



Celebration Event Palliative and End of Life Care Network NENC

15th September 2026



**North East and
North Cumbria**

Celebrating Regional Progress in Palliative and End of Life Care

NENC 2025 -2026

Deciding
Right relaunch

Deciding
Right e-
learning
developed

Regional
Clinical
Templates

Caring for the
Dying Patient
Document
embedded

Regional
Project ECHO
education
established

Boost Learning
Academy
programme
launched

Hospice Digital
Funding
secured

Compassionate
Communities
work expanded

24/7 care and
medicines
pathways
reviewed

Lymphoedema
Community of
Practice
established

Secondary Care
working group
established

Regional
PEoLC
Guidelines in
place

- Completion of regional Ambitions for Adult and CYP
- Regional Health Needs Assessment completed
- Strategic Commissioning Plan developed
- Local Insight Packs Produced
- Early Identification and in equality data analysed
- PEoLC Dashboard Improvement Planned
- Hospice and VCSE Commissioning reviewed
- Children and Young People's pathways prioritised
- Universal Care Planning proposals developed
- Stronger Regional Governance and partnership working developed



**North East and
North Cumbria**

**NEXT:
Vicky Moody and Joy Evans**

**Palliative and End of Life
Care Health Needs
Assessment
Steps to Implementation
A Strategic
Commissioning Plan**

September 2026

Health Needs Assessment

1 HNA

Led by PEOLC transformation lead and Clinical Network

Written by Joy Evans and Vicky Moody

Developed by multiple stakeholders

6 Supplements

Technical
Document

Literature
Review

Community
Engagement

SPC
Workforce

CYP
SPC

Place
summaries

9 Key themes and recommendations

Strategic
Leadership

24/7 Access
to SPC

Early
identification

Recognition
of dying

Advanced Care
Planning

Record
sharing

Sustainable
Workforce

Embed PH
approach

CYP
SPC

Implementing the recommendations of the Health Needs Assessment

How we think they could be implemented

Who we think should lead

A whole system response

Providing insight to encourage local curiosity

Health Needs Assessment

Strategic Commissioning plan

- Long document
- Detailed document
- Clear, time bound actions with lead people/organisations attributed
- Number of NE&NC wide recommendations
- Gives local places ownership of key deliverables
- Includes benchmarking and comparisons where possible, however.....



Action responsibility

ICB

- Commission enhanced service to increase identification
- Enable digital information sharing
- Sustainable VCSE PEoLC funding – three-year transition
- Enhance dashboard and enable wider usage
- *Implement contract measures to support provider change*

Whole system

- Comms plan to support discussions about dying and preferences, to include targeted engagement work with underserved groups (men, working age adults, different ethnic groups and people with a learning disability)
- Ensure system governance in place for PEoLC
- Review intelligence packs and determine funding reallocation
- Ensure 24/7 access to SPC

Action responsibility

Providers – all

- Implement Deciding Right documentation
- Support digital information sharing
- Participation in regional PEOLC education delivery
- Support improved staff training in line with national recommendations
- Improve coding and reporting of PEOLC activity

Hospices

- Work with ICB to understand costs of service delivery and development of a sustainable commissioning model

Public health

- Improve workforce response to bereavement
- Expand Compassionate Communities approaches across the NENC

Early Identification – Enhanced Service

- Key stats if on PEOLC register in NE&NC
 - Twice as likely to die in preferred place of choice
 - LoS 1.5 days shorter (except in Gateshead!?)
 - Average admission costs c£850 less
- National assumption is 1% of reg. list dies per year - 75% of deaths were predictable
- Up to 2% of population would benefit from PC
- c1.2% of population on PEOLC register
- 41% of people that died in 12 months were on register
- Hitting the target or missing the point
- Best = Derwentside PCN
- Most opportunity = Darlington

Place Insight Packs

- Local governance and leadership
- Services in the area
- 24/7 provision
- Spend on services and benchmarking
- Hospices in the area and financial position
- NACEF findings – acute and community
- Identification
- Inequalities
- Unplanned activity and costs
- Outcomes
- Patient feedback

Local Intelligence Packs

- Geography covered – what will add most value for you
- Level of detail – core report v appendices
- Variation and inequalities
- Current commissioned services and spend – hospice sector, FTs, community services (core), CHC, secondary care activity (Em admissions, ED attends, 999 calls received – waiting for SDEC and VW)
- Provision of 24/7 SPC
- Outcomes
 - Inequalities
 - Identification
 - PPoD
 - Use of unplanned care
- Benchmarking



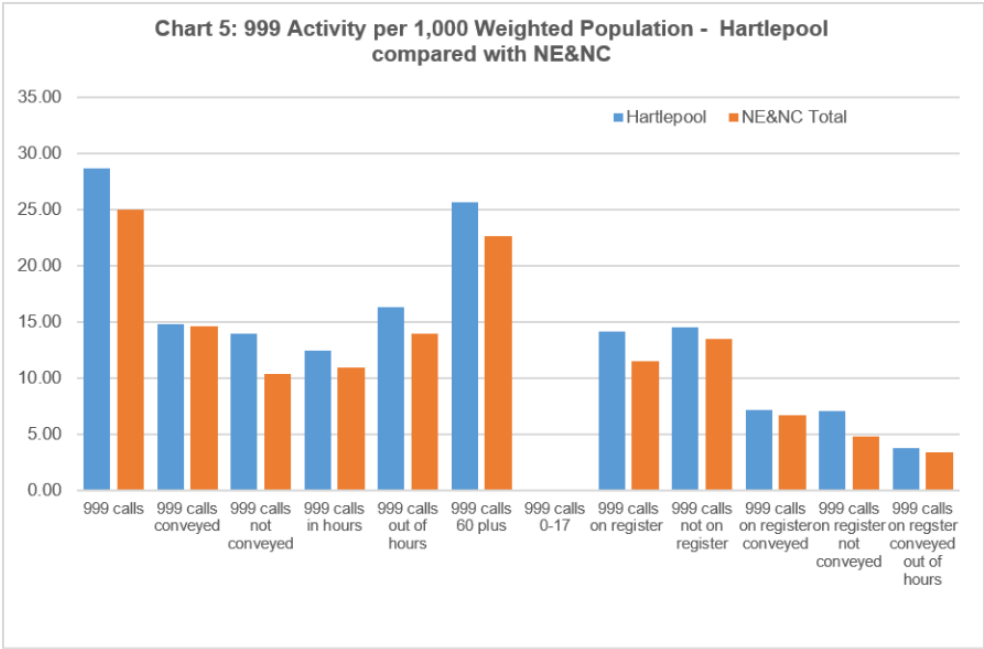
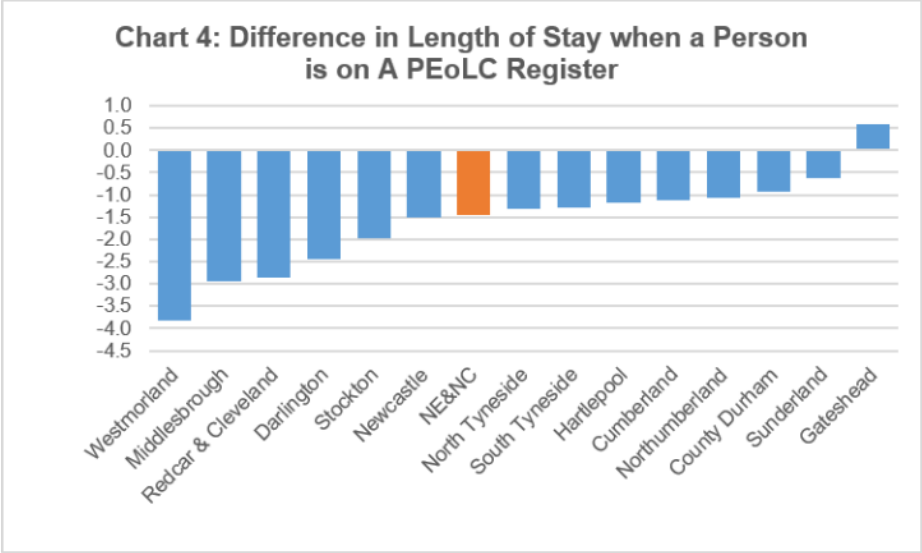
Place Insight Packs

- Not - judgements, criticisms or directives
- Are - collection of useful information to help identify areas for focus locally
- Example of observations

Example Summary Observations – xxx System

- There has been significant work in xxx area on the sustainability of SPC services.
- There are established groups and governance arrangements for PEOLC but they have not met in recent months. The joint working arrangements as part of the xxx Trust has streamlined governance.
- xxx does not provide some of the key elements of 24/7 services which are known to impact on patient outcomes
- The advice line in xxx is provided by the on-call consultant where there is direct access via trust switchboard.
- This reduces delays in advice being given to clinicians during crisis.
The NACEL audit identifies several areas for improvement. Sharing data within the Trust could increase the profile of this important area. No data was submitted for January-March 2026.
- Identification of people in their last year of life is better than the regional average but is variable by practice and PCN
- There are inequalities in identification of people in their last year of life by gender and age
- People on the PEOLC register are three times as likely to die in their preferred place of death although recording of PPC and PPD can be improved
- People in xxx have high rates of 999 calls but lower rates off ED attendances and admission to hospital in their last year of life
- 38% of people in xxx died in hospital which is the same as the regional average
- People in xxx are more likely to say that their health needs were met and less likely to say their social care needs were met at the end of life
There are opportunities to deliver some elements of SPC differently in xxx
Improvements in PEOLC can be monitored by the ICB dashboard

	NCIC	Nbria	Ncle	Ghead	S&ST	CD&D	NT&H	South Tees
Access to a SPOC								
Provide 24-hour consultant telephone advice				Via hospice*	Via hospice*			
7 day a week medical cover								
7 day a week nursing cover							***See below	
7 day a week Specialist Palliative Care Service								



More to do

- CHC
- CYP
- Bereavement
- Prescribing
- Education and regional approach
- Lymphedema
- Dashboard
- How we do it
- Supported by.....



