Strategy for Palliative and End of Life Care in Dorset

Pubished 24/01/24 Version 1.0

NHSD-EOLC1-1-EM-1-24

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Contents

Introduction

Dying is a process that affects everyone, and the quality of care we receive at the end of our lives can have a lasting impact. Approximately 1% of people die each year in the UK. In Dorset, 9,889 people died in 2022 out of 824,754.[1]; a total of 1.2% of the local population.

Each of us will have our own idea of what end of life care looks like, which is why it's important to have plans in place that put each person at the centre, helping them to receive the best possible care in a way that is most appropriate for them and the people they care about.

Dorset's all-age strategy for end of life care

The current national guidance for end of life care is set out in Ambitions for Palliative and End of Life Care: A national framework for local action 2021-26[2]. We have used this to inform our own local all-ages strategy for the people of Dorset.

The point of a strategy is to explain what we hope to achieve, and how we're planning to do that. This document considers both adult and children's end of life care. It aligns our aims and priorities, providing a clear strategy on how we can provide excellent, personalised palliative and end of life care to anyone who needs it, no matter their age, and offer support to each individual and those most important to them.

The difference between adult and children's palliative care

Children's palliative care services look after people between the ages of 0-18 with a range of diverse life-limiting conditions, and their families. Care can even begin before a baby is born, as we continue to improve ways of identifying conditions while a baby is still in the womb. In this document, the word 'children' is used to cover babies, children and young people up to the age of 18.

There are important differences between adult's and children's palliative care, which are explored in detail in the children's section of this all-ages strategy.

The number of children with a life-limiting condition has trebled over the last 17 years[3,4], with about 66.4 per 10,000 of children and young people (aged between 0-19) in England affected[5].

In Dorset, this means an estimated 1,038 0-19-year-olds who are likely to need access to palliative and end of life care.

The Dorset Palliative Care Steering Group

The Dorset Palliative Care Steering Group was formed in March 2020 in response to the pandemic. It includes representation from all those involved in end of life care in Dorset, including primary care, secondary care, social care, palliative care specialist services, district nursing, pharmacy, and commissioners. Their involvement and guidance has been vital in writing this strategy.

The Pan-Dorset Children's Palliative Care Group

The Pan-Dorset Children's Palliative Care Group has been in operation for ten years, providing a Dorset-wide collaboration between professionals from the NHS and the children's hospice sector, who provide palliative and end of life care for children across Dorset.

Our Aims

We want everyone in Dorset to have excellent, proactive, responsive, personalised and equitable end of life care. We have used information gathered from the people of Dorset, the Palliative Care Steering Group, the Pan Dorset Children's Palliative Care Group, and feedback from bereaved parents and carers to inform and develop this strategy.

We will use this strategy to guide Dorset's health and care system so every person in Dorset can get the best possible palliative and end of life care in the way that is most appropriate for them and those important to them.

Our vision and priorities

The vision statement and priorities for the adult section of this strategy were identified with the Dorset Palliative Care Steering Group, taking into account information gathered from the:

- Joint Strategic Needs Assessment (JSNA) for Dorset End of Life Care 2020[6]
- Results through relationships 2018-2020[7]
- Bereavement survey 2020
- Patient survey 2021
- Consultation with domiciliary care and district nurses
- Consultation with Dorset primary care networks.

On a national level we also used information gathered from:

- National ambitions for palliative and end of life care
- VOICES[8]
- National Audit of Care at the End of Life (NACEL)[9]

Priorities for the children's section were created in-line with those for the adult's section, with a focus on the different needs of young people. The Pan-Dorset Children's Palliative Care Group considered how these priorities fit within local, regional and national priorities for children with life-limiting and life-threatening conditions.

Our vision:

Achieving excellent, proactive, responsive, personalised and equitable palliative and end of life care for the people of Dorset and those important to them.

Our Priorities

1. Achieve timely, personalised care planning for people at end of life, taking into account what matters most to them, and their individual preferences.

2. Co-ordinated care across services with effective joint working and improving continuity of care at end of life.

3. Supporting people to live and die in their preferred care setting with timely symptom relief, personal care, support of and for carers and healthcare professional support.

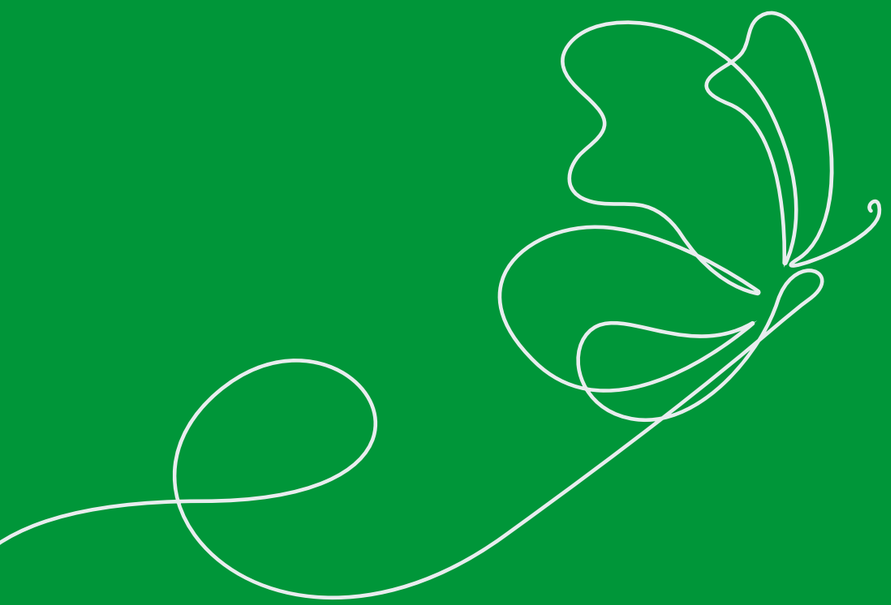
4. Supporting education, training, resilience and wellbeing across Dorset for all staff involved in end of life care.

5. Ensuring effective, consistent and timely bereavement care for people in Dorset.

6. Helping to develop caring, inclusive communities with openness about death and dying and willingness to help in emotional and practical ways.

7. Ensuring continued feedback and involvement of people at end of life, those people important to them, carers and healthcare professionals in Dorset.

Adults Section



Priority 1

Achieve timely personalised care planning for people at end of life, taking into account what matters most to them, and their individual preferences.

Background

People are approaching the end of life when they are likely to die within the next 12 months[10].

If we want to provide good care and support people and their families appropriately[11], then we need to know when people are approaching this point. If we can do that, then:

- people at end of life and their carers have time to deal with the news and realign their priorities
- people at end of life are less likely to be subject to treatments that might not help them
- health and care professionals can plan appropriate end of life care rather than work within a series of crises
- well-organised community support can halve the cost of hospital admission and allow 70% of people who choose to die at home.

The NHS Long Term Plan[12] identifies the development of personalised care planning (including personal health budgets) as a priority for end of life care so people at end of life and those important to them receive care holistically and in a more person-centred, co-ordinated way, to deliver outcomes and services that meet their needs.

In Dorset, the Joint Strategic Needs Assessment identified conversations to develop shared understanding of wishes as essential to improving end of life care. The patient survey identified that having clear plans, discussed in advance with people at end of life and those important to them, often came up as a priority. Discussions with domiciliary care agencies, district nurses and the ambulance service also highlighted the need for clear, care plans, shared between providers, to allow people at end of life to remain in their chosen setting, with what matters to them being made a priority.

Aims

Everyone involved with care and support at end of life feels confident having conversations about what matters to people in their last weeks and months of life, and those close to them.

Everyone involved with care can identify people approaching end of life and undertake care planning.

- Standardised education and training offer across Dorset for everyone involved in care including:
  - GPs
  - hospital specialists
  - district nurses
  - care agencies
  - care home staff
  - frailty teams
  - specialist nursing teams including heart failure and respiratory nurses
  - palliative care at home team
  - any other stakeholders involved in end of life care

- Advance care planning across all settings
  - People across all settings should be offered personalised advance care planning towards end of life. This includes people at end of life at home,

in hospices, in hospitals and in care homes.
  - » Engagement in advance care planning in all settings and with everyone involved in care.

- ◊ Aim for all advance care planning documents to have relevant, helpful information for everyone involved in care for people at end of life and
  - » Prevent people at end of life and those important to them having to repeat conversations.

- ◊ When considering advance care planning for young people transitioning between paediatrics and adult services, both the paediatric and adult teams will work with the young person and their family at the earliest opportunity.

