

# Improving palliative care for people in remote, rural and island communities

Big Conversation  
Wednesday 25<sup>th</sup> June 2025

# Welcome and introductions

Katie Reade, Head of Policy & Public Affairs  
Hospice UK

# Housekeeping



Please keep your mic muted unless you are asking a question



Please note that the presentations (excluding the Q&A) are being recorded.



The recording and slides will be shared with you after the event, and we'll notify you by email



Please use the Chat function to ask any questions



AI bots are not permitted in these meetings and will be removed

# Agenda

11:00	Welcome and introductions	<b>Katie Reade</b> , Head of Policy & Public Affairs Hospice UK
11:05	Bringing Care Closer to Home: Improving palliative care in remote, rural and island communities	<b>Helen Malo</b> , Senior Policy and Public Affairs Manager Hospice UK
11:20	Sidmouth Integrated Model for Specialist Palliative Care (SIMSPC)	<b>Mary Ashby</b> , Nurse Lead Sidmouth Hospice at Home
11:35	Questions and discussion	All
12:00	Collaboration To Allow For Choice Of Place Of Death in Paediatrics	<b>Louise Esson</b> , Diana Children's Nurse Children's Hospices Across Scotland (CHAS)
12:15	Questions and discussion	All
12:25 – 12:30	Close	<b>Katie Reade</b> , Head of Policy & Public Affairs Hospice UK

# Bringing Care Closer to Home:

Improving palliative care in remote, rural and island communities

Helen Malo, Hospice UK

# Why is this important?

- Patchy access to palliative care
- Palliative care need is rising
- Faster ageing population
- Harder to access care
- Share learning



# Key findings

- Nearly two thirds of people said that they or the person they cared for with a life-limiting condition *did not* receive the care and support they needed
- Two thirds of rural health and care staff surveyed said there are not enough staff with the right skills to support people with life-limiting conditions.

"I found it extremely **distressing and frightening**. I was frightened because I didn't think we were meeting his needs because the district nurses **during the night weren't able to get to him in time.**"

"In one of my teams there is often **only one nurse on duty** to cover a large rural area, meaning it is sometimes **impossible to visit our palliative patients.**"

# Key findings

- People are being forced to choose between where they live and the care they receive.
- Families of children with life-limiting conditions living rurally face significant additional barriers to accessing care and support.

“A lot of people in rural communities **want to die at home**, in their own place. But we find it more difficult to get carers to do that. So people through no fault of their own then **end up somewhere in the middle of a built-up area** in a town where they’re not used to and, actually, they **deteriorate a lot more** and a lot quicker. Because they’re **not with their family**.”

“**Nobody in our rural area was familiar with or trained in severely disabled children**. Even stays in our local hospital meant we were showing staff how to use tubes for feeding.”