Our Ask of You

- Champion PEOLC and the recommendations
- Engage in local conversations using information provided
- Collaborate with partners
- Be curious not furious!

Any Questions ?



**North East and
North Cumbria**

**NEXT:
Dr Jenny Johns
Via Teams**

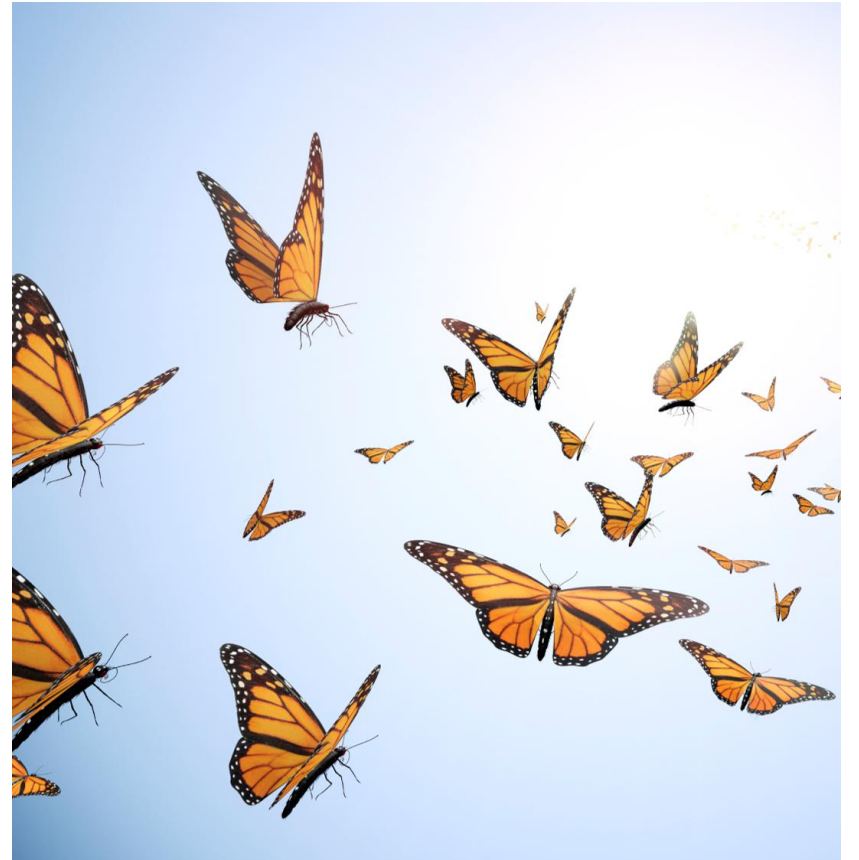
Trauma Informed Care in Palliative & EOL Care

Dr Jenny Johns,
Consultant Clinical Psychologist
Clinical Lead for Psychology, NCA/ Northumbria
Cancer Psychology Service



Overview

- What is Trauma Informed Care?
- What impact can it have?
- What can this look like in Palliative & End of Life Care
- Video: Dr Hannah Gunn, Consultant in Palliative Care – Trauma Informed Care in Practice



Taking care of ourselves



You may have experienced trauma inside or outside of work.

Thinking about trauma in this session may trigger difficult thoughts or feelings for you. If this happens feel free to take a break and look after yourself in the ways that you usually would.

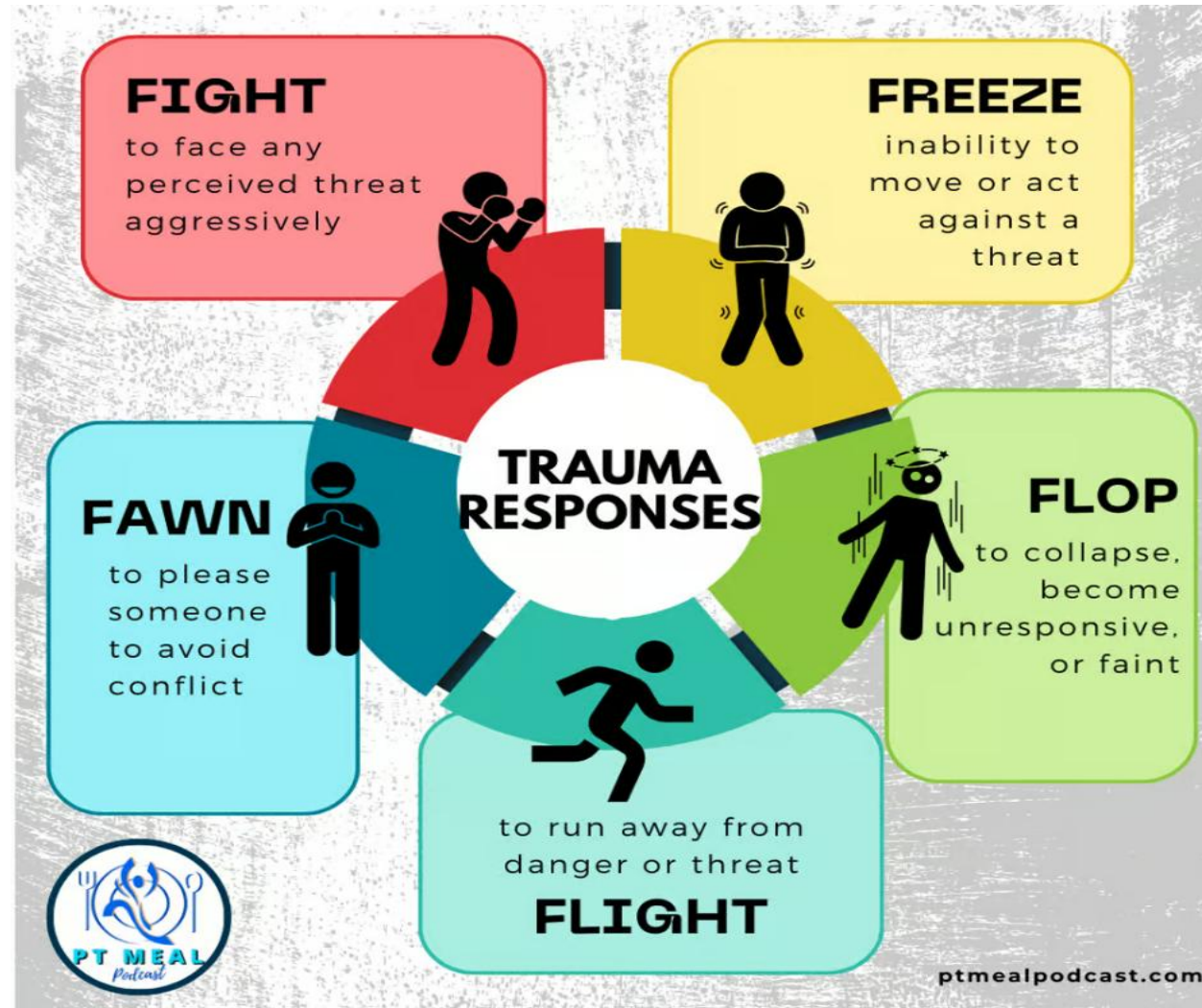
If you would like any signposting to sources of support, please contact me after the session
jenny.johns@nhct.nhs.uk

What is Trauma & Trauma Informed Care?

“Trauma results from an event, series of events, or set of circumstances that is experienced by an individual as harmful or life threatening. While unique to the individual, generally the experience of trauma can cause lasting adverse effects, limiting the ability to function and achieve mental, physical, social, emotional or spiritual well-being.”

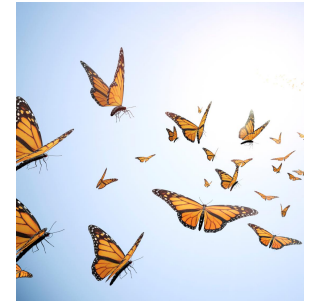
“Trauma Informed Care involves designing our organisations with the impact of trauma in mind. We consider how it might feel for a patient, a family member, or a staff member, who has experienced trauma, to move through our organisation. We do what we can to make that experience as good as it can be, and prevent additional trauma.”

Understanding the trauma response



What might trauma look like?





What do we do? The Core Principles of TIC

- Collaborate, empower, provide choice where possible
- Create safety
- Create trust
- Recognise strengths
- Minimise re-traumatisation – consider co-production
- Be sensitive to cultural context

What do we do if we are 'trauma informed'?



- The 4 Rs
 - Realise - that trauma can have a lasting impact
 - Recognise – notice the signs that might suggest trauma
 - Respond sensitively and connect people to sources of help
 - Minimise re-traumatisation in the way we operate in our organisation
- It's not a list of behaviours, it's a mindset
- We move from asking 'What is wrong with you?' to 'What happened to you?'
- Relationships as repair – most trauma happened in relationships. Power was abused and misused, needs were not responded to safely and consistently. Every interaction that provides something different can be healing.

What impact can TIC have?