- Standardised content for care plans
  - ◊ What matters most to the person at end of life
  - ◊ Treatment escalation plans and preferred place of care
  - ◊ DNACPR information
  - ◊ Functional status
  - ◊ Summary of medical problems and level of frailty
  - ◊ Medication summary
  - ◊ Details of carers and relationships

- There is a standard national template for children and young person advance care planning at www.cypacp.uk.

- Good access to advance care plans across settings
  - ◊ Care plans should be available to the person at end of life, and those important to them, as well as all health and social care professionals involved in their care. This will include but not be limited to specialist palliative care, GP practices, the ambulance service, out of hours service, domiciliary care and social care.

Resources for information about care planning to be made available to people at end of life, those important to them, and all involved in their care.

During discussions about care planning, it can be difficult for people at end of life and those important to them to take on information, and conversations may be emotive. To help make these conversations easier and reduce any misinformation, the following resources should be available:

- Easily accessible, reliable and useful information about understanding what may happen in the last hours, weeks and months of life, advance care planning and resuscitation. This may include written and audio-visual formats.

- Advance care planning information videos and leaflets have been produced in Dorset and approved for use.

- Access for all staff involved with care to advance care planning supporting information. Kathryn Mannix has produced many videos increasing understanding of, and preparation for, dying. These explore the art of participating in conversations that may feel emotional, frightening, or daunting[13].

Every effort should be made to find a person's means of communication. Often carers who know them well can interpret sounds, sign language and eye movements, using a variety of aids, or they may recall their wishes prior to the loss of capacity. A lack of communication cannot be assumed to mean that an individual lacks capacity because they lack communication skills.

For those assessed as lacking capacity for advance care planning, there needs to be full discussion with carers and family involved in supporting that individual. In the absence of a deputyship or lasting power of attorney (for health and welfare) for adults who lack capacity, a decision should be taken in their best interests, involving the family, carers and professionals, and recording the decision appropriately, according to the Mental Capacity Act 2005. In the case of under 18s, decisions are made by their parents or legal guardian.

Summary

- Standard offer across Dorset for education and training around early identification and advance care planning to everyone involved in end of life care.

- All people at end of life should have the opportunity to express preferences regarding their preferred place of care.

- All involved in end of life care across all settings to engage actively in advance care planning and early conversations. Create learning opportunities to develop skills to do this with confidence.

- Standardised advance care planning so that the required information is available to all, whichever care plan document is being used. Continuously test and learn what is working well and how to improve this.

- Advance care plans should be available to people at end of life, people important to them and all involved in care across all settings.

- Sharing the advance care planning videos and written information to all involved with end of life care to assist with early conversations.

- Early conversations to understand what matters most with people at end of life and those important to them.

- When transitioning between paediatric and adult services, care planning conversations will support the continuation of the established paediatric care plan. This can include how teams will work together and highlight any differences in services that the young people and those who are important to them may experience.

Actions

- Enable early conversations about what matters most to people. Identify the key enablers and barriers to this happening consistently and reliably – personally, locally and across Dorset.

- Develop education and training around early identification and personalised advance care planning for all of those involved in end of life care in Dorset, ensuring everyone has access to supporting materials such as the advance care planning videos and written information, including 'what matters' conversations.

- Work to ensure personalised care plans can be accessed across all settings.

- Enable those supporting people at end of life across Dorset to have early conversations about what matters most to them.

- Increase awareness and use of the children's and young person's advance care plan to support transition.

Priority 2

Co-ordinated care across services with effective joint working and improving continuity of care at end of life.

Background

People at the end of life, those important to them, and those involved in their care told us that appropriate and timely end of life care relies on excellent relationships.

Partnership working and shared communication was repeatedly mentioned as essential. Sharing information between organisations ensures that everyone involved has a full picture of the person, and early identification of their needs.

> “ To have a key person available to be able to speak and support with anything required for your specific needs. Not just sign-posting to numerous leaflets where you get bogged down with information which just piles up and is no help. ”

Aims

- Improving continuity of care for people at end of life
  - ◊ enabling healthy relationships to form
  - ◊ reducing the risk of duplication of effort and the risk of miscommunication in handover
  - ◊ recognising the benefits of getting to know people as people rather than patients[14]
- Improving support for people at end of life moving between care settings
- Co-ordinated care across services with effective joint working
- Relationship building and trust between colleagues
- Sharing of IT systems across services
- Provide links between services involved in end of life care
- Advocates available to help navigate system for people at end of life and those people important to them
- Shared care planning
- Provide clear point of contact
- To ensure that all aims are consistent for young people approaching the end of life at the point of transition.

9,889 out of **823,754** people died in Dorset in 2022.

Multidisciplinary team (MDT) meetings

- MDT involvement for people at end of life
- Access to the MDT and the ability to bring people for discussion available to all involved in end of life care
- MDT is essential when approaching time of transition between paediatric and adult teams.

Information technology

- Primary care currently use SystmOne, with NHS hospices and hospitals on EPR and DPR
- Move to a standardised way that personalised care plans can be shared between all services as outlined in Priority 1:
  - ◊ Via Dorset Care Record (see below)
  - ◊ Printed and given to people at end of life
- Access to SystmOne for all hospices in Dorset if possible.

Dorset Intelligence and Insight Service (DiiS)

Proactive identification of individuals approaching and registered as end of life using a population health management approach.

Using technology, we will:

- Identify people likely to be dying in the coming months/weeks/days
- Identify people who are already recognised as approaching the end of life through the recognition and collation of an end of life register

Dorset Care Record and other solutions

- Support co-ordinated care, joint working, and people’s preferences through digitally enabled services
- Standardisation of the systems we use, the data we collect, and the way in which this is shared across the integrated care system
- Look to extend and develop integrated working practices through our digital solutions
- Enable people at the end of life and their support network to contribute to their care planning through digital solutions.

Good discharge planning for people at end of life

- People moving between services at end of life need good planning and co-ordinated care
- Key workers to co-ordinate care and review needs
- Discharge summaries and anticipatory care plans available for all to view
  - ◊ Dorset Care Record
  - ◊ Printed and person-held

Establishing a clear point of contact

- Directory for all available services that support people across Dorset at end of life for health care professionals and for people at end of life and those important to them

- 24-hour advice line in Dorset shared with all people at end of life and those important to them
- Care co-ordinator or key worker available for people at end of life
- Young people in transition between services may have named worker in both paediatric and adult services
- During transition between paediatric and adult services at end of life, clarity on point of contact for the family is particularly important.

Summary

- MDTs available for discussion of people at end of life
- IT solutions to help facilitate sharing of information between services
- 24-hour help and support for people at end of life whenever needed
- Directory of palliative care services available in Dorset
- Key workers co-ordinating care for people at end of life
- Effective continuity of care for people at end of life moving between care settings, including between paediatric and adult services.

Actions

- Establish a directory of specialist and generalist palliative care services for Dorset
- Test and learn about how to effectively share information about what matters
- Develop IT solutions for sharing information including personalised care plans across all services
- Establish multi-skilled key workers for people at end of life to ensure co-ordinated, personalised care
- Learn about the best ways to co-ordinate care for people at end of life
- Establish MDT working to help co-ordinate care for people at end of life with involvement of key workers and advocates
- Establish MDT working for transition focused discussions between adult and paediatric services.

Priority 3

Supporting people to live and die in their preferred care setting with timely symptom relief, personal care, carers support and healthcare professional support.

Background

People at end of life, those important to them and those involved in their care highlighted the need for timely and adequate symptom control, provision of equipment, and access to home care, especially when there is a rapid change in symptoms or needs.

> “ Being listened to. Good and clear information on what help can be provided practically, emotionally and spiritually. And quick access to it. ”

Aims

Care provision

- All people at end of life to have access to equitable care throughout Dorset, and multi-skilled key workers to facilitate this
- Assistance for people at end of life and those important to them with collection and disposal of medication

Carers support

- Awareness and acknowledgement of the burden on carers looking after those at end of life
- Active sharing of information with those close to people at end of life
- Access to advice line
- Involvement of those important to people at end of life with decision-making and advance care planning where appropriate
  - ◊ supported by advocates
  - ◊ resources explaining end of life decision making (videos and leaflets)
  - ◊ awareness and acknowledgement of a parents/carers voice when their child is reaching transition between palliative care services.

Symptom relief

- Early identification of need for symptom relief and anticipation of what may happen in the last hours, days, weeks and months of life
- Timely prescribing, supply and administration for end of life medications
- Assistance for people at end of life and those important to them with collection and disposal of medication

Night Service

- Overnight care and/or visiting service if needed
- Early conversations and regular updates are required when considering young people transitioning from paediatric services to adult services.

Equipment

- Early identification of equipment needs for people at end of life
- Priority provision of this equipment.