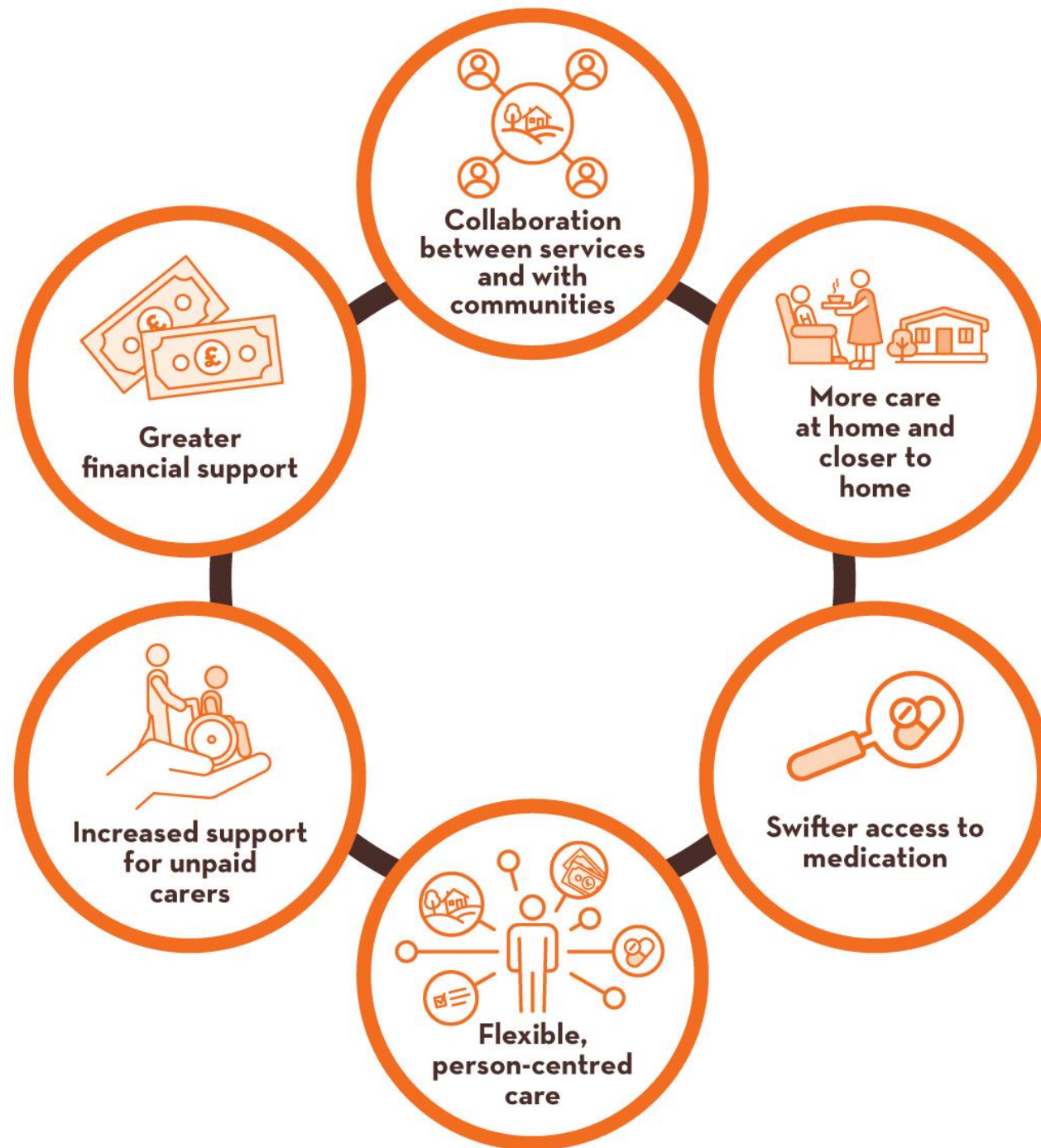


# Key findings

- Families and unpaid carers will reach crisis point without more support
- People face a double financial burden: the higher cost of living in rural communities, combined with the added financial strain of caring for someone at the end of life

“We need to get this right. It’s **too important to rely on the good will** of the limited resources available. The **impact on families is catastrophic.**”

“My **electricity is over £700 a month** due to running equipment. But of course, I am a full-time carer. Why is there no grant so that if your child is on palliative and hospice care, that you can apply for an electricity discount, or grant?”





- Flexible intensive support
- Expanding hospice care at home to address gaps
- Virtual wards
- Digital/virtual services
- Domiciliary/home care
- Palliative care helplines
- Community hubs
- Outreach services at other healthcare centres
- Mobile services
- Compassionate community initiatives
- Flexible staffing models
- Collaboration & making best use of local resources

Underpinned by



**Supported and  
skilled health and  
care workforce**



**Fairer funding and  
commissioning**



**Robust rural  
infrastructure**



**Rural-proofed policies  
and service delivery**



**HospiceUK**

# Key recommendations:



- Work together to address gaps, particularly around care at home, out of hours care, access to medication and training
- Work in partnership with local communities to understand need and build on existing strengths
- Person-centred, culturally sensitive care that maintains people's links to their community
- Needs assessment of current and future needs of rural communities in local area



# Key recommendations:

- Assess and be accountable for how palliative care services meet the needs of rural communities
- Commission and fund 24/7 palliative care helplines
- Increase support for unpaid carers & provide welfare advice
- Promote greater awareness and use of direct payments and personal budgets
- Clearer, more flexible approaches to commissioning palliative care across borders and boundaries
- Review policies to reimburse travel and accommodation costs



# Key recommendations:



- Fund a shift to more community-based palliative care
- National workforce planning to recruit and retain skilled staff to meet growing need
- Funding allocations and sustainable funding that reflect higher costs
- National policies and strategies consider the needs of rural populations

# Thank you

[policy@hospiceuk.org](mailto:policy@hospiceuk.org)



# Sidmouth Integrated Model for Specialist Palliative Care (SIMSPC)

Mary Ashby Nurse Lead  
2025  
[Mary.ashby@nhs.net](mailto:Mary.ashby@nhs.net)



**Sidmouth**  
**Hospice at Home**  
REGISTERED CHARITY NO: 1153338

## SIDMOUTH

**Sidmouth** is served by the Sid Valley Medical Practice, with a joint population of 14,400, both rural and coastal communities

**Sidmouth** is 100+ years ahead of 85+ years curve

Nationally, 0.9% of population are over 90, Sidmouth has 6% over 90

**Sidmouth** is a potential lead in providing services and support for the elderly, and to develop age-friendly communities