For patients and families:

- Improved engagement with screening, scans, treatment, less DNAs
- Improved outcomes in terms of physical and mental health
- Improved ability to access services that can support 'a good death'

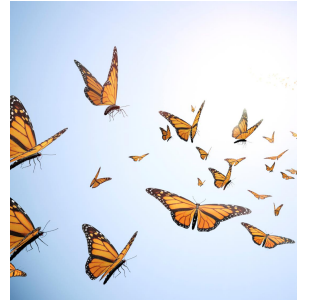
For staff and organisations:

- Reduced sickness from mental and physical health problems
- Reduced grievances and conflict
- Reduced complaints and reputational damage to the organisation
- Less time needed from HR and managers in dealing with all of the above
- Increased recruitment and retention
- Increased job satisfaction
- Improved team working, creativity, psychological safety



What might this look like in Palliative and EOL Care?

For patients and families



- **Preventing re-traumatisation** – minimise potential triggers: physical restraint, feeling trapped or unable to leave, loss of privacy, sudden touch without consent, procedures without explanation, being spoken about rather than spoken to
- **Creating emotional and physical safety** - introducing yourself and your role clearly, explaining procedures before commencing, seeking permission before examinations or personal care, minimising unnecessary exposure during washing or nursing care, providing predictable routines where possible, ensuring difficult conversations occur in private, calm environments
- **Awareness of loss of power/autonomy** - offering choices wherever possible, shared decision-making, advance care planning, respecting preferences about treatment and place of care, allowing patients to decide who is present during discussions
- **Sensitive communication** about deterioration and dying - checking readiness for information, providing information in manageable amounts, allowing time to process emotions, returning to discussions over several contacts, avoiding unnecessarily abrupt delivery of difficult news
- **Bereavement care** – bereavement can reactivate previous losses and trauma - recognising different grief responses, identifying those at risk of traumatic or prolonged grief, avoiding assumptions about how people "should" grieve, providing ongoing opportunities for support and review

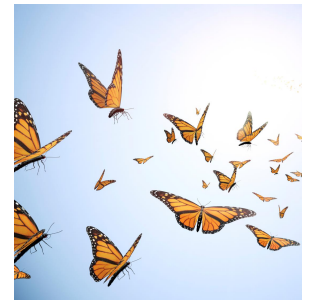
What might this look like in Palliative and EOL Care? For staff

Staff are regularly exposed to

- Distressing diagnoses
- Emergency presentations
- Death & dying
- Complex family dynamics

Working well with this might involve:

- Recognition of the cumulative emotional burden
- Reflective practice groups
- Psychological safety within the team
- Compassionate leadership
- Access to staff support



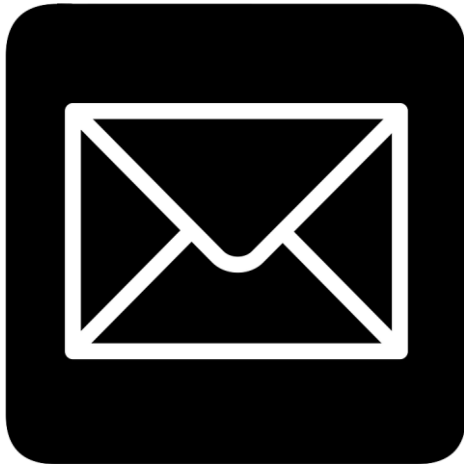
Trauma informed care

Staff experiences



Hannah Gunn

Consultant in palliative care



Any questions? Please get in touch

jenny.johns@nhct.nhs.uk

NEXT:

Jane Boyle, Jill Coates

Helena Hardman, Rebecca Athey

Integration of the Paediatric Palliative Care Team in the Haematopoietic Stem Cell Transplant Journey

Quality Improvement Project

Jill Coates & Jane Boyle – CHIPS team

Helena Hardman & Rebecca Athey – BMT team

Who are the CHIPS team?



- Started January 2021
- Children's Holistic Integrated Palliative Care Service
- Tertiary service specialising in the holistic care of children with life limiting and life-threatening conditions
 - Children with oncological diagnosis under care of separate team (CYPOONS)
- Regional: covering North East & North Cumbria
 - Available weekdays and weekends during working hours
 - Expanding to be able to deliver 24/7 on call by end of 2027

Together for Short Lives categories

Category A: Life-threatening conditions

Clinical Definition

Conditions for which disease-modifying treatment is available but may fail, or where intensive therapy is required to prolong life. These conditions carry a significant risk of death if treatment is pursued.

Clinical Characteristics

This can include situations where:

- Curative treatment exists but response is uncertain.
- Child requires intensive or life-sustaining treatment for function or survival.
- Treatment decisions involve significant risks and benefits due to uncertainty.
- There is significant risk of death if treatment is not pursued.
- Situations where survival is uncertain.

Category B: Life-shortening conditions

Clinical Definition

Conditions where death in childhood or early adulthood is expected due to the progressive nature of the condition or the absence of effective curative treatment.

Clinical characteristics

This includes situations where:

- The condition is expected to shorten life
- The child experiences progressive decline or deterioration
- The focus increasingly includes quality of life and palliative management

Category C: Severe medical complexity

Clinical Definition

Children with severe medical complexity and vulnerability, including multi-system involvement, profound neurological impairment, technology dependence, or extreme frailty, where there is a significant risk of life-threatening events.

Clinical characteristics

This includes situations where:

- A child relies on medical technologies for vital functions (e.g., ventilation, feeding, oxygen, shunts).
- There is high risk of sudden deterioration
- There is an increased susceptibility to life-threatening events, even when the underlying condition is static.
- The child has significant functional impairment and care needs
- There is clinical frailty, particularly in adolescents transitioning to adult services.

Background

Evidence supports that early palliative care integration in HSCT leads to improved patient and caregiver outcomes¹

Early and universal involvement of palliative care before the start of HSCT reinforces the message that palliative care should not be equated with end of life or a poor prognosis²

1. El-Jawahri A, LeBlanc T, VanDusen H, et al. Effect of inpatient palliative care on quality of life 2 weeks after hematopoietic stem cell transplantation: A randomized clinical trial. JAMA. 2016;316:2094–2103. doi: 10.1001/jama.2016.16786.
2. Deena Levine et al. Strange Bedfellows No More: How Integrated Stem-Cell Transplantation and Palliative Care Programs Can Together Improve End-of-Life Care. Journal of Oncology Practice. 2017 Sep; 13(9): 569 -577

The Problem

- Small number of HSCT patients referred to CHIPS team close to end of life (6 patients referred July '24 – July '25)
- Recognised earlier referral may have improved quality of life and provided more choices for children & families

Aims

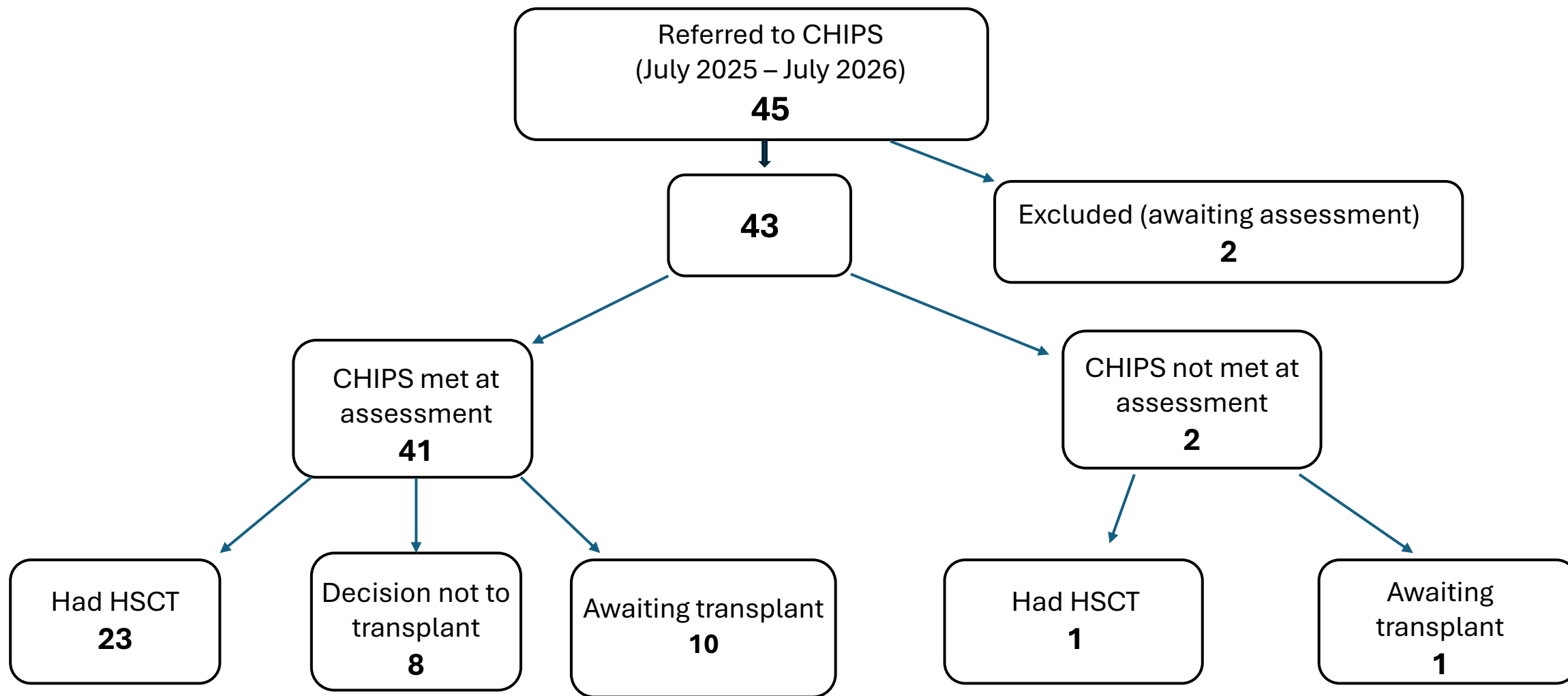
- For all paediatric patients with immunodeficiency to:
 - Have equitable access to specialist paediatric palliative care services from the point of referral for assessment for HSCT
- To introduce the CHIPS team to all patients attending HSCT assessments between July 2025 and July 2026 and to evaluate parental acceptability and optimal timing