Summary

- Care available to all people identified as end of life who wish to die at home
- Support to those caring for people at end of life and those important to people at end of life
- Identification of need for symptom relief and timely provision of medication in timely manner
- Night service to assist with care and symptom relief
- Timely provision of equipment needed as care needs change.

1.2% of people in **Dorset** will need end of life care.

Actions

- Key workers/patient advocates for people identified as end of life to help co-ordinate care, and to support and advocate for people and those important to them
- A system that prioritises equipment and medication for people at end of life to ensure their needs are met in a timely manner
- A night service for care provision overnight if needed for people at end of life.

Priority 4

Supporting education, training, resilience, and wellbeing across Dorset for all staff involved in end of life care

Background

Workforce wellbeing and resilience are fundamental to providing quality end of life care. Consistent education and training across services would improve confidence and support staff, with time for shared reflection.

Aims

Education across Dorset for staff involved in end-of-life care

- Development of a centralised palliative care resource for Dorset with contributions from all specialist care services.
- Consistent education for end of life care across Dorset
  - ◊ Available to all health and care staff involved in end of life care including care home staff and domiciliary care home staff
  - ◊ Include training on:
    - » recognising approaching end of life
    - » ‘what matters’ conversations
    - » symptom control
    - » advance care planning
    - » available resources
- Webinars, podcasts and presentations uploaded to a central site
  - ◊ Some specific to different HCP and some universal
  - ◊ Resources can be used for primary care network protected learning time or for GPs and other HCP to work through individually.

Staff resilience and wellbeing

- Recognise the things that help wellbeing and thriving, and those that don’t
- Reduce activities which don’t add value (eg repetitive paperwork)
- Create conditions for compassionate care, which is associated with less risk of burnout
- Ensure appropriate support, including peer support / mutual support as well as access to counselling
- Time for staff to be able to reflect and debrief
- Open environment where sharing is encouraged
- Emphasis on building relationships within and between organisations to support each other
- Helping staff with confidence in their practice built from education and understanding what matters to people at end of life.

Actions

- Develop a standardised education across Dorset for staff involved in end of life care, especially for advance care planning
- Set up a centralised palliative care resource for Dorset with contributions from all specialist care services
- Support staff resilience and wellbeing
  - ◊ development of an open environment and time for staff to debrief and reflect
  - ◊ equitable access to clinical supervision and counselling if needed
  - ◊ support staff via education and development to improve capabilities and confidence
  - ◊ build relationships between organisations

Priority 5

Ensuring effective, consistent and timely bereavement care for people in Dorset

Background

The information gathered from patient/family surveys and working with Dorset's primary care networks highlighted a need for improved access to bereavement services and for better written information.

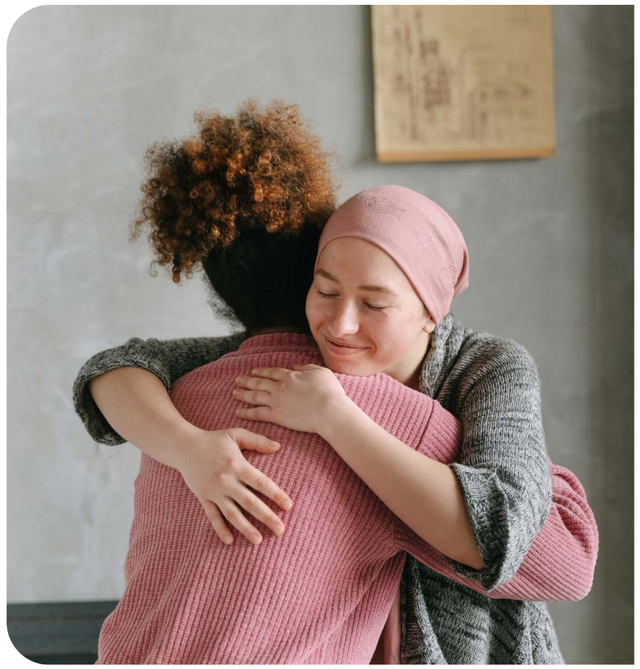
This was further confirmed by domiciliary care and district nurses, who highlighted a need for a consistent approach when people die and more access to information about available bereavement services.

Aims

- Compassionate relationships to support people when their loved one is at end of life. This will be through a range of community and peer support.
- Bereaved people are followed up with in a consistent way, offering after-care and signposting to bereavement services.
  - ◊ All bereavement services added to central resource for bereaved people and HCP to see what is available
  - ◊ Sharing the Help and Kindness website
- Written information summarising all bereavement services available in Dorset.
- Timely bereavement counselling for those that need it.

Actions

- Create environments and time to develop compassionate relationships to support loved ones, before, during and after death.
- Formulate a centralised resource of bereavement services for people to access after bereavement.
- Ensure this resource is shared those caring for people at end of life and following up after bereavements so that they are able to signpost effectively.
- Establish consistent follow-up for bereaved people in Dorset and ensure timely bereavement counselling for those that need it.



Priority 6

Helping to develop caring, inclusive communities with openness about death and dying and willingness to help in emotional and practical ways.

Background

To encourage support, conversations and networking at a neighbourhood level, in line with ICB strategic priority. Creating supportive networks between those needing palliative and end of life support and those who can provide it. Offering equitable services that are both educational and compassionate, to ensure that end of life care is consistent, and peoples wishes are upheld.

Aims and Actions

Awareness and engagement

- Normalising openness around dying
  - ◊ Acknowledging that this is hard
  - ◊ Embracing and provoking open conversations about death, dying and bereavement across Dorset
- Working with community groups and institutions to encourage more openness around death and dying
- Community development programmes in end of life care, led by local people
- Linking with Dying Matters[15] for support and resources in starting conversations around death and dying
- Linking with integrated neighbourhoods programme to encourage awareness and highlight available services
- Increasing awareness of the difference between palliative and end of life care.

Making connections between people that want to help and those that need it

- Working with existing community groups
  - ◊ Identifying volunteer groups willing to help support people at end of life and linking them to those that need help
  - ◊ Using community volunteering hub in Dying Matters to assist with this
- Centralised up-to-date information available to people at end of life and those important to them regarding available help in the community and networks for both pastoral support and practical help.

Priority 7

Ensuring continued feedback and involvement of people at end of life, those people important to them, carers and healthcare professionals in Dorset to inform service development and improvements.

Background

To understand whether we're making the difference we want, it's crucial to listen to the views of people we're here for. It's important we understand what matters to people at the end of their life and in bereavement, and whether what matters was what happened.

Recognising that people choose to share their views in different ways, it's important people feel they have a choice in whether and how to participate.

Conversations enable generation of new ideas, seeing things from new perspectives. This isn't just about improving services. People are creative and can often find ways to be the architect of their own solution – far more powerful than any service.

> **" Patient involvement means more than simply engaging people in a discussion about services. Involvement means having the patient voice heard at every level of the service, even when that voice is a whisper. "**

Aims

Establish a mechanism of regular feedback from all involved with end of life care to inform ongoing development and support.

Quantitative Data

- Collating quantitative data that is relevant to end of life care into a dashboard
- Data for consideration:
  - Unplanned activity for people at end of life, for example unplanned admissions, attendances at emergency departments, calls to the ambulance service
  - Flow of end of life care, for example:
    - wait times for care packages at end of life
    - wait times for equipment at end of life
    - referral to contact time to different services at end of life
  - Demand and wait times for bereavement services
  - Using information from the DiiS

Qualitative Data

- Taking time to listen to people at end of life and those important to them, and ensuring the system encourages and attends to this feedback
- NACEL – National Audit for Care at End of Life
- Patient and family journeys/carers' experiences
- Enabling feedback, comments and suggestions via a variety of routes, for example:
  - conversations
  - semi-structured conversations
  - free text
  - online platforms, eg Care Opinion
  - bereavement surveys
- Joint strategic needs events
- Understanding the views of health professionals involved in end of life care including:
  - GPs
  - district nurses
  - comiciliary carers
  - specialist palliative care professionals
  - ambulance service

Engagement and action from feedback

- Based around Dying Matters week when conversations around death and dying are encouraged in the community
- Involving people with lived experience

Actions

- Establish a system for gathering quantitative and qualitative data to help measure the quality of end of life care in Dorset
- Use this data to establish regular engagement events to action change if needed both at local and pan-Dorset level
- Establish local improvement/sense-making forums to understand and act on what emerges from listening and learning from people approaching the end of life, and the people supporting them (families, carers and staff).

Children's Section

Introduction to Children's palliative care

Defining children's palliative and end of life care:

"Palliative care for children and young people with life-limiting or life-threatening conditions is an active and total approach to care, from the point of diagnosis or recognition throughout the child's life and death. It embraces physical, emotional, social and spiritual elements and focuses on enhancement of quality of life for the child/young person and support for the family. It includes the management of distressing symptoms, provision of short breaks and care through death and bereavement"[16]

There are some important differences between adult's and children's palliative care. In comparison to adults, the number of children dying are small[17]. Individual life-limiting conditions in children can be extremely rare, and may run in families. This means that more than one child in a family may be affected[18].