**SIMSPC** is providing a growing demand for palliative care at home

Age Distribution C 2021	
80+ years	2,086
70-79 years	2,809
60-69 years	2,276
50-59 years	2,007
40-49 years	1,271
30-39 years	925
20-29 years	827
10-19 years	1,205
0-9 years	964

## Why this model?

### Six Ambitions for Palliative and End of life Care 2021-26

Individual  
Fair care  
Comfort and wellbeing  
Co-ordinated Care  
Competent and prepared staff  
Supportive community

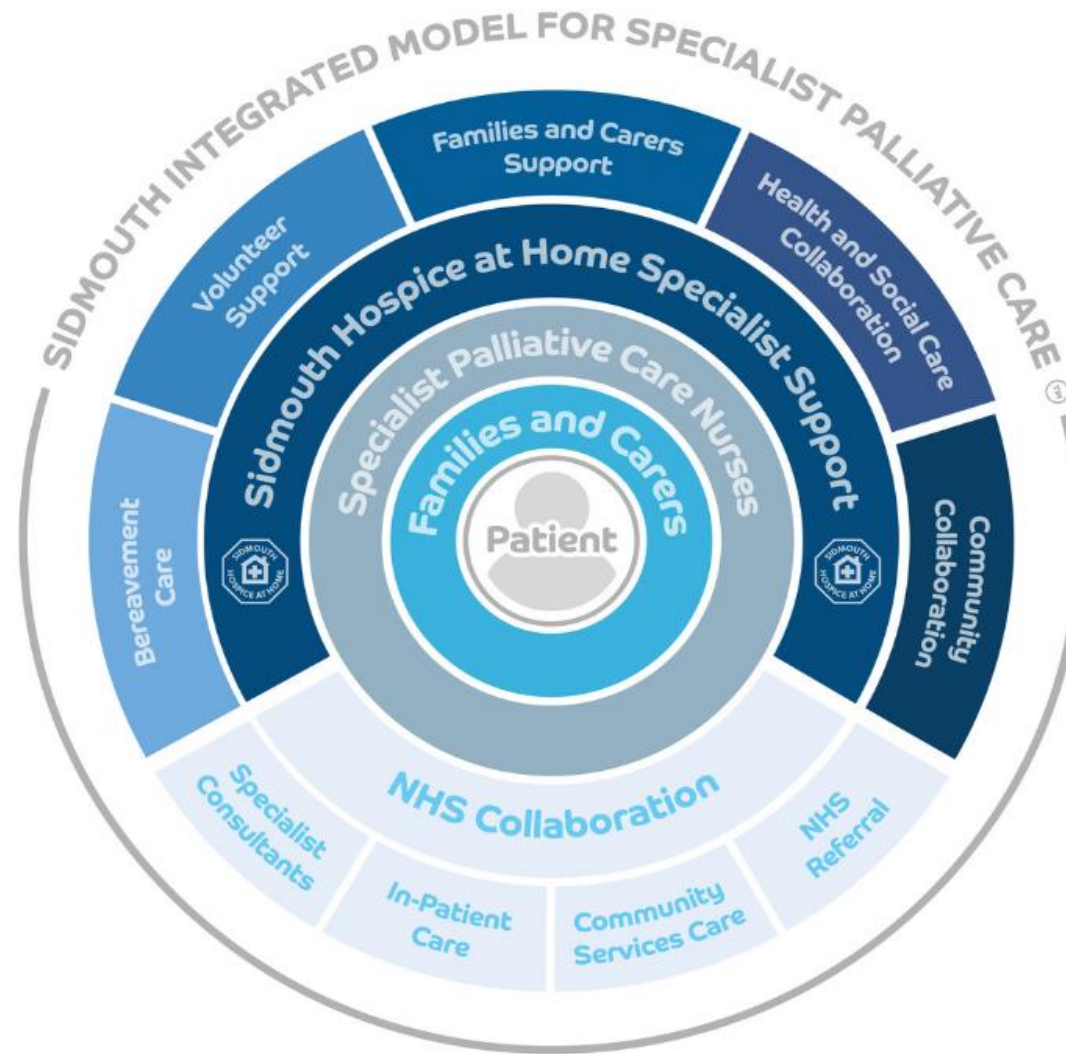
### Sidmouth Integrated Model for Specialist Palliative Care 2020

Patient is at the centre  
Whole system, wrap-around 24/7  
Personalised care  
Integrated, single point of access  
Educated, experienced, specialists  
Support of 80+ volunteers



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We work with our partners in the NHS and other healthcare agencies to ensure the very best support for patients and their families to help them access and receive the most appropriate personal and social care when needed.



