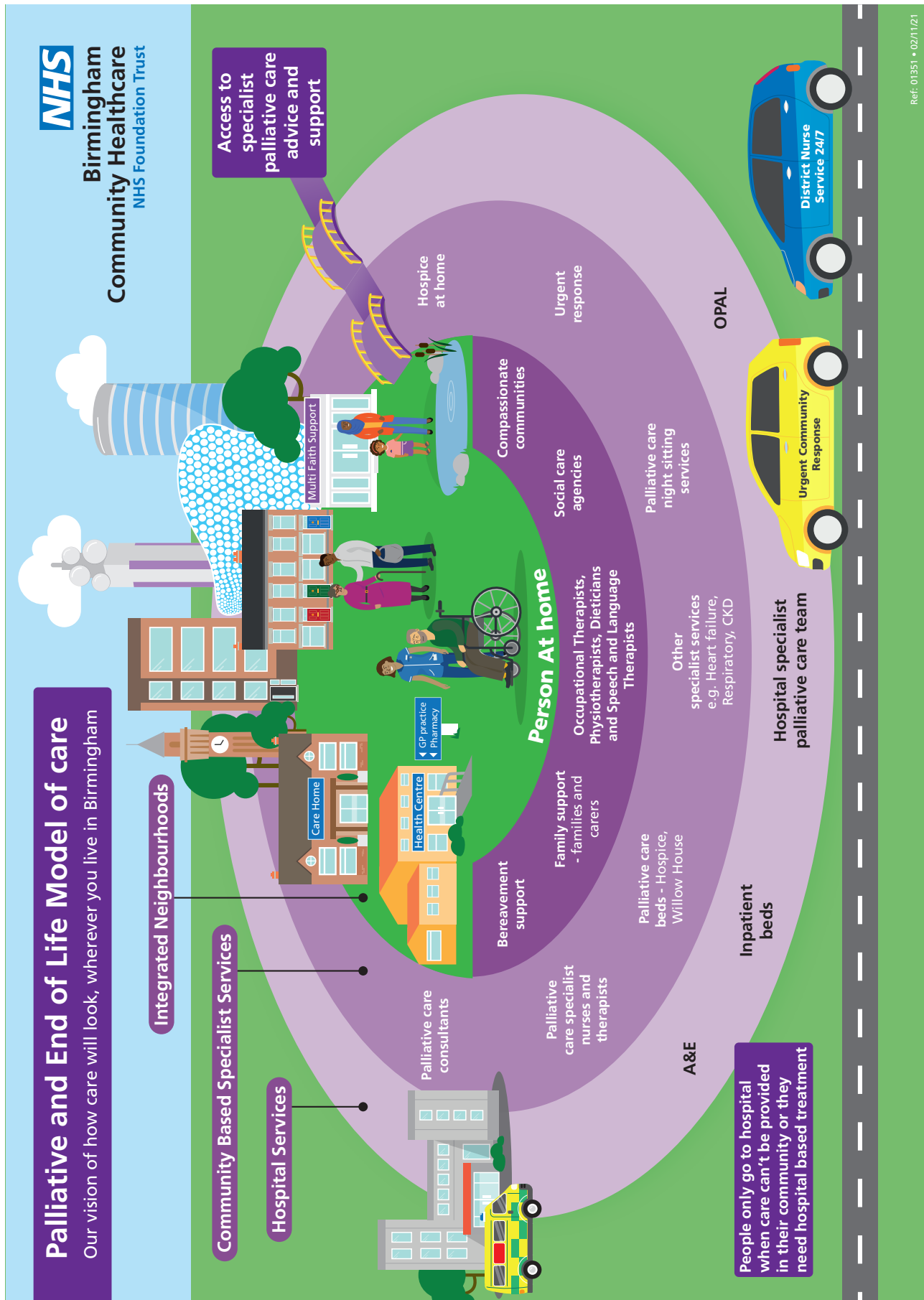
How we aim to make this vision a reality is set out across each of the six ambitions throughout this strategy. Within this work we have included a focus on transition; setting out our ambition to ensure all young people and their families have a positive experience when their care transitions to adult services.

The six ambitions are summarised in **figure 2** (below)

Figure 2

Ambition number	Ambition for palliative and end of life care
Ambition 1	Each person is seen as an individual
Ambition 2	Each person gets fair access to care
Ambition 3	Maximising comfort and wellbeing
Ambition 4	Care is coordinated
Ambition 5	All staff are prepared to care
Ambition 6	Each community is prepared to help

Central to achievement of the six ambitions within this strategy is a focus on partnership working across health and social care as our integrated care systems (ICS) evolve and this is reflected in our overall model for palliative and end of life care.