The pattern of illness in children with life-limiting conditions can be long and unpredictable, where emergency care needs to be considered as part of their care plan[19].

Some children may go through periods where they seem to be near the end of their life, then recover for a while[20]. This can happen multiple times over the span of years. This uncertainty is extremely challenging for the children, their families, and those who care for them, and needs a co-ordinated and compassionate approach to their palliative care. It also means that it's not possible to separate planning end of life care for children from planning their palliative care.

As children grow and develop, physically, emotionally and cognitively, their educational, developmental and play needs also need to be met right up until the end of life[21]. This requires flexible care across home, hospital, hospice, short break and school settings. A child's approach to decision making and their autonomy also develops over time[22].

Another difference between adult and children's palliative care is the focus on working with and supporting families. Parents are carers are impacted by a heavy burden of care needs. Research shows this has a significant impact on their physical and mental health, and even their life expectancy[23].

Siblings are vulnerable and need specific support[24].The dynamic of caring for whole families and decision-making in partnership with parents is specific to children's palliative care and can present unique ethical challenges[25].

Who needs children's palliative care?

Early in the development of children's palliative care, four categories of life-limiting and life-threatening conditions in children were proposed.

Life-limiting conditions are defined as 'those for which there is no reasonable hope of cure and from which children will die'[26].

These conditions can involve continuous deterioration, increasing dependency and disability with complex health needs.

Life-threatening conditions are those 'for which curative treatment may be feasible but may fail'[27]. For these conditions there can be significant changes in goals of care depending on the outcome of active treatment.

Figure 1 (Appendix 1) details the four categories of life-limiting and life-threatening conditions and has been included to give a picture of the breadth and depth of needs for such a diverse population.

Figure 2 summarises how this has been applied to the perinatal population. It is important to note that a significant number of life-limited children do not have a defined diagnosis[28].

The identification of different phases in the life of children with life-limiting conditions aids planning for appropriate levels and types of support. These phases have been identified as stable, unstable, deteriorating and dying.

Originally defined and applied in practice in adult palliative care, research has provided objective definitions in order to assess the scope of need for children's palliative care .

Our vision:

Achieving excellent, proactive, responsive, personalised and equitable palliative and end of life care for babies, children and young people with life-limiting and life -threatening conditions and their families across Dorset.

Our Priorities

1. Achieve timely, personalised care planning for babies, children and young people at the end of life, including supporting their family and carers.
2. Co-ordinated care across services with effective joint working and improving continuity of care at end of life.
3. Supporting children with life-limiting conditions in all settings, and enabling choice in place of care at the end of life with timely symptom relief, support for family and carers and health care professionals.
4. Supporting education, training, resilience and well-being across Dorset for all staff involved in children's palliative and end of life care.
5. Ensuring effective, consistent and timely bereavement care for the families of children with life-limiting and life-threatening conditions in Dorset.
6. Helping to develop caring, inclusive communities with understanding of the needs of children with life-limiting conditions and the impact on their families and a willingness to support them in emotional and practical ways.
7. Ensuring continued feedback and involvement from children and young people with life-limiting and life-threatening conditions and their families, carers and health and other professionals in Dorset, providing transparency throughout.

Priority 1

Achieve timely, personalised care planning for babies, children and young people at the end of life, including supporting their family and carers.

Background

To achieve timely, personalised end of life care planning it is crucial to identify children with life-limiting and life-threatening conditions and to provide equitable access to palliative care from the time of their initial diagnosis.

Recent guidance for integrated care boards states that all organisations who provide palliative and end of life care should ensure they comply with their legal duties and professional obligations. This includes addressing health inequalities for palliative and end of life care by improving equity of access to services and reducing inequity of outcomes and experience[29].

Building trusting relationships between parents, carers and professionals who get to know a child and their family over time is vital in developing personalised care plans for these children, including advanced care plans[30].

Understanding the likely progression of a child's condition over time and having an awareness of changes in their clinical condition, rate of deterioration and acute life-threatening episodes is key to enabling timely care planning.

Advance care planning is the process whereby parents and when possible, children and young adults, discuss in-depth their hopes and plans for current and future treatment, including care at the end of life[31, 32].

Children with life-limiting conditions are 75% more likely to die on a Paediatric Intensive Care Unit than children without life-limiting conditions[33].

Advance care planning is vital if a family wishes for their child to be cared for at home or in a hospice at the end of life[34].

> **" Our advanced care plan was implemented two weeks before our son died, it was dynamic to his needs and interchangeable. These plans need to be individual to families' beliefs and wishes ".**

A standard template for advance care planning for children is used across Dorset.

It is available at:

www.cyacp.uk

and includes resources for professionals, parents and young people[35]. In 2023, it became the recommended national template for children and young people's advance care planning.

> “ Being involved and informed about what would happen… relieved anxieties. The same can also be said about understanding what to expect leading up to our daughter’s death, being aware of the changes we may see ”.

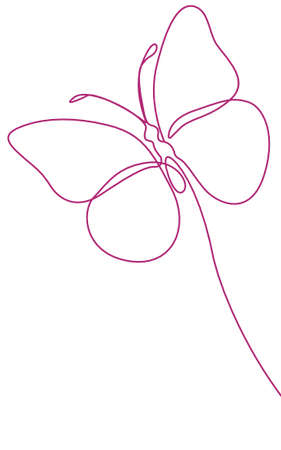
The new CYACP includes a version specific to the antenatal and perinatal care of babies with palliative care needs and their families. This supports existing national and regional guidance for perinatal palliative care[36, 37].

Aims

- To develop processes to identify all children with life-limiting and life-threatening conditions across Dorset, including during antenatal and perinatal care.
- To give these children and their families opportunities for timely access to children’s palliative care services in order to provide support and build trusting relationships which enable joint decision-making with parents and, ideally, children and young people.
- To develop joint referral processes for children’s palliative care services across Dorset at key time points in a child with a life-limiting condition’s life. (For example, when becoming unstable, when reaching the end of life) including equity in access to children’s palliative care services from antenatal and perinatal care.
- To provide all professionals working in children’s palliative care (across all sectors) with education and training in communication and compassionate conversations with parents of children with life-limiting conditions.
- To provide lead clinicians and nurses from children’s community nursing teams and hospice teams with specific training in use of the CYACP.
- To develop shared processes for dissemination and updating of advance care plans to ensure all those involved in the care of a child and family have access to the document when needed, including ambulance services, out of hours primary care services, GPs, hospitals and emergency departments.
  - ◊ This would enable… “consistent support in line with the advance care plan and the families wishes and beliefs. For our son, some unconnected professionals posed questions that were premature to the advance care plan and exacerbated our anxiety and stress” (parent quote).

Actions

- Establish a Dorset-wide database for children with palliative care needs
- To agree a joint referral processes for access to children’s palliative care services in Dorset.
- Access education and training in advanced communication skills and advance care planning for professionals working with children with life-limiting and life-threatening conditions.



Priority 2

Co-ordinated care across services with effective joint working and improving continuity of care at end of life.

Background

Parents of children with life-limiting and life-threatening conditions tell us that having to repeat their child’s story to each new professional is frustrating and distressing. Research has identified co-ordination of care as a key component of quality in palliative and end of life care for children[38,39].

It is a NICE quality standard for all children with a life-limiting condition to have a named medical specialist who leads and co-ordinates their care.

> “ We did have a POON [Paediatric oncology outreach] nurse who we liaised with (sporadically) and our community nurse was excellent. But, as parents, bridging the gap between multiple professionals could (and did) leave room for miscommunication and some error (medications from day ward to home discharge etc). ”

Parents of children with life-limiting conditions want their child to be cared for by someone who knows their child and has taken time to develop a relationship of trust with the whole family. This becomes increasingly important as their child approaches the end of their life. They also need access to ongoing advice from specialists who have knowledge of their child’s specific condition and timely access to advice from specialists in paediatric palliative medicine.

In order to provide care that is both unique to each child and family and that enables coordination across organisations, we need to promote co-ordination of care through palliative to end of life care and integration of care from a number of care providers. This co-ordination is needed both between local children’s palliative care services and across the region with tertiary paediatric services and the regional specialist children’s palliative care team.

In Dorset we have been working to integrating care between children’s palliative care providers, eg hospital, community and hospice, which we aim to build upon with this strategy. See Appendix 3: Dorset model for integration of children’s palliative care services.