CYCLE 1- PLAN

- THE CHANGE
 - Joint collaboration between CHIPS and HSCT teams to embed formal introduction of CHIPS to all routine pre-assessment transplant patients
- METHODS
 - Retrospective patient note review
 - Parent feedback survey and stakeholder evaluation meeting
 - Measured parent-reported acceptability of the service and preferences regarding timing of introduction
- PREDICTION
 - Early introduction during the assessment phase would be acceptable to parents and HSCT professionals and reduce anxiety about palliative care involvement

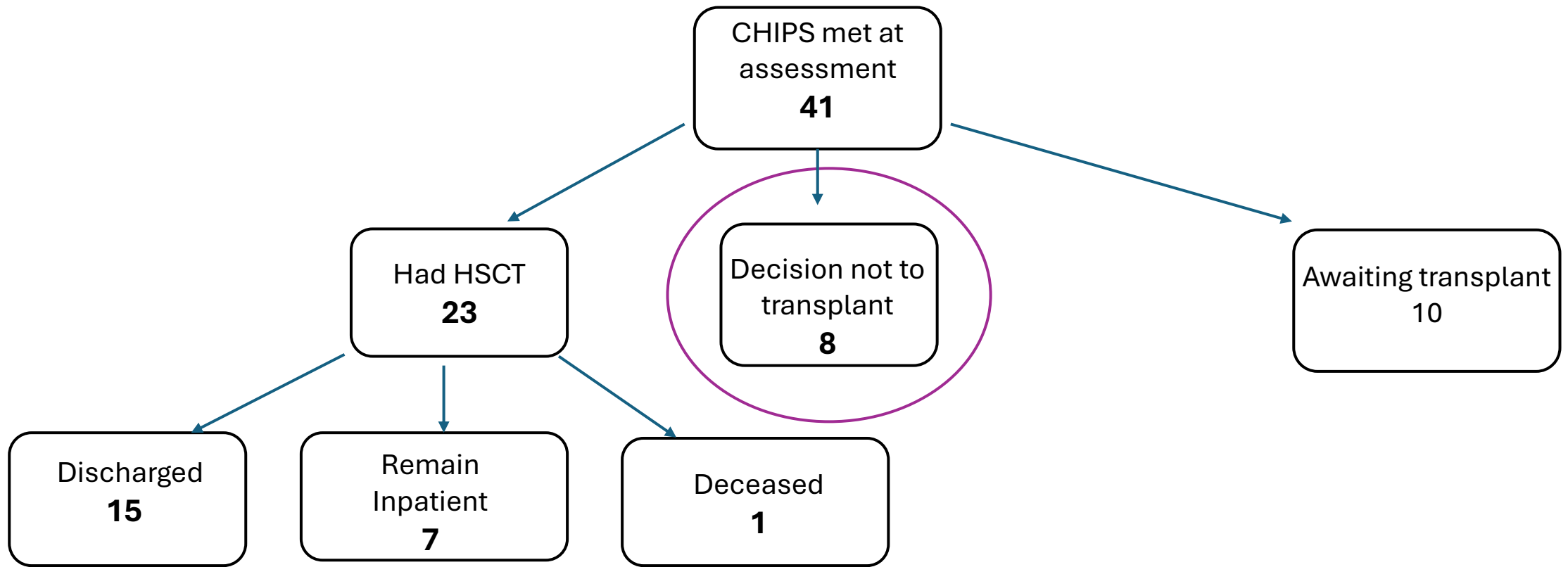
CYCLE 1 - DO

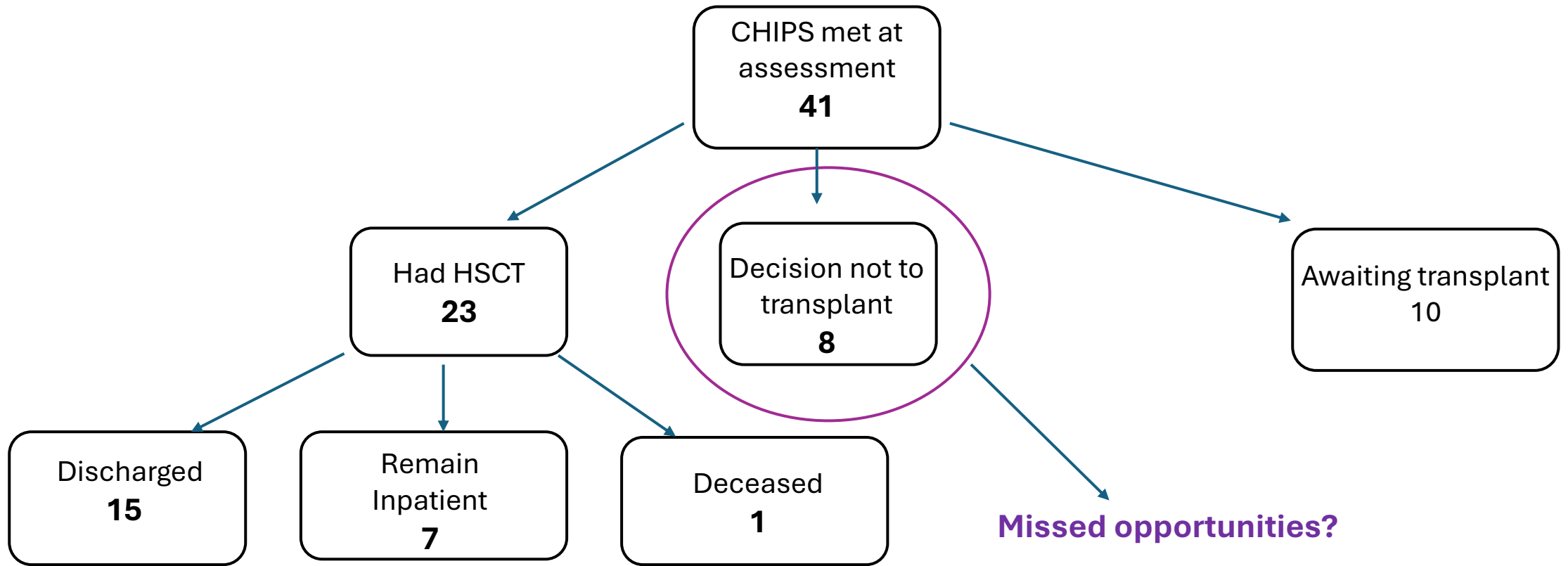
- Conducted over a 12-month period from July 2025 to July 2026
- **Referrals to CHIPS increased by 7.5-fold from 6 the previous year to 45.**
CHIPS successfully met **43 (95.5%)** patients referred for HSCT assessment.
- 22% of the families met at assessment had ongoing palliative care needs and received subsequent visits from the CHIPS team during the child's inpatient stay.
- **Hurdle:** Two patients were missed at assessment due to scheduling conflicts but were subsequently met during their transplant admission.



Who did CHIPS visit again?

- 9 out of 41 patients met at assessment were visited again (22%)
- Of those, all received multiple visits and significant input
- Advance care planning, sibling support, complex symptom management, liaison with local palliative care teams, coordinating end of life care, bereavement follow up





Missed opportunities?

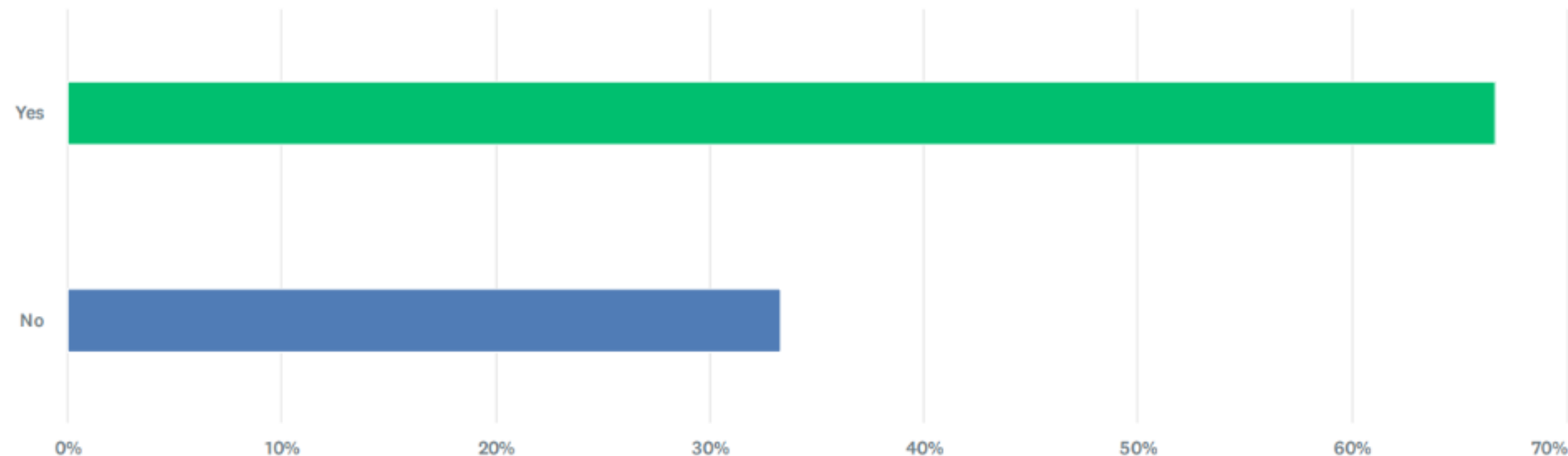
- Either no palliative care needs or already known to local PC team