Ambition 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.’	
How we will achieve this ambition	Outcomes
Honest conversations: <ul style="list-style-type: none">• Ensuring that our patient’s and family’s needs can be fully explored through honest conversations• Provision of training within the Trust Palliative care education programme to ensure staff have the skills and confidence to have honest conversations about dying, death and bereavement• Ensuring that the voice of the child and young person is heard and their views are taken into account where it is appropriate to do so	<p>Staff are confident and competent in having and documenting these honest conversations - core part of the education programme</p> <p>Evidence within clinical records that this practice is embedded within the team</p>
Advance care planning - Individualised care planning: <ul style="list-style-type: none">• We will support adults, children and young people to make timely decisions about their care through our focus on proactive and individualised care planning, ensuring choices are recorded and communicated• We will work with our communities to ensure that information and advice about end of life care is accessible for all and to raise the profile of our services• Cross organisational working to raise awareness of the children and young people advance care planning document and what support is available for staff to increase their confidence in completion of this document	<p>Evidence that patient choice has been documented, supported and achieved at the end of life</p> <p>Evidence of advance care plans for children and young people providing a robust plan around management of deterioration including maximising quality of life and capturing their wishes and those of their families</p> <p>Increase in the number of individualised care plans in place</p> <p>Culturally sensitive information is available that can be freely accessed</p>

Honesty and realism. No euphemisms or sugar-coating bad news.

Total honesty RE: prognosis, and to be treated as an equal partner in the process.



Ambition 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.'

How we will achieve this ambition	Outcomes
<p>Engaging with our communities and faith groups:</p> <ul style="list-style-type: none">• We will strive to understand where communities may not be accessing palliative and end of life care - actively engaging with our communities and faith groups to understand and address barriers accessing our services• We will use data to understand the reach of our services and identify how we can address inequalities in access and use - this includes clinical diagnosis (malignant and non-malignant disease) and ethnicity - To start this work we will complete an audit to identify and understand our palliative and end of life patient caseload with a specific focus on diagnosis and ethnicity, locality, accommodation status e.g. hostel, care home etc and which services are being utilised• We will review and reflect on our approach to engagement and capturing feedback to ensure there is a specific focus on that of ethnic minority groups and homelessness, with improved routes into our diverse communities• We will continually review the quality of care we provide through a range of clinical quality and audit measures that focus on patient experience, effectiveness of care and safety reflecting recommendations in the Trust 'Learning from Deaths in Care' plan.	<p>Community partnerships/networks in place, working as part of the integrated care system and incorporated within the development of neighbourhoods across the city</p> <p>Refreshed and simplified referral pathways in place with ongoing engagement to raise awareness</p> <p>Implementation of an agreed action plan to address inequalities identified to accessing our services for palliative and end of life care - including a focus on ethnic minorities and clinical diagnosis (cancer / non cancer conditions)</p> <p>Evidence of ongoing improvement in the quality of palliative care for all through the use of outcome measures, clinical audit and patient/family experience measures - reviewed against ethnic minorities' data and clinical diagnosis in line with the supportive and palliative care indicator tool (SPICT)</p>

Many people I know would have little awareness that these services exist let alone have problems accessing them.

My father was end of life and we had no idea what we were entitled to and whether we could bring our father home, we had to push for that service to be done at home.



Ambition 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'

How we will achieve this ambition	Outcomes
<p>Skilled assessment and symptom management:</p> <ul style="list-style-type: none">• Staff will be supported to develop their knowledge and skills in assessment and management of symptoms, working in partnership with specialist palliative care to ensure there are clear referral pathways in place for access to specialist advice and support 24/7• We will ensure there is a focus on personalised care planning through the use of the Supportive Care Plan and End of life Care plan for adults and for children and young people the Symptom Flow Chart and Assessment Framework, working in partnership with the wider MDT• We will support staff to better meet patient's spiritual needs, working with our spiritual care team and community and faith groups to develop spiritual care assessment tools reflecting recommendations in the Trust 'Learning from Deaths in Care' plan	<p>Timely referral to specialist palliative care with clear referral pathways in place</p> <p>Ongoing palliative and end of life care education programme in place - staff confident and competent in assessment and management of symptoms</p> <p>Evidence of achievement of five priorities for care of the dying person through quality review/audit of care across inpatient and community settings</p> <p>Evidence of achievement of Together for Short Lives Core Care Pathway for children's palliative care</p> <p>Access to spiritual care service across the Trust with assessment tools in place</p>
<p>Measuring comfort and wellbeing:</p> <ul style="list-style-type: none">• To enable us to understand what really matters to each individual at the end of life we will introduce the use of patient centred outcome measures• We will proactively support children and young people to maximise memory making experiences, optimising their quality of life• We will support a rehabilitative approach to support people in the achievement of their personal goals and maximise their independence - this will include scoping of need for better access to Occupational Therapy, Physiotherapy and Respiratory physiotherapy for children with palliative care needs and access to wider MDT members, including play therapy	<p>Quality of life outcome measures reflect a level of improvement or maintenance for patients</p>