The Starfish Team

The Starfish Team is a team of nurses from across local hospital, community and hospice settings who can work together to provide nursing provision for end of life care for a child in any setting. (Appendix 4: aims and purpose).

Working together in this way means care can be more co-ordinated, and also means care can continue when staffing levels are low.

Our daughter's story: parents' feedback

"We thought the teams from [local children's hospice and local hospital] of nurses and doctors worked really well together. They were very attentive of our daughter's needs and despite being so ill they managed to treat her like a baby rather than just another patient who was receiving end of life care.

"They allowed us to do all we could to look after our little girl ourselves but were always nearby for additional support, and stepped in when it came time for us to just be there with our daughter in her final hours without having to worry about her medications, etc. We could trust that they were doing everything they could for her just as they would have their own child. This is something that was very important to us as we had spent 15 weeks of our daughter's short life in hospitals where we met many different doctors and nurses. Unfortunately, not all were able to see past the illness and see her for the baby she was.

"They were brilliant in helping us make memories. We got to take our daughter to the beach, something we didn't think was possible. They took photos and even picked a couple of seashells for us as keepsakes of that morning. Not only do we have the memories of that morning to cherish forever, we have something to share with her little sister… we take a seashell home for our daughter every time we go to the beach."

Multidisciplinary teams (MDTs)

In Dorset, existing structures for MDT work for the care of children 0-16 years with cancer who require palliative and end of life care. These are co-ordinated from the centre, with input from tertiary children's cancer specialists and regional specialist children's palliative care teams working with our Dorset-based children's palliative care teams and professionals who know the child and family.

Our hospital children's palliative care teams, together with the local children's hospice team, have developed a structure for MDT working for children with non-cancer life-limiting conditions.

This involves MDT discussions, regular reviews and updates for the child's whole team. This system needs to be sustainable and equitable across Dorset.

As young people with cancer age 16-18 years reach a stage of unstable symptoms and deterioration of their condition, the MDT for some areas of Dorset includes joint working with the local adult specialist palliative care team.

For all young people needing transition into adult palliative care services, there is a need to develop an MDT process to integrate and co-ordinate the adult palliative care teams with children's palliative care teams.

This needs developing and resourcing to provide an equitable and sustainable service for this group of young people across Dorset.

- First point of contact
  - ◊ Having a clearly named professional as a first point of contact is key to the coordination of a child's palliative and end of life care for both the family and the MDT. This is addressed as part of advance care planning (see Priority 1) with a professional named on the plan. For children this is often the child's community nurse. As the end of life approaches this first point of contact becomes essential.
  - ◊ Research and national guidance confirms that parents and carers of children with life-limiting conditions need access to advice from someone who knows their child, 24/7 at all stages of their child's life[40, 41]. Currently each organisation in Dorset has its own system for access to this 24/7 advice and there is a need to coordinate and build on this provision so that there is consistent and equitable access to advice from professionals who know these children and have expertise in children's palliative care.

Aims

- To develop MDT processes for all children approaching the end of life in Dorset to enable equity across conditions and ages.
- To develop an MDT process for palliative care transition.
- To work collaboratively to seek IT solutions for sharing documentation (including advanced care plans and symptom management plans) across organisations.
- To review the current provision of 24/7 first point of contact for parent and carers of children with life-limiting conditions across Dorset.

Actions

- Establish a directory of children's palliative care services for Dorset which can be accessed via each service's website.
- Agree pathways for transfer of a child at the end of their life between settings, eg hospital to home, hospital to hospice, hospice to home.
- Develop IT solutions for sharing information. In particular use of the Dorset Care record and SystmOne across organisations.
- Following a workshop with adult and paediatric palliative care providers in Dorset to seek resources to support a palliative MDT transition process.
- Establish a coordinated and equitable approach to a first point of contact 24/7 for parents and carers of children with life-limiting conditions across Dorset at all stages of their life.

Priority 3

Supporting children with life-limiting conditions in all settings, and enabling choice in place of care at the end of life with timely symptom relief, support for family and carers and health care professionals.

Background

Support in all settings during life

Children with life-limiting conditions need support to live their lives to the full in the same way as any child. Their families want them to have every opportunity to access education, activities, social events and to play. The fact that their lives are likely to be limited in length only increases the importance of making this possible. The focus of children's palliative care is on quality of life at every stage of life.

Children with life-limiting conditions often have complex health care needs and are supported across a number of settings including schools, short break units, hospices, home-based respite with care providers, and at home with their families.

In all settings, children with life-limiting conditions need to have their care needs and symptoms addressed in a way that is co-ordinated and safe. As their symptoms change children often require increasing medications and medical interventions. Professionals in every setting need support to respond to these changing health care needs and to manage increasingly complex care and medication plans in a timely way.

Symptom management plans

Symptom management plans in children's palliative care are written by doctors or nurses with specific training in children's palliative care when a child is deteriorating or dying, and is likely to experience increasing symptoms. They are unique for each child and the child's condition, including how this is likely to progress over time. They include both non-pharmacological and pharmacological treatments and have a summary of existing medications and options for next steps in symptom management, as well as planning for sudden crises and guidance on who to call for advice.

Once a symptom management plan is in place it can be used across all settings. Therefore, in any setting the person directly caring for a child requires access to all medications which may be needed and an up-to-date medicine administration chart. There must be a first point of contact named on the plan in case there is a need to progress to 'next steps' if a child's symptoms are uncontrolled.

For children approaching the end of their life, this type of symptom management plan replaces existing individual care plans for specific symptoms (for example for seizures or dystonia) and becomes a guide for holistic management of symptoms during their care in any setting.

> " Parents and carers would like to have involvement in the discussions about symptom management and an awareness of basic symptom management ".

We need to ensure consistent symptom management planning is available to all children in Dorset with life-limiting conditions when they reach a time of deterioration, and for end of life care.

> **"Our daughter's book with MAR chart, symptom management plan etc was a game changer for us. Every change of location (school, respite, home) it removed the need for complex handovers. It also made hospital admissions easier. The data also gave us a better understanding of the medicine schedule […] and enabled doctors to see correlations between our daughter's symptoms and medication use. I started work on a digital version of this for us".**

Choice in location for end of life care

In Dorset, we want children and their families to have a choice about where they receive care at the end of a child's life. This could be at home, at the local children's hospice or in hospital. Planning for this will be part of advance care planning.

Both Dorset County Hospital and University Hospitals Dorset have dedicated areas for end of life care in their children's units, resourced by a specific trust fund within the hospital charity.

While we want children and families to choose the location of care, the most important thing to consider is that a child is comfortable, can receive the right care and treatment, and that care can be delivered safely.

Research supports that parents' primary focus as their child reaches the end of their life is that they are free from pain and distress and that where they are cared for is a secondary factor[42].

24/7 nursing and medical support for end of life care

For a child to be cared for in the community at the end of life they need to have access to 24/7 at home nursing care provided by the Starfish Team. This access to 24/7 community nursing care is a quality standard in NICE guidance[43].

For children cared for at the end of life at home, provision of 24/7 telephone support from a consultant in paediatric palliative medicine is a NICE quality standard. For all children with life-limiting conditions, NICE recommends that care includes members of the specialist children's palliative care team[44]. Nationally, paediatric palliative medicine has only been a recognised specialty since 2009[45], and therefore regional consultants with this sub specialist training are nationally and regionally a limited resource.

In Dorset our aim is for this 24/7 medical support to be provided by a small group of local paediatricians with a special interest in paediatric palliative medicine. Support is provided by telephone, virtual and face-to-face review of children being cared for at the end of life in any setting.

Currently, advice from a specialist consultant in paediatric palliative medicine based at our tertiary children's hospital is available by telephone within weekday daytime hours and is not formally commissioned out of hours, and is focused on proactive symptom management planning and planned review.

For children with cancer reaching the end of life 24/7 telephone advice is available from a team of paediatric oncology and supportive care clinical nurse specialists from the tertiary centre. For young people aged 16-18years in East Dorset, this specialist palliative medicine advice is provided locally 24/7 as part of an integrated MDT across children's and adult palliative care.

The support of a paediatric pharmacist is also essential. Paediatric pharmacy time is needed to co-ordinate medications for children with multiple and changing medications and for end of life care prescribing and dispensing support in all settings.

Caring for the whole child and whole family at the end of life:

As a child's care needs change, there may need to be an increase in care at home to support parents. It is vital that the holistic needs of the whole family are met. In particular, play therapy, sibling and family support workers are an important and under resourced provision in the NHS.

Parents, siblings and children with life-limiting conditions need access to psychological support at this time.