CYCLE 1 – STUDY

Parent survey

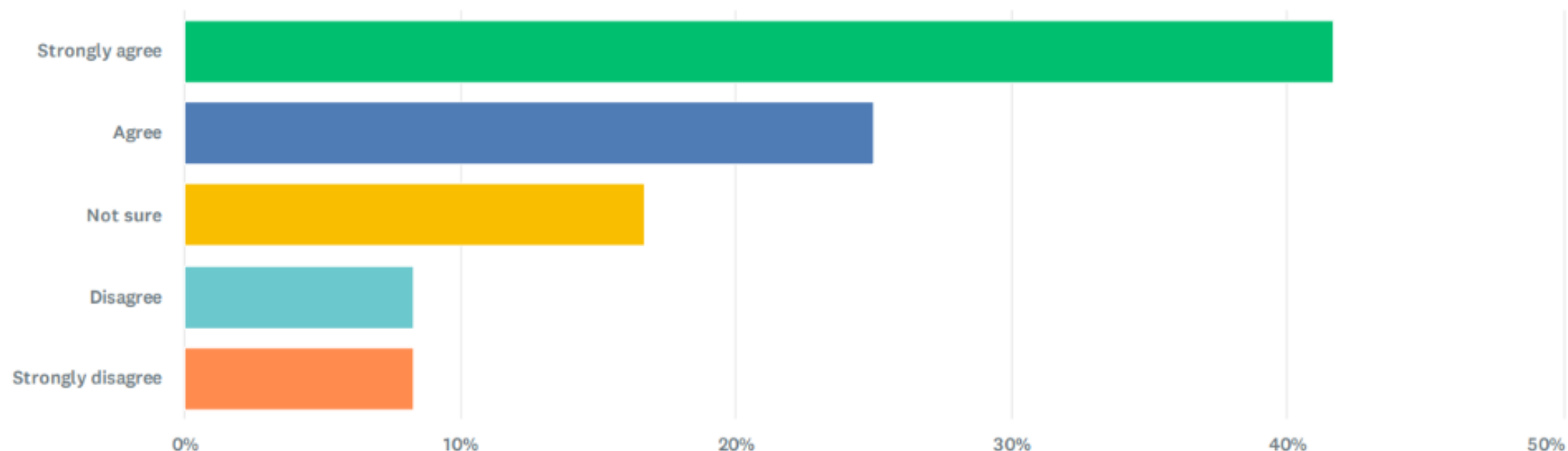
- Sent via email to 27 parents who had been through transplant assessment process or met CHIPS team since July 2025
- 12 responses (45%)
- Benefit
 - Highly appreciated by families whose children later developed complex palliative needs. Majority reported the introduction helped them clearly understand the available support
- Risk
 - Subset of parents reported anxiety at the introduction, highlighting a need to refine how the service is framed
 - Some parents commented that they never saw CHIPS again after initial introduction which contradicted the 'offer' of holistic support

Before meeting CHIPS, had you heard of palliative care?



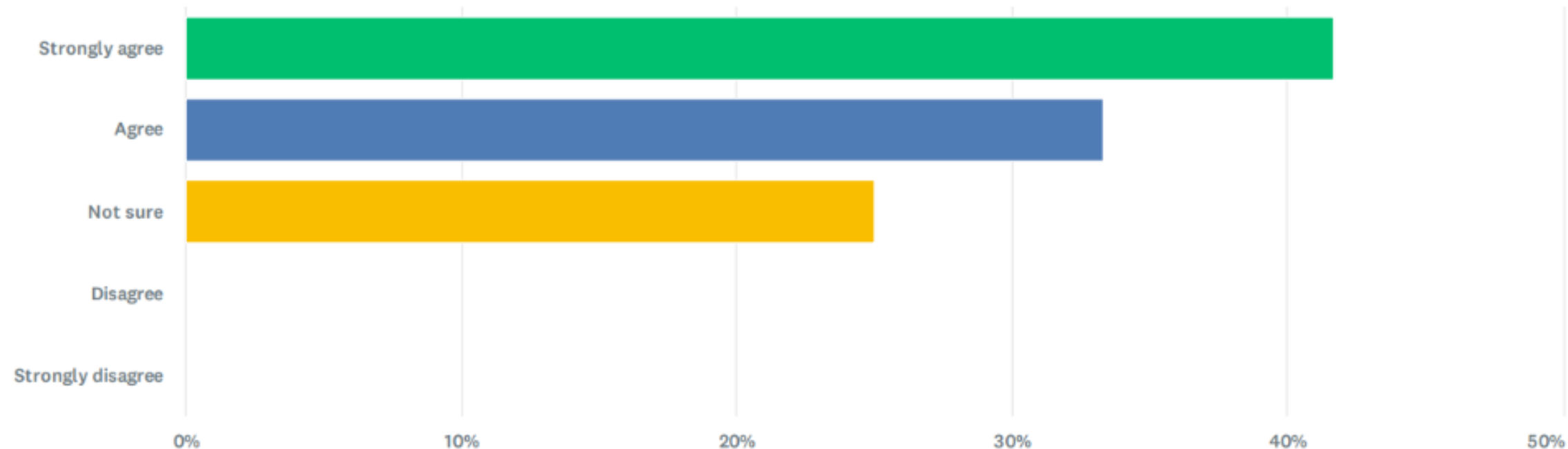
#	IF YES, PLEASE TELL US MORE	DATE
1	I had but associated with end of life care	5/12/2026 5:54 PM
2	In the context of end of life care	4/5/2026 7:49 PM
3	Generally associated with end of life, but had been told this was not necessarily the case during [REDACTED] first time in ICU.	3/31/2026 1:05 PM
4	Know to us as end of life care	3/30/2026 7:50 PM
5	Medical background	11/28/2025 8:01 PM
6	Only in relation to end of life care.	10/18/2025 10:01 PM
7	Basically waiting to die	10/17/2025 5:38 PM

I/we found meeting the CHIPS team helpful.



#	PLEASE TELL US MORE	DATE
1	The member of the team we met was so lovely	5/12/2026 5:54 PM
2	They were all extremely helpful - and really listened to us and did practical things to help	4/5/2026 7:49 PM
3	I didn't like meeting them at the early stages as I was fully convinced we would have no need for it (indeed [REDACTED] had been assessed as low risk). However, the benefit of having already met the team when we were in ICU far outweighed my initial reservations. I now think it is very important that all parents of stem cell transplant patients understand the risks involved, even if their child is not deemed to be high risk.	3/31/2026 1:05 PM
4	We only seen the once during the whole process	3/30/2026 7:50 PM
5	Didn't see them	10/17/2025 5:38 PM
6	It was nice to know that the service was there but we didn't hear from them during or after the transplant so we didn't use them for support.	10/17/2025 4:22 PM

All families should meet the CHIPS team during a stem cell transplant assessment.



#	PLEASE TELL US MORE	DATE
1	Without scaring families but also to be clear what the outcomes of transplant can be	4/5/2026 7:49 PM
2	As above, I think all patients need to be aware that complications are a risk for all HSCT patients.	3/31/2026 1:05 PM

Q10 Did you have any worries or concerns meeting the CHIPS team?

Answered: 9 Skipped: 3

#	RESPONSES	DATE
1	Yes the name of the team makes it sound like end of life care. Even receiving the feedback email prior to transplant has made me feel anxious.	5/12/2026 5:54 PM
2	Yes because when we met them things were very serious	4/5/2026 7:49 PM
3	Yes, I didn't like meeting them at the start. I felt they were there for other more vulnerable patients and that [REDACTED] was strong and healthy (albeit with a serious condition that was under control). At the same time, I understood why they were there, I was just able to convince myself we didn't need them (which was a little deluded in hindsight).	3/31/2026 1:05 PM
4	Only met them once it was also quite triggering being introduced to palliative care.	3/30/2026 7:50 PM
5	It is a little scary when you first meet the CHIPS team as it's a reminder of the seriousness of the procedure.	3/30/2026 3:48 PM
6	No	11/28/2025 12:09 PM
7	No	10/18/2025 10:01 PM
8	We didn't meet them	10/17/2025 5:38 PM
9	When they said it was palliative care it was a bit worrying because it has connotations to a child dying so it was a bit scary when going through the assessment that it was said when our child hadn't been through the transplant yet.	10/17/2025 4:22 PM

Q11 Any other comments or suggestions?