Good communication with the patient and family member collaboration commitment, respect my autonomie

The most important part is being in control of my care journey and not being told what care I need



Ambition 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 day or night.'

How we will achieve this ambition	Outcomes
Working in partnership across the integrated care system: <ul style="list-style-type: none">• We will work with our partners across health, social care and education to design and implement a 24/7 centrally coordinated pathway for palliative and end of life services• We will adopt a key worker approach to the management of palliative and end of life care• We will improve coordination of care for; children who transition into adult services, those living with dementia and people with learning disabilities	Key partner and provider of a centrally coordinated pathway across Birmingham with 24/7 access to care
<ul style="list-style-type: none">• We will develop a Trust wide Bereavement Policy and explore options for a dedicated bereavement coordinator role for both children's and adult services across the Trust that will support access to timely and culturally sensitive information for bereaved families	Improved access to bereavement information and support for families
Transition of care from Children to Adult services: <ul style="list-style-type: none">• We will work with the Trust and system wide transition leads to identify the level of resource required to support creation of timely, planned transition pathways• We will develop collaborative pathways that reflect the Together for Short Lives 'Stepping Up' standards and phases of care across paediatric and adult services, working to enable improved experience during the transition of care• We will raise the profile of transition and the 'stepping up' standards and phases of care, with adult and children's services actively working together to enable a smooth transition• We will inform system wide work related to access to children's and adult hospice services during the transition phases	Clear transition pathways in place across the Trust's children's and adult services Evidence of achievement of Together for Short Lives 'Stepping Up' standards and phases of care Staff are confident in managing the transition of care across services



continued...Ambition 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 day or night.'

How we will achieve this ambition	Outcomes
Improving communication: <ul style="list-style-type: none">• We will work with our partners across Birmingham and Solihull to explore digital solutions to accessing and sharing clinical records 24/7• We will work closely with community and faith groups across our localities to develop information and resources to enable patients and their families to have timely access to information and support in an appropriate format	Timely access to clinical information 24/7 All services have the same level of access to electronic patient records to enable continuity of palliative care for children and young people Accessible information/resources available with clear signposting to locally available services
Leadership: <ul style="list-style-type: none">• We will ensure there is clear leadership of palliative and end of life care across the Trust and within teams• We will strengthen clinical leadership of palliative and end of life care, scoping the need for specialist palliative care consultant access for adult services and increased consultant support for childrens palliative care	Dedicated strategic and clinical leadership and executive support to enable achievement of outstanding palliative and end of life care across adult and childrens services

Have the same care team, so I could build up trust with them

Once a care plan is conducted there is no key worker or point of contact. It becomes very difficult with a number of practitioners doing their bit but not co-ordinated



Ambition 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.'	
How we will achieve this ambition	Outcomes
<p>Education and training:</p> <ul style="list-style-type: none">• We will ensure our staff are confident and competent in the delivery of palliative and end of life care, utilising a competency framework that sets out the core knowledge and skills required for high quality care• We will include a focus on the diverse needs of our communities within our education programmes to ensure we understand what matters to different communities and faiths when approaching the end of life this will include developing and utilising a cultural toolkit.• We will ensure ongoing review and evaluation of our education programme, informed by learning from patient and family experience, including incidents and complaints• Recruit palliative care champions for teams in adult and childrens services, with clearly defined roles and responsibilities• We will build on our education programme to include a focus on training needs for non-registered clinical staff across the Trust• We will participate in research related to adult and childrens palliative and end of life care and	<p>Palliative and end of life care education programme and competency framework in place for Registered staff with ongoing review and evaluation - utilising technology within these sessions</p> <p>Identified palliative and end of life champions in all teams with evidence of sharing best practice across teams</p> <p>Education programme in place for non-registered staff</p>
<p>Supporting our staff:</p> <ul style="list-style-type: none">• We will ensure there are opportunities for staff to participate in clinical reflection sessions, to allow for reflection and learning, taking account of emotional labour and the need for support when caring for patients and families at the end of life reflecting recommendations in the Trust 'Learning from Deaths in Care' plan	<p>All staff have access clinical reflection sessions and Schwartz Rounds</p> <p>Inclusion of a wellbeing session as part of the Trust palliative and end of life care education programme</p>