> **" We found that the doctors interacted with [our daughter's siblings] in a warm and friendly manner and this helped them feel relaxed and comfortable. This was especially important whilst our daughter was in the hospices as the continuity of the medical professionals took away some of our children's fears. "**

Aims

- To build on the model of integrated care across organisations for children approaching end of life in Dorset so that the professionals who know the child and family follow them to provide care and support in any setting.
- To build on and expand the work of the Starfish Team of nurses to enable choice in place of care at end of life and sustainability of the nursing workforce. This will require increased resourcing of the CCN workforce.
- To achieve consistency and equity across Dorset in the use of symptom management plans for children with non-cancer conditions.
- Designated paediatric pharmacist time to support safe prescribing and dispensing of medication of palliative and end of life care in children across Dorset.

> **"To build on and expand the provision of psychological and wellbeing support for families during and at the end of life care. This could help with the increase in extreme anxiety, the management of decision making and the anticipatory trauma/shock experienced by families at this time."**

Actions

- Develop and agree a Dorset-wide approach for paediatric symptom management plans across all settings.
- Dorset-wide documentation including a single medicine administration chart that is used across all settings.
- Develop and resource the children's palliative care nursing workforce (Starfish Team) and give access to education and training in children's palliative care.
- To develop paediatric medical support with paediatricians who have a special interest in paediatric palliative medicine.
- Designated paediatric palliative care pharmacy time to support safe prescribing and oversee the dispensing of medication for children with life-limiting conditions.
- To develop and resource counselling or psychology posts for children's palliative care in Dorset.

Priority 4

Supporting education, training, resilience and well-being across Dorset for all staff involved in palliative and end of life care for children.

Background

In addition to health care professionals, everyone involved in the care of a child with a life-limiting or life-threatening condition needs access to education and training in the core knowledge and skills involved in the delivery of children's palliative care. This includes carers, teachers and teaching assistants, and social care professionals.

Existing courses and resources are available and are being developed, and funding has been secured for a project aimed at developing and providing education and training in children's palliative care across the South West.

Providing palliative and end of life care to children can be emotionally draining, and being part of a balanced, well-functioning team with shared values and a supportive and open approach is known to enable this resilience and wellbeing of staff[46].

Providing joint education and training opportunities across organisations alongside an integrated model of care enables sharing of best practice, skills and knowledge and development of the good working relationships that allow each child and family to remain at the heart of the care provided.

At present, team debriefs are offered within organisations providing children's palliative care in Dorset, enabling staff to continue to provide compassionate care[47].

Professionals (either psychologists or counsellors) skilled in facilitating these debriefs are a limited resource, and this needs further development and resourcing to reflect a commitment to the resilience and wellbeing of staff.

Aims

- For all doctors in Dorset with a lead or key role in providing children's palliative care to have specific education and training in paediatric palliative medicine to the level of a special interest, and to have the time and funding to achieve this.
- For all children's nurses with a lead role in children's palliative care to have specific education and training in accordance with the Royal College of Nursing framework for competencies in children's palliative care[48] and to have the time and funding to achieve this
- In collaboration with the South West Children's Palliative Care Strategic Clinical Network, access training for the children's palliative care workforce in Dorset[49].
- To build on the current Starfish Team training program and develop a rolling program of training that can be accessed virtually by Dorset's children's palliative care workforce.

> “ All NHS staff, even those not directly involved with children’s palliative care should do an introduction to children’s palliative care. It would help to raise awareness amongst staff and also may help to identify children who would benefit from early intervention ”.

- To develop counselling or psychology posts for children’s palliative care in Dorset and as part of these posts to provide regular supportive debrief for those providing children’s palliative care as a core part of their role.

> “ As a parent it is something that we only experience once, for professionals they have to go through this repeatedly ”.

Actions

- To identify lead and key doctors in children’s palliative care in Dorset and support to access specific nationally recognised education and training in paediatric palliative medicine.

- To identify lead CCN and hospice nurses working in children’s palliative care and support to access specific education and training in children’s palliative care.

To develop the program of teaching for the Starfish Team, which can be delivered virtually as a rolling annual programme.

- To access the training delivered as an outcome of the South West Children’s Palliative Care Strategic Clinical Network Funding Bid.

- To provide or access a training event for advanced care planning for staff from across health, education and care providers in Dorset.

Priority 5

Ensuring effective, consistent and timely bereavement care for the families of children with life-limiting and life-threatening conditions in Dorset.

Background

The loss of a child impacts parents and carers, families and communities. Bereavement impacts on health and wellbeing, relationships and employment. It can make day to day life a struggle.

Continuation of care through bereavement is a key part of children’s palliative care. Families have told us that they have felt alone following their child’s death and that the sudden loss of carers and professionals involved in their life adds to the void following their child dying.

> “ Bereaved parenting, where parents are supporting bereaved children whilst being a bereaved parent needs professional guidance to reduce secondary issues for siblings”. We found there was “a limited professional support structure from statutory services, particularly schools ”.

Bereavement care can support parents’ recovery from the devastating loss of a child and potentially reduce the burden on their mental health[50].

Enabling families to remain with their child after the child has died, supported by professionals who know the family and have cared for them through their child’s life, can be an important part of bereavement care.

This ongoing care can be facilitated by close working with funeral directors and equipment such as cool cots and cool blankets that can be used at home, in hospital or in the hospice.

> “ I very much valued a meticulous plan of how our son would be taken care of when he died. It was an anticipatory plan and it alleviated a great deal of anxiety around his death. It also played a big role in navigating the bereavement as it was all within our control and there were no gaps in where he was. ”

Bereavement care for families in Dorset is currently offered by the NHS, local children’s hospice teams, independent organisations and volunteers, but there is need to further coordinate and resource this important aspect of children’s palliative care and to ensure all families have access to support.

Guidance on bereavement support recommends provision in accordance with need[51]:

- Universal Support – available for all bereaved people (provided by verbal, written and online information).

- Selective or targeted support – available for those seeking additional support or who are at risk of developing complex needs (provided by social support: self-help groups, faith groups, befriending and community groups or trained bereavement support workers).

- Support requiring specialist interventions – for a minority of bereaved people who have complex needs or prolonged/complicated grief (provided by specialist bereavement counsellors/practitioners, specialist mental health support/psychological support)[52].

The Childhood Bereavement Network has a checklist for good practice in supporting bereaved children and young people (Appendix 5)[53].

> “ Also, we needed guidance on the changes to carers allowance, home equipment, and motability. We had our housing benefit stopped five days after our daughter’s death. Nothing really prepared us for the financial changes. ”

Aims

- For all parents who experience the loss of a child with a life-limiting or life-threatening illness to have access to bereavement care as a continuation of the palliative care provided to the child and family.
- For parents to have access to specialist bereavement counselling or specialist psychological support, and for this to be available during the end of life care to support parents through decision-making.
- For all siblings of children who have died with a life-limiting illness to have access to bereavement care, including support for their schools and social groups. (Statutory support through the local education authority under the Adverse Child Events remit.)
- For family support workers to provide a link for bereaved siblings between home school and the local education authority to coordinate and support ongoing bereavement care.

In Dorset, an estimated

1,038

0-19 year olds sare likely to need access to palliative and end of life care.

Actions

- Develop a Dorset-wide directory of bereavement services for families of children with life-limiting conditions.
- Develop a coordinated approach to bereavement care across organisations, providing appropriate bereavement support that includes universal support, selective or targeted support and specialist support.
- Improve access to specialist bereavement support with increased provision of trained counsellors.
- Develop Dorset-wide peer support/ bereavement support groups.

Priority 6

Helping to develop caring, inclusive communities with understanding of the needs of children with life-limiting conditions and the impact on their families and a willingness to support them in emotional and practical ways.

Background

Surrounding every unique child with a life-limiting condition is a unique family unit and a unique community. Feedback from families emphasises the importance of caring for a child within this context and supporting the families and communities around them.

Research shows that for children with life-limiting conditions social and educational activities are more important than their medical concerns[54].

Therefore a holistic approach to care is required to enable these children to live their lives as fully as possible, taking part in all the usual childhood activities.

This approach requires support for schools both throughout the life of a child with a life-limiting condition and through their end of life care and ongoing bereavement care for their family, friends and community.

Access to social events and venues for these children is needed, and raising awareness of their needs in communities is a key part of achieving this. Provision of specific social events has been reported by parents to be a lifeline in enabling them to feel part of a community who understand the challenges they are facing and can offer friendship and encouragement [55] .

Caring for whole families; short break/ respite care and sibling support

Families of children with complex needs and neurodisability are entitled to short breaks from their local authority. Access to and provision of these breaks varies widely. In addition, the voluntary sector, including children’s hospices, provide respite/short breaks for children with life-limiting conditions.

Respite provision for children with life-limiting conditions has been shown to support parents’ relationships and potentially prevent family breakdown[56].