Answered: 7 Skipped: 5

#	RESPONSES	DATE
1	Changing the name of the team. The role of the team sounds like amazing support and the lady we met was one of the most comforting people we met during the assessment.	5/12/2026 5:54 PM
2	Anything you can do to differentiate between palliative care and end of life care in people's minds will help put people at ease when you first meet them	4/5/2026 7:49 PM
3	We needed the CHiPs team and they made a huge difference to us in our darkest days. We do not have access to a similar team in Ireland and the difference between how supported we felt in Newcastle and how unsupported we feel here in Dublin is stark. It is essential that families meet the CHiPs team when they begin their HSCT journey. They need to understand that there are risks associated with the transplant that are out of the control of healthcare workers and that anyone undergoing a HSCT transplant can die, not just the most vulnerable patients. We honestly believed that the worst that could happen to [REDACTED] was that he might need a second transplant and that we would need to stay longer in Newcastle. Sadly, this was not the case and he passed away only 40 days after receiving the transplant from something, as far as we can tell, was due to the transplant, not his underlying condition (although we accept we cannot know this for sure). I think it's important that people understand this as they start their journey. I also think it's important that people meet the CHiPs team sooner rather than later because a familiar face makes a huge difference when things start to go wrong and you are bombarded with information from lots of different healthcare professionals with lots of different specialities. We are so grateful for the help and support the CHiPs team gave us during the worst time of our lives. We don't know how we would have coped without them.	3/31/2026 1:05 PM
4	I would recommend they use a different name when dealing with transplant patients as I know this was very triggering for us and other parents said the same. Also be more involved I still don't really know what they were involved for.	3/30/2026 7:50 PM
5	We lost our little boy to complications from the transplant. Being linked in with the CHIPS team from the initial stages was so important to us as we had a good relationship with the team once things started to go wrong. We found the support we received from the CHIPS team far outweighed any psychological or social work support we received.	3/30/2026 3:48 PM
6	We felt there was pressure to share our thoughts/feelings in the present. Our meeting with chips was on the last day at which stage we were particularly tired and overwhelmed. We had travelled from Ireland so perhaps be more beneficial to schedule for earlier in assessment.	10/18/2025 10:01 PM
7	It was nice to see them during the assessment to know that they're there to help during a difficult time but after that we did not hear from them so we didn't use them.	10/17/2025 4:22 PM

Meeting with key stakeholders

- Presented initial results at MDT meeting April 2026
 - 22 key stakeholders
 - BMT consultants, specialist and ward nurses, psychologists, PICU, palliative care consultants and specialist nurses, AHP (physio & OT)
- Brainstorm exercise to generate improvement ideas
- Recorded on post-it notes
- Results grouped into themes



Positives – what is working well

- Relationship building
- Introducing CHIPS team early so parents and families build trust
- Formed a relationship before needed
- Equitable offer to all patients
- Families who had CHIPS input appreciated meeting early
- Joint service – much improved MDT
- Joint learning and experience

Negatives – what could be improved

- Is it harmful to meet families who are unlikely to need you?
- The word 'palliation' may scare people
- Timing of introduction – wait until admission for transplant?
- How do we know when is the right time to introduce?
- Is there a negative impact of early contact
- Time consuming for CHIPS team

CYCLE 1 – ACT

- Weekly CHIPS ward round on BMT ward
- CHIPS presence in weekly MDT meeting
- Further staff +/- patient feedback to measure impact of change
- Leaflet created
 - Included in pre assessment pack
 - Electronic + paper copy
 - Feedback from parents

How does the CHIPS team work?

The CHIPS team meet every family whose child is coming for an assessment for Haematopoietic Stem Cell Transplant. This is so that we can support families during the HSCT process, this can be as much or as little as required. Our team's approach is 'integrated' because it brings together all the different teams and services available to provide the support your family needs. We make sure the care you receive is coordinated, continuous, and centred around the emotional, social, and practical aspects of your lives, as well as your child's medical needs. We are here to provide all-encompassing care in parallel with your child's treatment for as long as necessary.

Our job is to understand what makes a good day for you & your child, what we can do to have more good days, and what's really important as we think about the future.

Meet the Team

Doctors

Helen Aspin (Head of Service) Jane Boyle
Jo Davies Adam Bridges Lee Woodgate

Nurse Specialists

Rebecca Emma Jill

Other Professionals

Alicia Adams Michael Phoenix Katie Clinical Educator
Sara Psychologist Lizzy Psychologist Shobha Assistant Psychologist

Telephone Number:
0191 2826408
7 days a week, 9am - 5 pm

Support & information for children undertaking a Haematopoietic Stem Cell Transplant and their families

What is the role of the CHIPS team?

CHIPS is the Children's Holistic Integrated Palliative Care Service for the North East and North Cumbrian region. Our team provides specialist care and support to children and their families, living with complex health

Examples of support we can provide:

- Co-ordinating a multi-disciplinary team approach to looking after your child. Helping you to navigate the range of services available to you.
- Support with co-ordinating family experiences, 'wishes' and memory making activities for the whole family to enjoy, and help remember your time together.
- Supporting you to make an Advance Care Plan for your child.

Supporting you in making decisions and plans

Your child's wellbeing and your family's wishes are at the heart of all decisions and plans. 'Advance care planning' is like checking the weather forecast to prepare and be ready for any kind of conditions. It's a series of conversations with your healthcare team about what care and treatments are important to your family, especially if your

Summary

- Recognised need for integrated palliative care input for paediatric patients undergoing HSCT
- QI project aimed to improve the acceptability of early introduction of the palliative care team to patients referred for assessment for HSCT & their families
- Referrals to CHIPS increased significantly
- 22% of those referred had ongoing input from CHIPS
 - Those families recommended we meet every patient at the time of assessment, to make it easier to accept the help when they needed it
- More education required to 'normalise' palliative care

Additional feedback



- You listened to understand, it felt like you wanted to get to know all of us and understand the situation
- You acted, often very promptly, making progress on things such as allowing the use of compression stockings
- You were imaginative in your response, finding a way for me to be allowed to cook for Lexi and for her sister to be allowed into the room
- You were practical- getting Lexi a fan to help her breathe
- You were clear with us; you promised to tell me without prevarication anything that we needed to know, even if/ when it was hard- and you did so; that meant I could trust you very quickly
- You communicated with empathy, but that empathy didn't stop you saying what needed to be said - in fact I think you understand that clear communication is kindness in those situations.
- Your advice on capturing digital and physical memories in those last 48 hours has borne out; the hand cast, finger print necklace, handprint painting and voice memo from Lexi have all been a source of great comfort over the last ten months.



**North East and
North Cumbria**

**NEXT:
Suzanne Garbarino**

Eden Valley Hospice and Jigsaw, Cumbria's Children's Hospice

Providing care and support to people with life-limiting conditions
and their family, friends and carers.



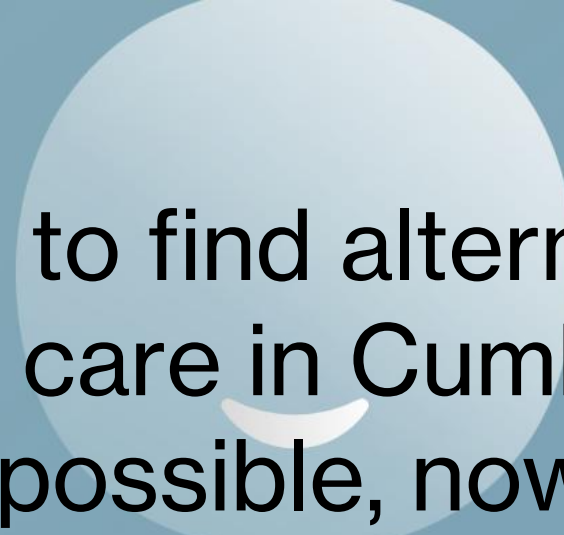
Registered charity no. 1008796



TRANSITION - TO WHAT? IT'S A WHOLE NEW SERVICE.

Children's Palliative Care	Adult Palliative Care
Focuses on infants, children and young people.	Focuses on adults, often older people.
Many conditions are rare, genetic or present from birth.	Most conditions are acquired later in life, such as cancer, heart failure, COPD or dementia.
Care may be provided over many years, sometimes from diagnosis through childhood into adulthood.	Care is often provided in the later stages of a progressive illness, although it can begin earlier.
Emphasises growth, development, play, education and family life.	Emphasises maintaining independence, comfort and personal goals.
Parents and families are usually central decision-makers and caregivers.	Patients are usually the primary decision-makers where they have capacity.
Services include support for siblings and the wider family.	Services focus primarily on the patient and their chosen support network.

THE ISSUES!



“Trying to find alternative respite care in Cumbria was impossible, nowhere was suitable to provide for my son’s complex care needs.”

WHY?



For those aged 25+ with complex medical conditions attending Jigsaw, Cumbria's Children's Hospice, but not nearing the end of their life, there was no respite alternative for young adults in our rural county.

One family who regularly attended Jigsaw found it particularly challenging to find the right care setting for her son, Josh, and support for her family - despite Josh meeting the criteria for CHC funding.

MEETING OUR YOUNG PEOPLE'S NEEDS...

We used a PDSA (Plan, Do, Study, Act) approach to figure out how we could support their needs.



Without funding from CHC, caring for this cohort was not going to be sustainable or feasible, as we cannot fundraise to support their needs.



We managed to secure CHC funding for Josh, which covered our staffing costs.

STAFFING AND ENVIRONMENT CHANGES...

new environment and
new staff.

Initially, the Jigsaw
team supported our
young people on the
adult unit,

while they were
introduced to a new
environment, it didn't
engage the adult team
in supporting care.

'ringfence' sessions so
the young people can
use the children's
hospice space in an
age-appropriate way.

engaged mixed staff
teams to work
together in each
other's environments,

LD nurse was at the
heart of the pilot.

CREATING A NEW SERVICE...

The service is now a true mix of children and adult support.

We now have 2 young people in our Young Adults with Complex Needs service

regular breaks each month 4 days/3nights

we staff, monitor, review and audit as a standalone pilot service.

We are challenging and developing our staff and ensuring the funding underpins roles.

BENEFITS TO YP AND FAMILIES

Trying to find alternative respite care for R in Cumbria was impossible, nowhere was suitable to provide for his complex care needs.

It was an extremely stressful time for us as a family and we searched for over 2 years to find alternative respite provision, to no avail.

Having jigsaw except R as part of the transition program was such a relief. It enabled us go to any social events or visit other siblings who live away.

This service changed our life as a family ,and enables is to charge our batteries. And do some of the things that would not otherwise be possible.