Specialist nursing team link in with the wider NHS Community Nursing Teams to ensure that our patients receive the most comprehensive wraparound care possible.

Where we can we work to prevent admission to and speed up discharge from in-patient care. We work with our colleagues to ensure the best outcome for all of our patients and to respect their wishes for their preferred place of death.



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# Specialist Palliative care clinical service

1.0 WTE Clinical Nurse Specialist Lead  
5.8 WTE 7 Clinical Nurse Specialists  
2.2 WTE 3 Assistant Practitioners  
+0.6 WTE Wellbeing lead

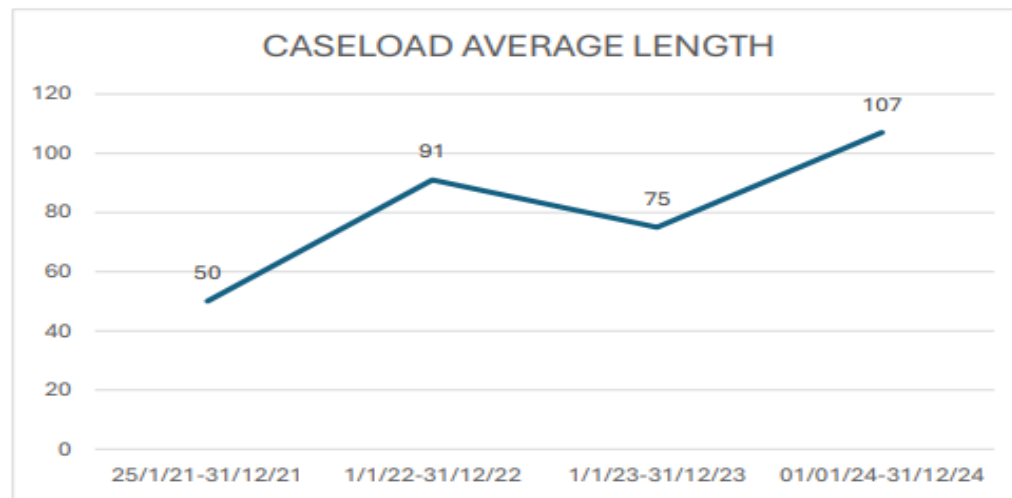
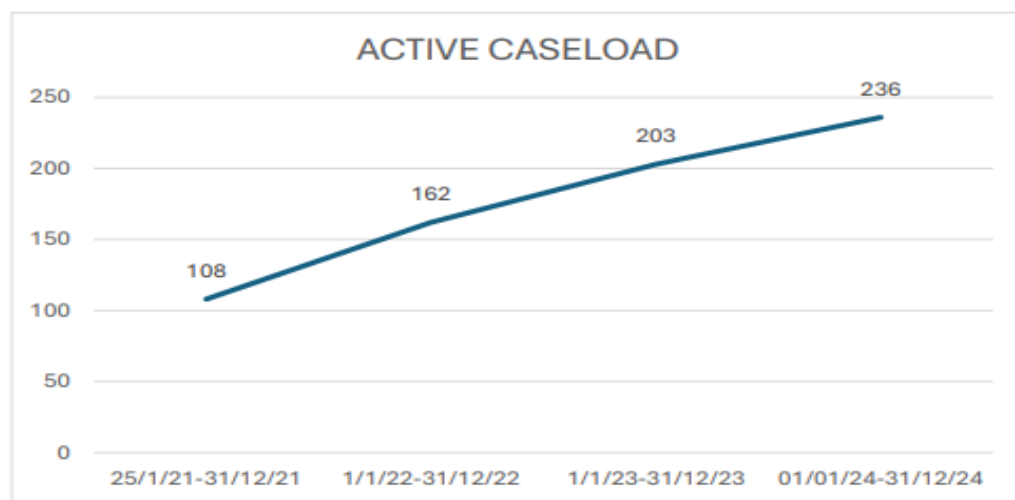
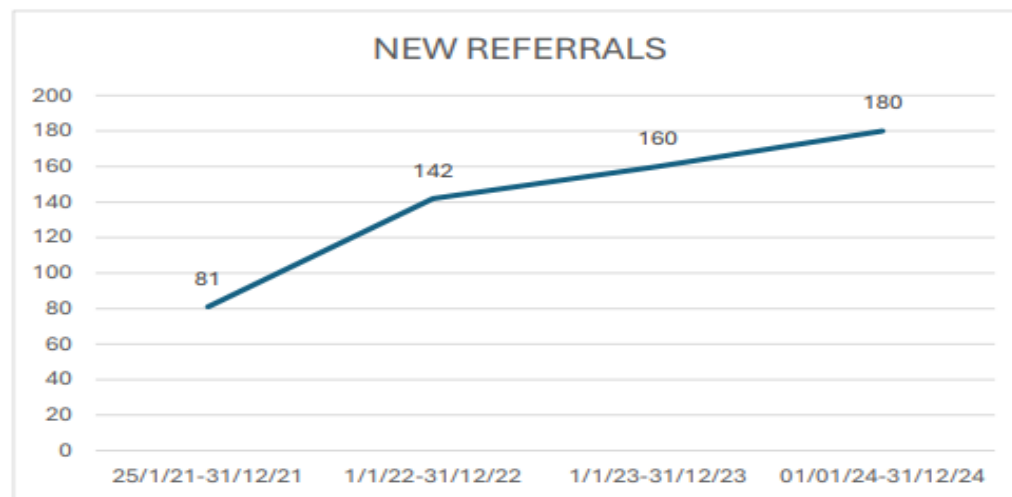
Royal Devon University Healthcare NHS Foundation Trust  
Palliative Care Medical Consultant  
Palliative Care Nurse Consultant  
Palliative Care Lead Nurse for Community