Specifically, this research demonstrated that parents in a stable relationship were receiving on average 43% more respite hours than those in unstable relationships; and of those who had already separated, 75% had been receiving no respite breaks from any service at the time[57].

A study has found that mothers of a child with a palliative care need were twice as likely to develop heart disease or a serious mental health condition and 59% more likely to die prematurely than mothers of healthy children[58].

There is overwhelming evidence that more short break/respite care is needed to prevent family breakdown and to protect the health and wellbeing of the parents providing 24/7 care to children with life-limiting conditions, however short breaks are a limited, vulnerable and threatened resource.

Siblings of children with life-limiting conditions are known to be impacted by their sibling's care needs. Many are unrecognised young carers, carrying a burden of responsibility and knowledge way beyond their years.

They need time outside of this caring role to have fun, to be children and to receive emotional support when needed.

Sibling support in Dorset is currently provided by a number of services with different approaches to support.

Improved access, a co-ordinated and equitable approach and increased provision of this important resource is needed.

Aims

- Enable children with life-limiting conditions to continue to attend pre-school or school for as long as possible with teachers who understand their needs and have access to support from the wider children's palliative care team.
- Increase the provision of short break/respite care for children with life-limiting conditions in Dorset to enable a consistent and equitable approach to this provision.
- Develop opportunities for bespoke social events and access to mainstream social venues and events for children with life-limiting conditions.
- Develop the work of supporting siblings of children with life-limiting conditions in Dorset as a collaborative approach across organisations.

Actions

- Develop processes for the integration of schools and education colleagues within children's palliative care teams for individual children and on an organisational level with joint training and education opportunities.
- Review of current short break and respite provision in Dorset with analysis of the current offer alongside the need to plan for the resourcing of an increase in this provision.
- Develop a research proposal to measure the impact of an increase in short break provision.
- Collaborate across organisations to build on the work of the local children's hospice and other charitable organisations in developing social events and opportunities.
- Provide training and education on the impact of caring for a child with a life-limiting condition on parents for professionals and volunteers across sectors.
- Build on the work of the existing sibling teams and improve awareness and access to this service through specific education and training sessions.

Priority 7

Ensuring continued feedback and involvement from children and young people with life-limiting and life-threatening conditions and their families, carers, and health and other professionals in Dorset.

Background

Understanding children's and their families' experiences of palliative and end of life care is key to the ongoing development of children's palliative care and measuring the impact of services.

Until recently there have been no validated measures of outcomes in children's palliative care. The children's palliative outcomes scale is currently under validation 13 and University Hospitals Dorset is a pilot site for this research.

However, the most powerful force for change and improvement in children's palliative care has always been the experiences and journeys of individual children and their families. Listening to their stories and responding to what matters to them must be at the heart of everything we do.

To date, individual feedback from families has taken place as part of bereavement support provided to the family.

The Child Death Overview Panel provides a format for family and professional feedback and discussion of a child's palliative and end of life care.

Aims

- Improve our understanding of the experiences of children with life-limiting conditions and their families in Dorset.
- Establish a rolling program of data collection on outcomes of children's palliative care provision, both quantitative and qualitative.
- Involve parents and young people with life-limiting conditions in the planning and development of future services.
- Consider development of a research project to evaluate the Dorset model of integrated children's palliative care.

Actions

- Once available, use the Children's Palliative Outcomes Scale in practice.
- Develop the process for listening to feedback from parents and children via a range of forums including individual discussion, semi-structured interview and online platforms such as Care Opinion[59].
- Establish a co-production workshop with parent representatives and young people's involvement as a forum for feedback on development of children's palliative care services in Dorset.
- Establish a research group across organisations and in collaboration with Bournemouth University with parent involvement to develop a research proposal.

Reference section

Glossary

The Dorset Intelligence & Insight Service (DiiS)
a collaborative project to deliver a live, linked health and social care dataset across Dorset Integrated Care System (ICS). The aim is to make health and social care data open, easy to access, and available to create actionable insights. It is being used to support data-led service improvement, planning and decision making at a system and organisational level. We've been working together from the start with partners, community groups, and industry to provide analytics to deliver better health and wellbeing outcomes for Dorset people.

Palliative Care
an approach focussed on improving the quality of life of patients with life limiting illness and their families. These patients often, but not always, have a prognosis of less than 12 months. Good palliative care is integral to good end of life care.

End of life care
support for people who are in the last months or years of their life. End of life care should help you to live as well as possible until you die and to die with dignity.

Advance care planning
A voluntary process of discussion about future care between an individual and their care providers. If the individual wishes, those identified as important to them may be included. It is recommended that with the individual's agreement this discussion is documented, regularly reviewed, and communicated to key persons involved in their care.

DNACPR
Do Not Attempt Cardiopulmonary Resuscitation

SystemOne
The digital system which is used in all GP practices across Dorset, 2 hospices and Dorset Health Care.

EPR
Electronic patient record

End Notes

1 The Dorset Intelligence & Insight Service (DiiS)
2 ambitions-for-palliative-and-end-of-life-care-2nd-edition.pdf (england.nhs.uk)
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9 NACEL Audit Outputs — NHS Benchmarking Network
10 Treatment and care towards the end of life - ethical guidance summary - GMC
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12 NHS Long Term Plan
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Appendix

Appendix 1
Figure 1 Categories of life-limiting and life-threatening conditions. Adapted from the Guide to Children’s Palliative care 1.

Category	Examples
Category one Life-threatening conditions for which curative treatment may be feasible but can fail, where access to palliative care services may be necessary when treatment fails, irrespective of the duration of that threat to life. On reaching long-term remission or following successful curative treatment there is no longer a need for palliative care services.	Cancer, organ failures of heart, liver, kidney, transplant and children on long-term ventilation
Category two Conditions for which premature death is inevitable, these may involve long periods of intensive disease-directed treatment aimed at prolonging life and allowing participation in normal activities. Children and young people in this category may be significantly disabled but have long periods of relatively good health.	Cystic fibrosis, Duchenne muscular dystrophy and SMA Type 1
Category three Progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years.	Batten disease, mucopolysaccharidoses and other severe metabolic conditions.
Category four Irreversible but non-progressive conditions causing severe disability leading to susceptibility to health complications and likelihood of premature death. Palliative care may be required at any stage and there may be unpredictable and periodic episodes of care.	Severe cerebral palsy, complex disabilities such as following brain or spinal cord injury.

Figure 2 Categories of life-limiting and life-threatening conditions as applied to perinatal and neonatal care 25.

Category	Examples
Category one	Life-threatening conditions for which curative treatment may be feasible but can fail. **Examples: extreme prematurity, severe necrotising enterocolitis, congenital heart disease.**
Category two	Conditions where premature death is inevitable. **Examples: chromosomal abnormality, severe spina bifida, bilateral multi-cystic dysplastic kidneys, bilateral renal agenesis.**
Category three	Progressive conditions without curative treatment options **Examples: anencephaly, skeletal dysplasia, severe neuromuscular disorders.**
Category four	Irreversible but non-progressive conditions causing severe disability, leading to susceptibility to health complications and likelihood of premature death. **Examples: severe hypoxic ischaemic encephalopathy.**

Appendix 2
Summary of Child Death Overview Panel data for Dorset for past five years.

East Dorset

Year	Unexpected Child Deaths*	Expected child deaths/ planned palliative care	Total child deaths East Dorset
2019	16	5	21
2020	15	5	20
2021	18	7	25
2022	10	5	15