I don't know what I would do without jigsaw . And the worry about what would happen in an emergency has been lifted from our minds. knowing jigsaw could continue to provide complex nursing care to R .”

Collaborative working between
and and children's teams

Upskilling of staff

Sustainable funding model for
future

SATURDAY CLUB





NEXT STEPS

We have 32 Children on caseload.

7 are 16+ years

1 x 15 year

6 x 14 years

We are looking to develop this service further.

REFERENCES

Transition' describes the purposeful and planned process of supporting young people to move from children's to adults' services" National Institute for Health and Care Excellence (NICE). Transition from children's to adults' services for young people using health or social care services: NICE guideline [NG43]. 2016 Feb 24 [cited 2025 Apr 10] "The number of children and young people with life limiting conditions is increasing, and a growing number are living into adulthood" Fraser LK, Gibson-Smith D, Jarvis S, Norman P, Parslow RC. Estimating the current and future prevalence of life-limiting conditions in children in England. Palliat Med. 2021;35(9):1641-1651 <https://www.england.nhs.uk/midlands/wp-content/uploads/sites/46/2019/05/bridging-the-gap-between-children-adult-palliative-care.pdf> Noyes J, Pritchard A, Rees S, Hastings R, Jones K, Mason H, Hain R, Lidstone V. (2014) Bridging the Gap: Transition from Children's to Adult Palliative Care. Bangor University, United Kingdom.



**Tea and coffee break
Re-start at 14.40**

Education Programme Reach and Engagement

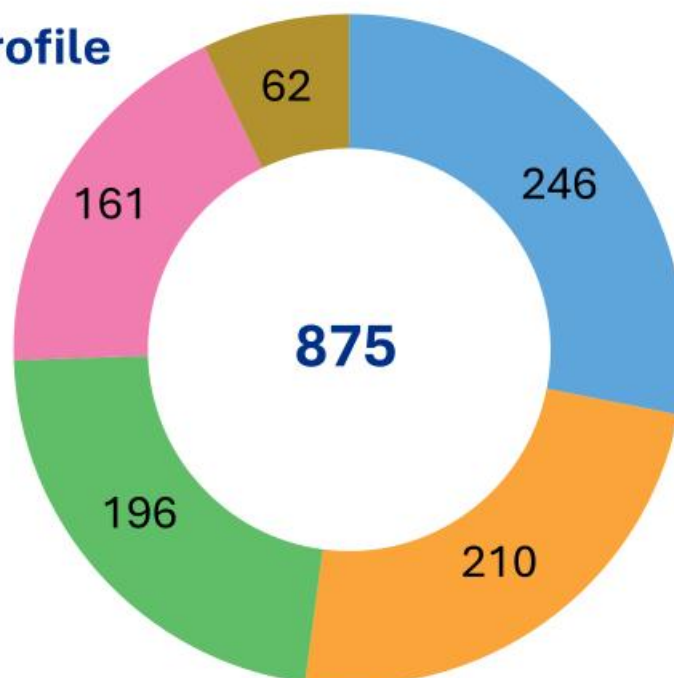
Board Dashboard Summary | Total Attendance: 875



St. Benedict's Hospice
& Centre for Specialist
Palliative Care



Attendance Profile



Breakdown

- Care Homes: **246** (28.1%)
- Recognising Dying: **210** (24.0%)
- Deciding Right: **196** (22.4%)
- Symptom Management: **161** (18.4%)
- Primary Care: **62** (7.1%)

Key Insights

- Care Homes delivered the largest reach (28%).
- Recognising Dying and Deciding Right comprise 46% of all attendance.
- Primary Care engagement remains low at 7%, creating opportunity for targeted growth.
- 875 attendances demonstrate strong system-wide education reach.

Recommended Action

Target Primary Care audiences while sustaining high-performing Care Home and End of Life Care programmes.



North East and
North Cumbria



South Tyneside and Sunderland
NHS Foundation Trust



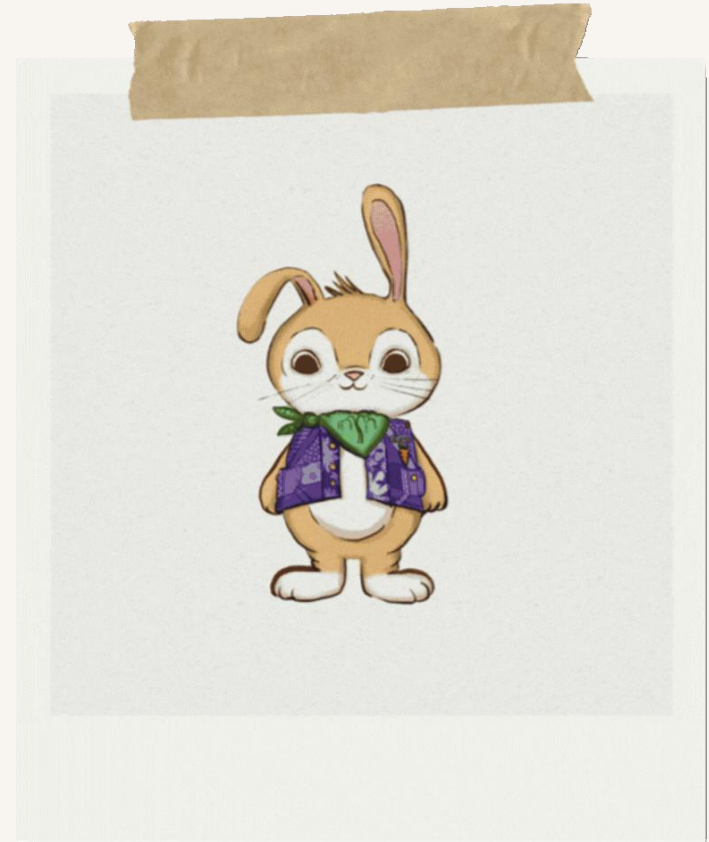
**North East and
North Cumbria**

**NEXT:
David Barker**



Will O'Burn

Mascot | Grief Advocate | Community Connector



Hello

David Barker MBE
Chief Executive
Willow Burn Hospice

✉ dbarker@willowburnhospice.org.uk

☎ 01207 529 224

www.willowburnhospice.org.uk



Will O'Burn

- Willow Burn Hospice Mascot - joined the team on 14 February 2025.
- Designed by illustrator Helen Turner in memory of her mum who died at Willow Burn Hospice.
- Introduced to break down barriers for children and young people when visiting the hospice with a loved one, joining us as a member of the community or when accessing bereavement counselling.
- To support children and young people, helping them to feel more confident in talking about death, dying and bereavement, and helping to ensure that no child feels alone during the most difficult of times.



The Need

- 1 in every 29 school-age children (roughly one child in every average classroom) has experienced the death of a parent or sibling (Children Bereavement Network)
- Reduced services in County Durham for children's bereavement
- Increased referrals to Willow Burn Hospice for counselling.
- Willow Burn is a community hub, increasing numbers of young visitors to the hospice



Strategic Priorities

- **Community Engagement**
 - Compassionate Willow Burn
 - Community Partnerships
 - Raise Public Profile



Book Character



Friend



Memory Keeper



Fundraiser



Grief Advocate



Community Connector



Impact So Far

- Through school visits and community events, Will has opened up conversations about kindness, remembrance and caring for others. This has supported service delivery by encouraging earlier engagement with families and helping children better understand the role of the hospice, while also shaping a more child-friendly environment.
- Will wears a Jacket of Memories, which provides a tangible way for families to remember loved ones. Anyone is welcome to send a piece of clothing or meaningful fabric to the hospice and it is sewn into Will's jacket so that their legacy lives on in every appearance.

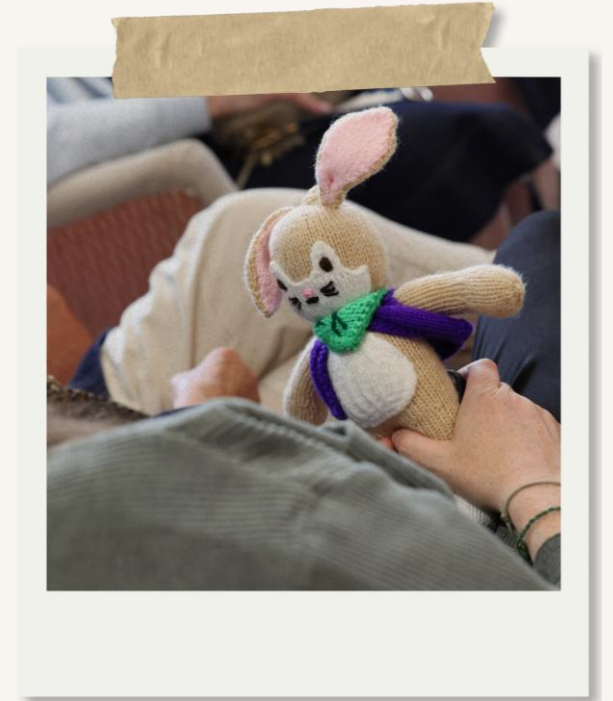


Impact contd

Children who are counselled at the hospice, can now take home a mini-Will and have reported that they talk to him and share their feelings because they have someone at home now that really listens. This helps provides reassurance and informs future counselling sessions.