*Face to face, Single point of access, 24 hour specialist palliative care nurse who has expert knowledge is crucial for patients, their families and the delivery of the SIMSPC*

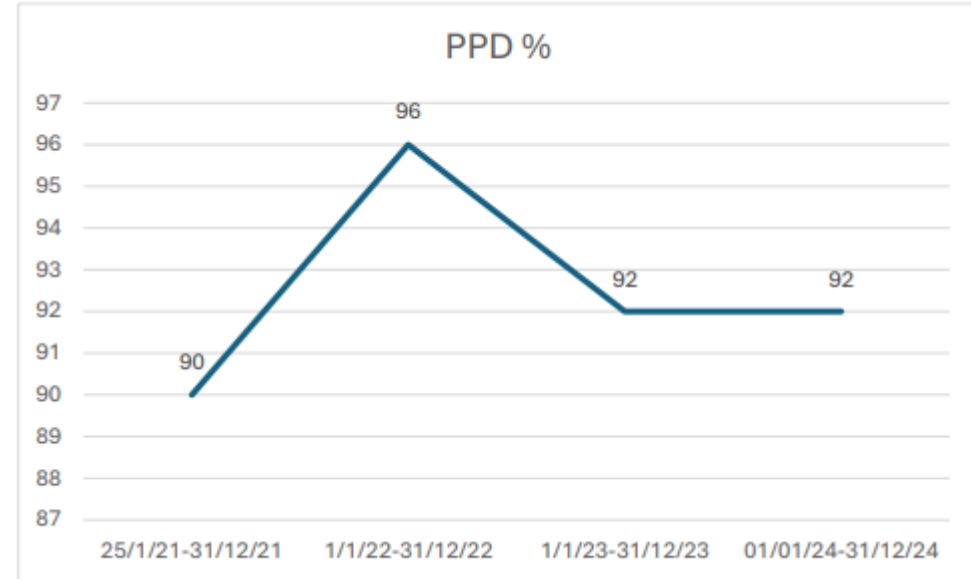
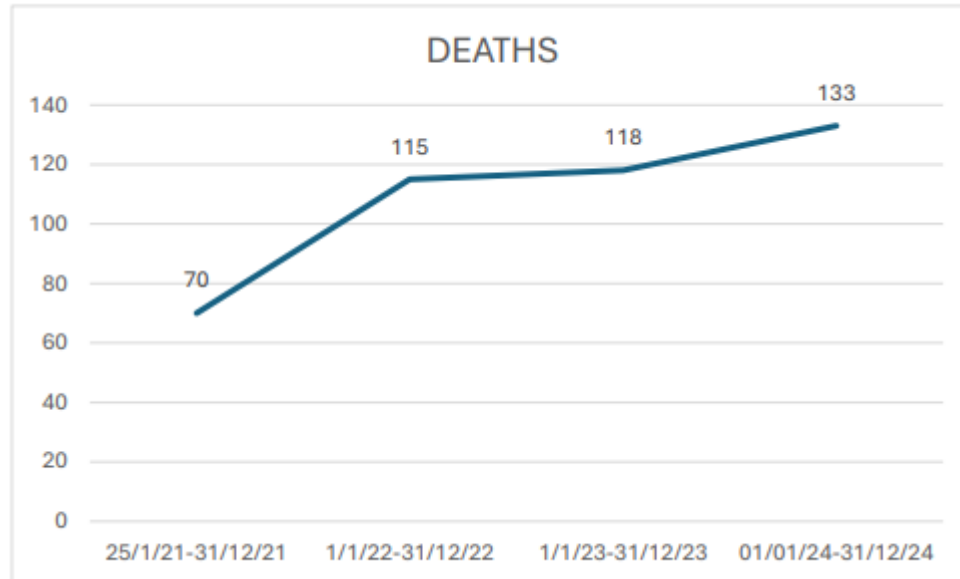