West Dorset

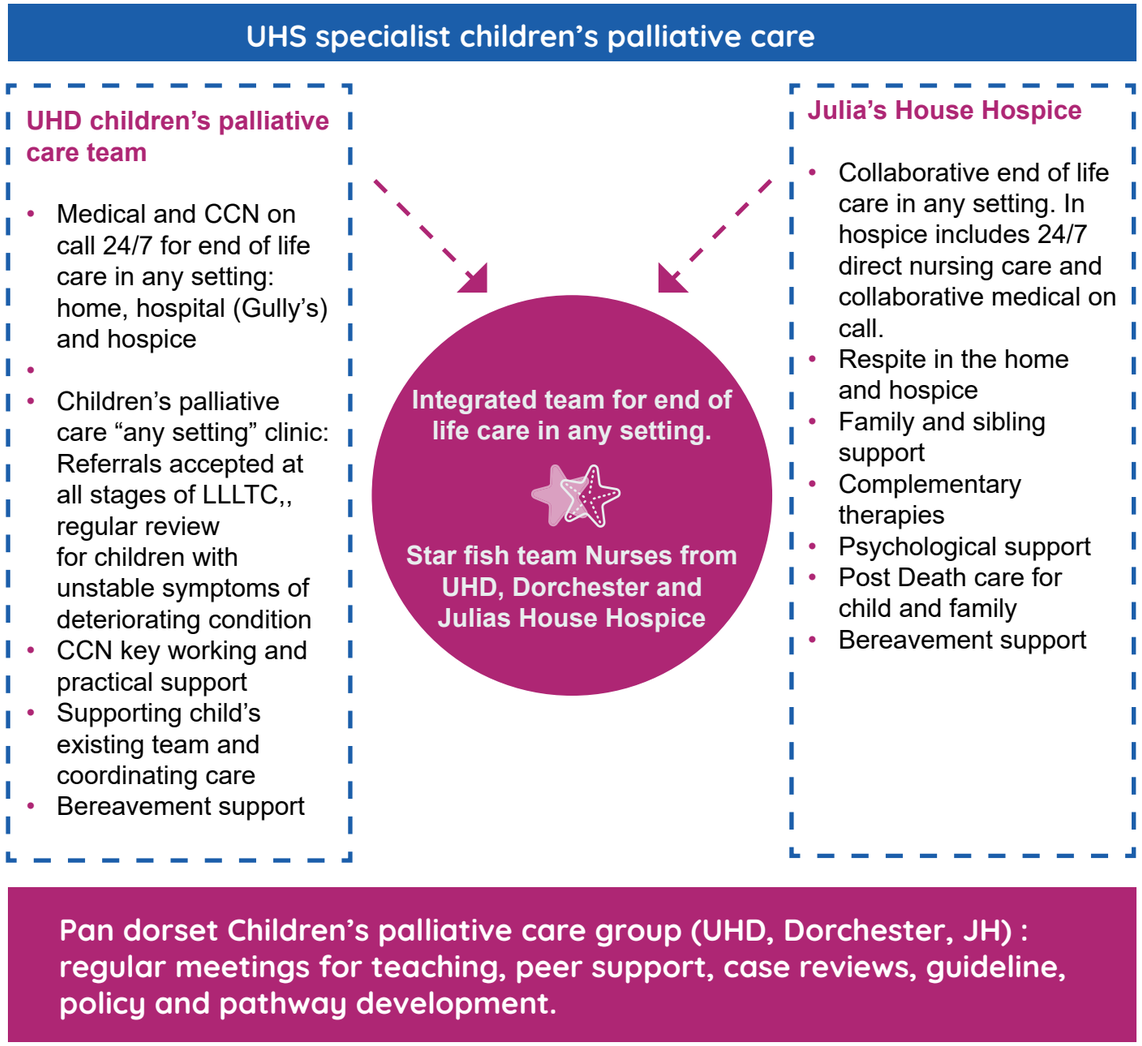
Year	Unexpected Child Deaths*	Expected child deaths/ planned palliative care	Total child deaths West Dorset
2019	6	2	8
2020	12	3	15
2021	3	2	5
2022	18	2	20

Total Dorset

Year	Unexpected Child Deaths*	Expected child deaths/ planned palliative care	Total child deaths East Dorset
2019	22	7	29
2020	27	8	25
2021	21	9	30
2022	28	7	35

*Unexpected child deaths are those caused by accident, sudden event (including SUDI) or unexpected deterioration in health.

Appendix 3
Dorset model for integration of children's palliative care services



Appendix 4
Starfish Team aims and Team

The Starfish team's purpose:

To support members in the delivery of best practice and standards in end of life care for children, young people and their families across Dorset, enabling family choice in place of care.

Aims:

- To promote effective collaboration across organisational boundaries to ensure the best use of resources, facilities, knowledge and experience to improve the quality of end of life care and outcomes for children, young people and families.
- To provide an opportunity for key members of these organisations to meet regularly.
- To provide peer support to colleagues though the sharing of knowledge and advice
- To develop, share and disseminate best practice across the network and to collaborate on initiatives designed to enhance patient care.
- Regular education for Starfish team members and wider teams
- Improved staffing availability to be responsive and equally effective regardless of location.
- Team support and supervision to assist resilience.

The team:

- UHD Children's Community Nurses
- UHD Ward Nurses
- Paediatricians with special interest in paediatric palliative medicine Pan Dorset
- Dorchester Community Nurses
- Dorchester Ward Nurses
- Julia's House Nurses

Hopes of the team:

- Children and their families receive the best care in the place of their choosing (Home/ Gully's Place (hospital) /Mermaid Suite (hospice)
- Ability to offer varied and flexible levels of support in accordance with the family's changing needs.
- Children and families do not have to navigate multiple professionals,
- Improved communication, upskilling current clinical staff and providing a bigger team.
- Children and families remain the focus of care at all times.
- Psychological, social and spiritual support
- Care and support for the child and families during and after death (Mermaid (hospice), Gully's (hospital), Home)
- Nurses and medics feel supported and empowered.

Appendix 5
Childhood Bereavement Network (2007) Checklist for good practice in services supporting bereaved children and young people.

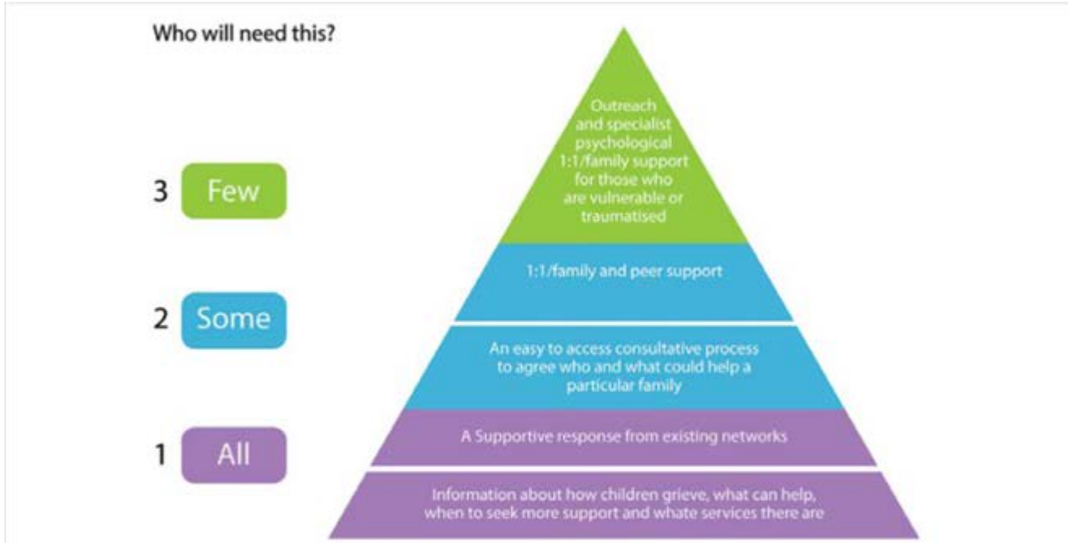


Figure 1: what good local provision for bereaved children and their parents & carers looks like

Appendix 6
Table 1: Population data and estimated prevalence data for children in Dorset with life-limiting and life-threatening conditions.

Age Range	Area	Source of Data	Total Number	Estimated prevalence of CYP with LLTC: based on prevalence 66.4 per 10,000
0-19 years	Dorset County	Local Dorset data from ONS 2021 census	72,668	482.5
0-19 years	Bournemouth, Poole and Christchurch	Local BCP data from ONS 2021census	83,687	555.7
0-19 years	All Dorset	Combined Dorset County and BCP census data 2021	156,355	1038.2

Appendix 7
Useful links

1. DiiS and NHS Dashboard
2. Dorset statistics and census information - Dorset Council
3. Ambitions for Palliative and End of Life Care: A national framework for local action 2021-26. https://www.england.nhs.uk/wp-content/uploads/2022/02/ambitions-for-palliative-and-end-of-life-care-2nd-edition.pdf
4. Joint Strategic Needs Assessment (JSNA) for Dorset EOL Care outcomes document https://www.publichealthdorset.org.uk/jsna/insights/end-of-life-care
5. Results through relationships | Next Stage Radicals - Exploring Aloud
6. Office for National Statistics (2016). National Survey of Bereaved People (VOICES): England, 2015 National Survey of Bereaved People (VOICES) - Office for National Statistics (ons.gov.uk)
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10. NHS (2019) NHS Long Term Plan https://www.longtermplan.nhs.uk/publication/nhs-long-term-plan
11. Kathryn Mannix - Dying, Death, and Wisdom in an Age of Denial - Panel Discussion - YouTube
12. Compassionomics | Evidence That Caring Makes a Difference
13. Dying Matters | Hospice UK
14. A promise to learn – a commitment to act – Improving the Safety of Patients in England (publishing.service.gov.uk)

15. RCGP has developed the Gold Standards Framework Identification Toolkit