Taking as holistic a view as possible in arriving at the best outcome for an individual and their family or friends

Always show a lot of empathy. Not only hearing but listening to what the loved ones/family are requesting as always remember they know the person who is dying more than carers and health care professionals will ever do



Ambition 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'	
How we will achieve this ambition	Outcomes
<p>Community partnerships</p> <ul style="list-style-type: none">• We will embody the 'compassionate community' approach, of working in broad and varied partnership with our diverse communities - incorporating within the development of neighbourhoods, and promoting more openness around care at the end of life• We will work to develop a resource on the Trust website that will support patients and families to access timely information and support, working with local organisations and communities across Birmingham to inform content and signposting –• We will work in partnership with faith and community networks in the development of information and resources; identifying how best to communicate - utilising media of all types to raise awareness• We will work in partnership with acute, primary care and voluntary organisations to ensure we are delivering joined up care across childrens and adults services	<p>Key partner within the BSOL work to support 'compassionate city' approach for Birmingham</p> <p>Active participation in national awareness campaigns e.g. Dying Matters Week, to encourage early conversations about wishes/preferences at the end of life across communities</p> <p>Improved access to information on Palliative and end of life care for patients and families/carers - accessible for all</p>

Clear and simple information in a range of formats and locations

Help to inform those whom I want to know; especially family that might be living far away or abroad

We will create a road map which sets out how our ambitions will be achieved over the next three years. This will be underpinned by a detailed RAG rated action plan. Progress against the plan will be monitored through the Trust End of Life Care Working Group.

Appendix 2

May: Implementation of virtual clinic model for Childrens palliative care and rapid response

June: Nursing Times award finalists for team of the year - Childrens palliative care team

July: Secured service level agreement for support for staff wellbeing and spiritually and religious belief training with Birmingham Women's and Children's hospital for childrens palliative care and rapid response team

Oct: First Trust 'Care of the Dying Evaluation' (CODE™) report - reporting on bereaved relatives experience of end of life care

Dec: Introduction of new patient information leaflets 'what to expect when a person is dying' (adults) and 24/7 on call support for childrens palliative care visiting service

2019 Progress timeline

May: Implementation of the Trust Palliative and end of life care strategy

June: Palliative care section launched on the Trust intranet as a resource for staff - Adults and Children

July: Introduction of Trust Bereavement information packs and bereaved relatives survey (CODE) Children and Adults

Oct: Introduction of new Trust wide Adult Palliative and End of Life Care Education Programme for registered staff, with supporting competency framework

Dec: Secured £62K for training in paediatric palliative care visiting service

Jan/Feb: CQC review - End of Life Care rated 'Good' overall and 'Outstanding' in 'caring' category across the Trust

April: Expansion of verification of expected death training across community and inpatient teams as part of the Trust COVID response

August: Pilot of BCHC Charity funded 'Memory Boxes' for bereaved families of inpatients

Nov: Start of PEWS pilot to trial specialist tool to detect sepsis in children and young people with complex healthcare/palliative diagnosis

2020 Progress timeline

March/April: End of life care COVID response model developed and implemented

May: Implementation of internal child death overview panel meetings response

Sept: Launch of a dedicated phone line option (option 3) for palliative care patients and their families - added to the Trust Single Point of Access options

Dec: Introduction of BCHC Charity funded 'Dandelion' property bags for bereaved families of inpatients

Jan: Engagement survey completed - engaging with our communities to inform Trust priorities for Palliative and end of life care

April: Permeant funding secured for 0.5 WTE Consultant paediatric palliative care consultant

May: Launch of the 'Dandelion Room' at Moseley Hall Hospital

July/Aug: Review of Trust wide palliative and end of life clinical policies

Sept: Relaunch of Birmingham and Solihull (BSOL) end of life system wide group - 'End of Life Collaboration System Steering Group' and BSOL Operational System group

2021 Progress timeline

Jan: Honorary contracts agreed for some Acorns Hospice staff to rotate into the Childrens palliative care team to support end of life care

May: Re-visiting the need for neonatal pathway across the city

June: Pilot commenced of new End of Life Care Plan (inpatients)

Sept: Planning commenced for Trust wide palliative and end of life education programme for non-registered staff