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# First four years of service



# First four years of service



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## 2024 Support Service Statistics & 2025 Initiatives

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### Key Service Deliverables (2024)

- Sitting, Companionship & Dementia Sitting Sessions: 747
  - Information Hub Visits: 1,341
  - Bereavement / Pre bereavement Contacts: 851
  - Miles driven for prescription delivery & patient/family/carer drives: 6,184
  - Activity Programme
  - Wellbeing day service
- 

### Resources

- 60 hours paid staff PW inclusive of management hours
  - 70 patient/family/carer facing Volunteers
  - No additional Volunteer Management Team/ People Department
- 

### New for 2025

- Complementary Therapy Sessions (First half of 2025): 51
- Mens Brunch Club (September Launch)



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## Integrated working across Clinical and Support Services

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What makes this work so well?

- Teams working in close physical proximity
- Daily Handovers/ Weekly MDT
- Easy/quick referral pathways
- Good relationship between teams
- Flexibility according to patient/family need
- Small team which allows for quick pivots and autonomy of decision making
- Quick 'catch up at the kettle'
- The power of 'What if'
- Professional curiosity
- CRM integrated across Fundraising, Volunteering, Support Services and Finance

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June 2025

Vanessa James – Head of Support Services - [www.linkedin.com/in/vanessa-james-774b71185](https://www.linkedin.com/in/vanessa-james-774b71185)

[Vanessa@sidmouthhospiceathome.org.uk](mailto:Vanessa@sidmouthhospiceathome.org.uk)

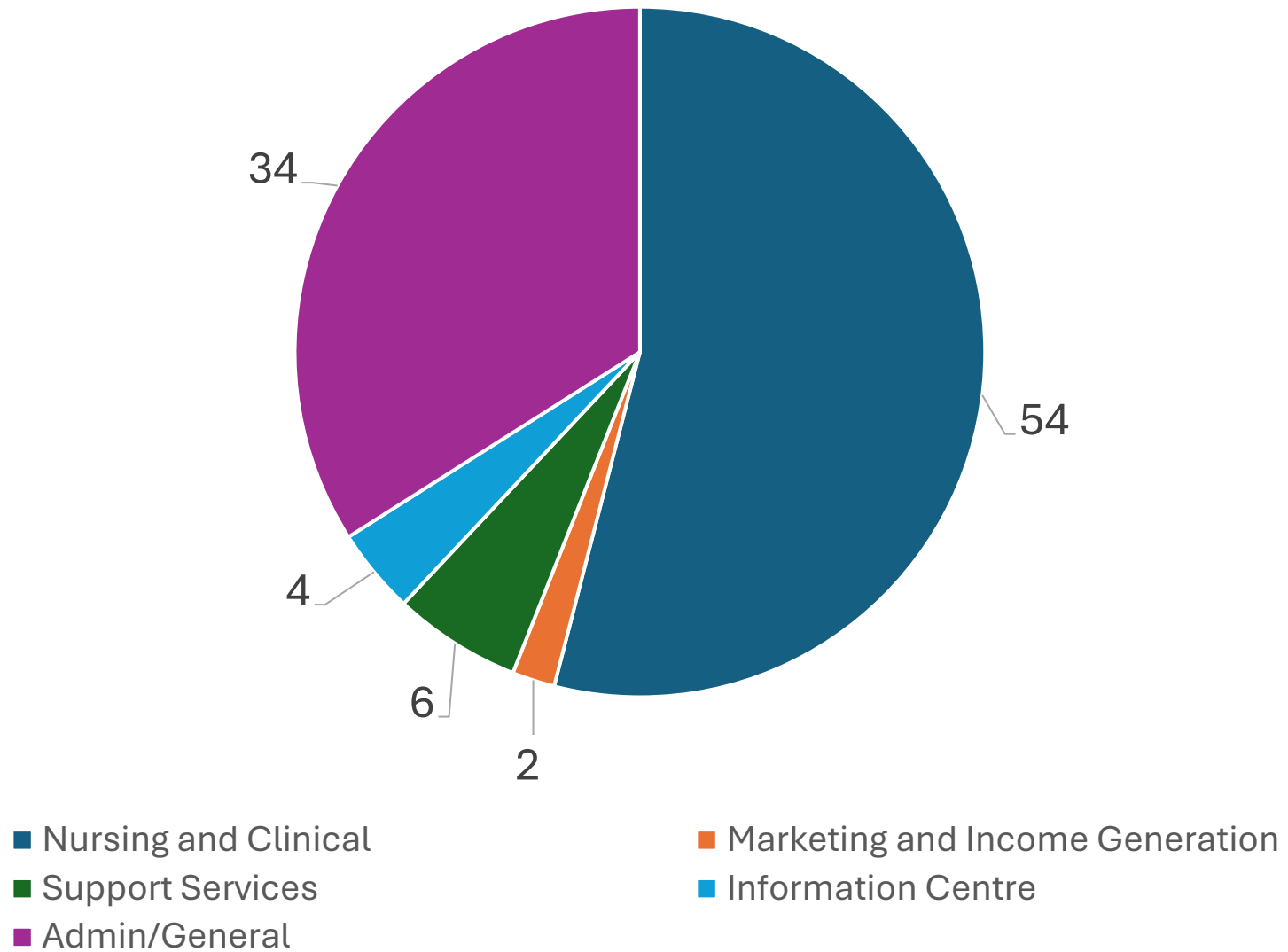


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# **The service that Sidmouth Hospice at Home provides, is only made possible via fundraising**

- The charity was founded in 1985 and is proudly celebrating it's 40<sup>th</sup> year of service across the course of this year
- Unlike other specialist hospice services in Devon, Sidmouth Hospice at Home does not currently receive any statutory funding to support day-to-day costs
- The specialist hospice service is funded entirely by the community, for the community, being reliant on donations alone
- Whilst proven to represent excellent value, in the coming year it will cost more than £980,000 to fully fund the entire team of 12 specialist palliative care nurses (which are currently commissioned and clinically managed via the RDUH), a range of support services, Sidford Wellbeing Centre and Sidmouth Information Hub
- The charity employs an administrative team; a FTE of less than 5, inclusive of the CEO

Budget Allocation by %



**Sidmouth**  
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The service saves the costs of acute inpatient admissions which are £556 per day (or £16,680 per month); the average nursing home cost is £6,000 per month.

Without H@H	%	Number of patients	Cost	Cost to Public Sector
Nursing	20	55	£ 1,340,152	£ 536,061
Residential	10	28	£ 475,357	£ 190,143
Acute	60	165	£ 4,112,064	£ 4,112,064
Home (no hospice)	10	28	£ 178,486.20	£178,486.20
	<b>100</b>	<b>275</b>	<b>£ 7,105,059.20</b>	<b>£ 5,016,754.20</b>

With H@H	%	Number of patients	Cost	Cost to Public Sector
Nursing	2	6	£ 134,015.20	£ 53,606
Residential	1	3	£ 47,535.68	£ 19,014
Acute	3	8	£ 205,603	£ 205,603
Home with H@H	94	259	£ 1,013,320	£ 543,900
	<b>100</b>	<b>275</b>	<b>£ 1,400,474</b>	<b>£ 822,123</b>

**Overall saving with SIMSPC**

**£ 4,704, 585.20**

**£4,194,631.20**



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# Questions and Discussion





## Collaboration To Allow For Choice Of Place Of Death in Paediatrics.



Louise Esson  
Diana Children's Nurse



Children's Hospices Across Scotland

# CONTENTS:

- 1) Geography
- 2) Context
- 3) Local Services
- 4) Service requirements
- 5) Professional supports
- 6) Actions
- 7) Algorithm
- 8) Outcome Summary



Children's Hospices Across Scotland

# Geography



- Population:
- Estimated in 2020 at 584,550
- Area: 8,697.72 km<sup>2</sup> (3,358.21 sq mi)
- Historically divided into 5 council areas- now consists of 3 which are Aberdeen city, Aberdeenshire and Moray



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# Context

Jan 2023 – Aug 2024

- 38 child deaths
- 26 Unexpected
- 12 Expected – 8 Families wish to be at home



Children's Hospices Across Scotland

# Local Services

- Grampian / Moray – 2.8 WTE CCN
- Part time Consultant
- Palliative care advisory service
- DCN / CHAS @ home
- GP service
- OOH service
- Adult Community Nurses



Children's Hospices Across Scotland

# Service Requirements

- Symptom Management delivery
- Syringe driver changes
- Verification/Certification of death



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# Professionals Supports

- Specialist paediatric palliative care advice
- Paediatric Nursing Advice
- Clinical skills support
- Orientation to documentation
- Communication



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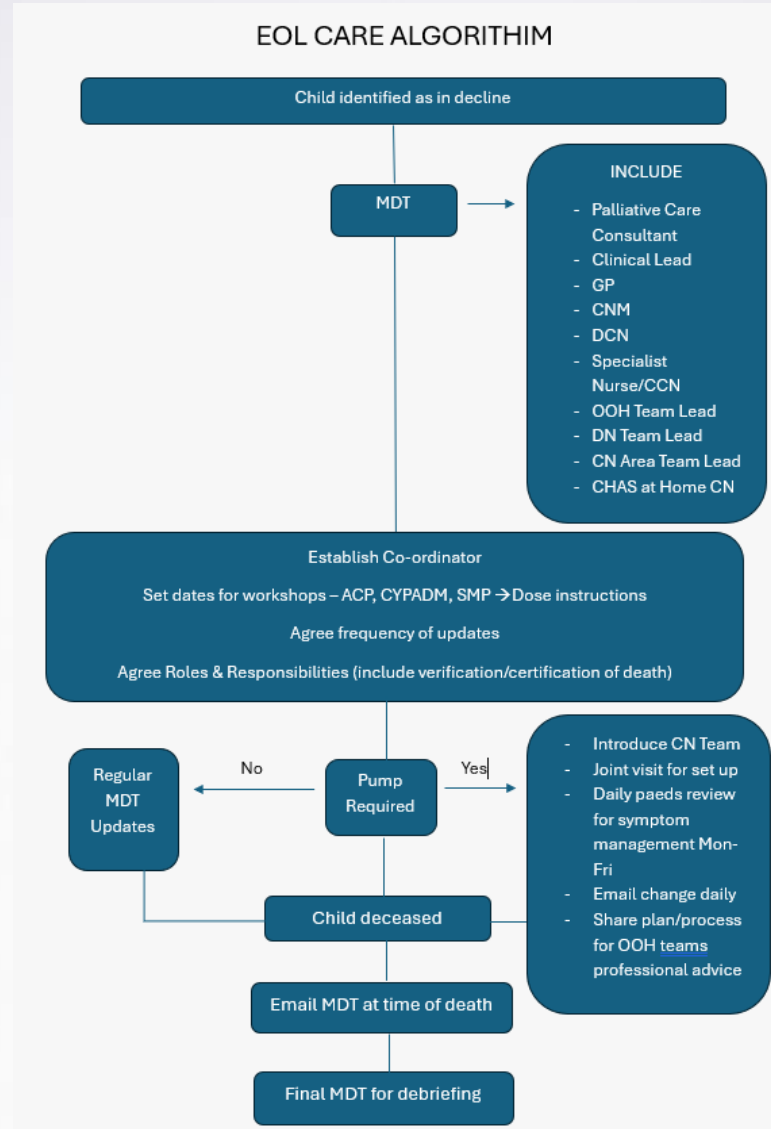
# Actions

- Education provision
  - Works shops - Orientation to paediatric palliative care
    - Child specific
- Early MDT for EOL care
- Information sharing
  - Ensuring access to information
  - Varied platforms
- Ongoing collaborative updates



Children's Hospices Across Scotland

# EOL Care Algorithm



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# Outcomes

- 8 Families wished to be at home
- 7 Supported with EOL in the community

## Quotes:

“ I actually had him in my arms at the time as he was floating in the water. He got his final wish. It's thanks to you guys for making sure he stayed at home. I will get so much more comfort knowing he passed in the bath.”

“You and the team empowered us to embrace the gift of caring for him at home.....It's been a beautiful experience in amongst tears and sadness so thank you. Forever grateful”



Children's Hospices Across Scotland



Children's Hospices Across Scotland

[www.chas.org.uk](http://www.chas.org.uk)



SupportCHAS

Children's Hospices Across Scotland is a trading name of Children's Hospice Association Scotland. Scottish charity number SC 019724.



# Questions and Discussion

# Feedback Survey

Improving palliative care for  
people in remote, rural and island  
communities



Please consider sparing a few minutes to answer this survey, so that we can continue to improve future Big Conversation events:

<https://forms.office.com/e/9C9rQz2Exd>

# Hospice UK data collation 2025

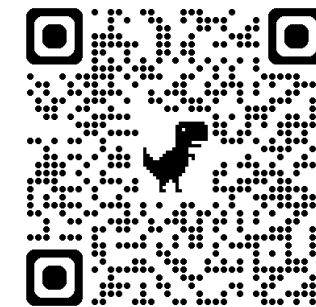
Every year, Hospice UK collates, analyses and shares data about hospice services. This forms a key part of our work fighting for hospice care for all who need it, for now and forever.

This year we are asking our members to respond to the following surveys by **30th June 2025**.

<https://www.hospiceuk.org/innovation-hub/clinical-care-support/hospice-data>

# Membership survey

Scan here for  
more details



# Thank you