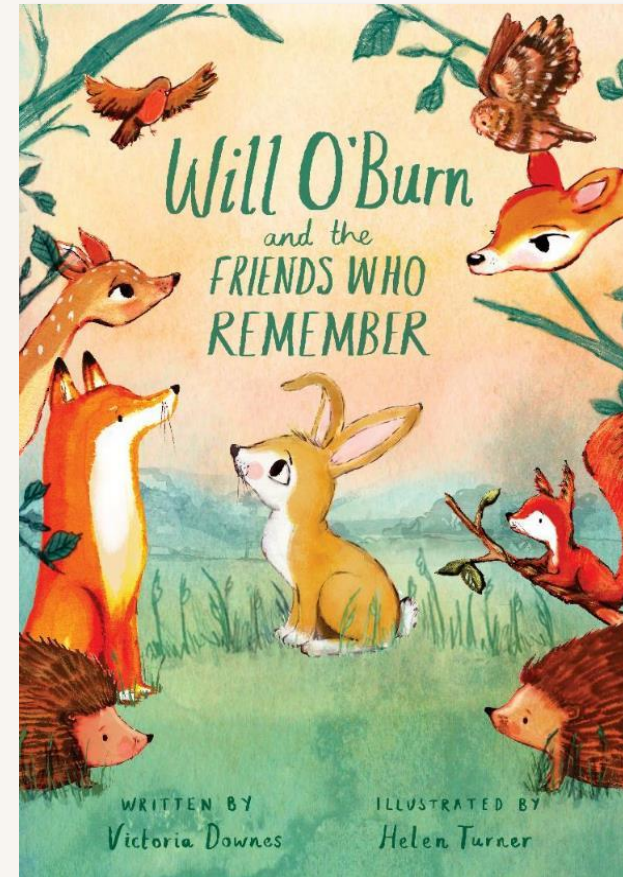
Will has worked with local author, Victoria Downes and, illustrator, Helen Turner to publish a children's book.

Will O'Burn and the Friends Who Remember. The book is set in the hospice gardens and follows Will as he learns about how his animal friends deal differently with the grief of losing someone they love.



Will O'Burn and the Friends Who Remember

- We recognised that we couldn't reach every child who needs support across County Durham and that the hospice couldn't counsel them all.
- The book has been designed as a resource to help children and families navigate difficult emotions in a gentle and meaningful way, whether they are experiencing loss themselves or supporting someone close to them.





<https://youtu.be/4yhqypw8TEg?si=KMstYGWWhlwAdkO3X&t=193>

“I can remember adults saying I was too young to understand, but I knew he was gone and I was heart broken, friends didn’t understand or know what to say, and they found it easier to just not talk about him.

Obviously 50 years ago there was nothing like this and no such thing as counselling,
No one thought of things like places to remember or anything like that,

It’s very educational around grief and beautifully written.”



Get Copies For Your Service

- Available from Willow Burn Hospice, in our shops and our website.
- RRP £8.99
- £7 per copy for all of the services represented in this room.

Order copies at the discounted rate from:

Rachel Quince

rquince@willowburnhospice.org.uk



Thank You
Any Questions?





**North East and
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**NEXT:
Hannah Billett**

Holistic needs of patients with ovarian cancer (at the NCCC)

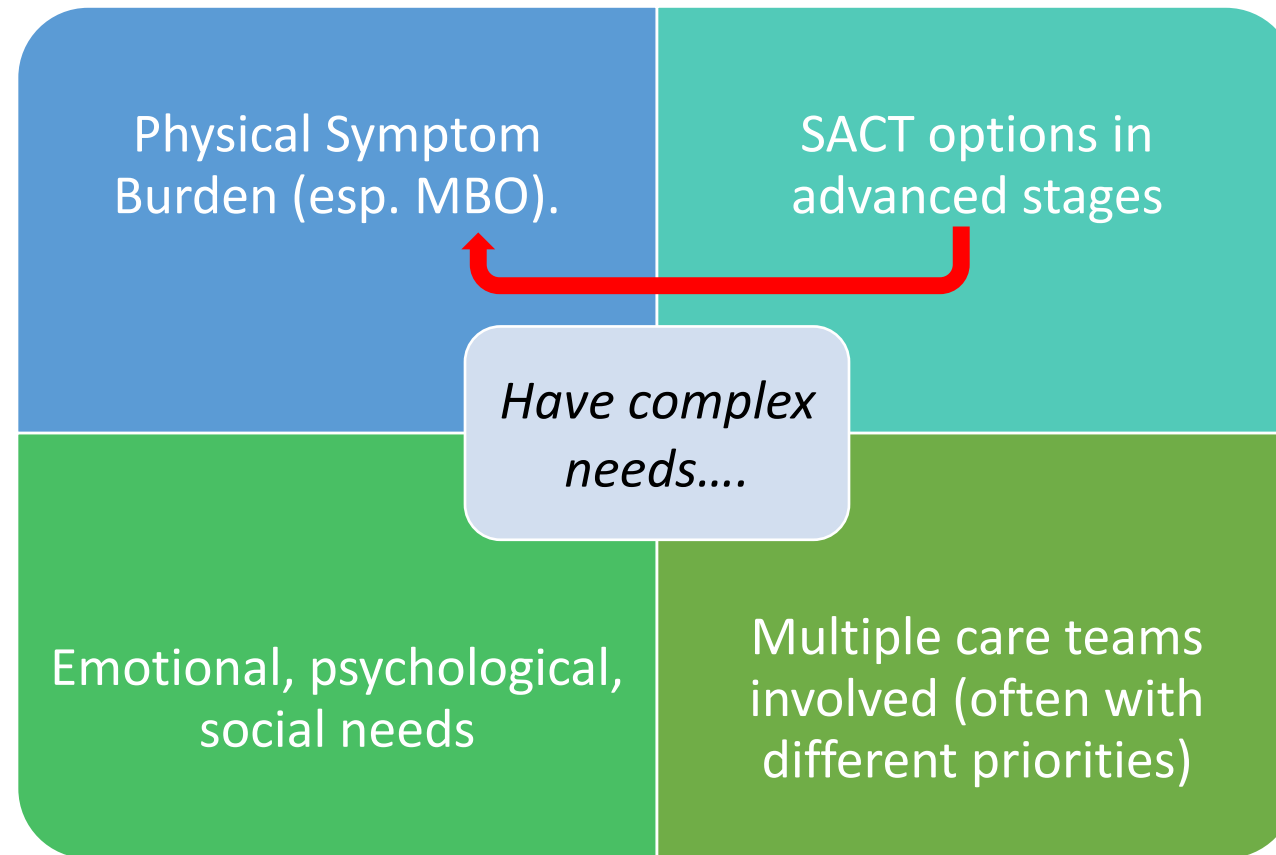
Dr Hannah Billett
Consultant in Palliative Medicine
Norther Centre for Cancer Care



Why this group/this project

- A group we commonly have on our caseload at the NCCC
- Have complex needs
- Often receiving care far away from home
- Often in for prolonged periods
- As a team who wanted to be understand the experience of these patients with a focus on how we can improve the care we provide
- Also wanting to consider how we work alongside oncology colleagues for the care of these patients





Background

- Survival rates in patient with recurrent ovarian cancer who receive palliative chemotherapy varies
- MBO + Recurrent ovarian cancer + no surgical options – often have poorest outcomes
 - BSC alone overall survival 2-5 months (Caparica et.al)
 - Palliative chemotherapy aims to shrink tumor and restore intestinal function
 - Concerns about efficacy and safety (data lacking)
- Patient centered approach key
- Decision about treatments need to be made in a case-by-case basis
- Patients need to be involved in this decision making

Caparica R, Amorim L, Amaral P, Uratani L, Muniz D, Hendlisz A, de Azambuja E, Glasberg J, Takahashi TK, Filho EA, Canellas R, Saragiotto D, Sabbaga J, Mak M. Malignant bowel obstruction: effectiveness and safety of systemic chemotherapy. BMJ Support Palliat Care. 2020 Dec 17;bmjspcare-2020-002656. doi: 10.1136/bmjspcare-2020-002656. Epub ahead of print. PMID: 33334819.



Palliative care perspective

- *Are oncology colleagues overly optimistic with outcomes?*
- *Can meaningful QOL be achieved while having palliative chemo for MBO?*
- *Is enough parallel planning being done in this group?*
- *Concern that outcome measure of 'survival' does not tell the full picture (QOL in this time)*



Who included?

- Inpatients at the NCCC with Ovarian cancer receiving **inpatient palliative chemotherapy**
- 6 month period at the start of 2025

Method

- Retrospective case note review, chemocare (IP Chemo with palliative intent)
- 6 month period at the start of 2025
- Data related to interventions, PCS input, ACP, outcomes

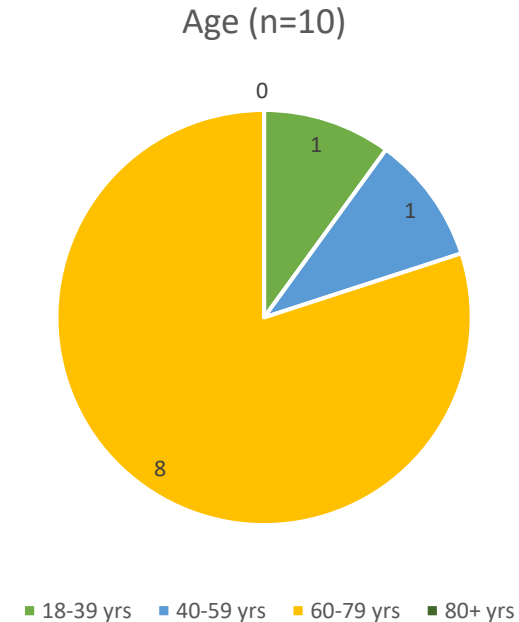


Results

10 Patients met inclusion criteria

Cancer Type	N = 10
Ovary- High Grade Serous Carcinoma	8
Ovary- Clear Cell Carcinoma	1
Ovary- Carcinosarcoma	1

- All patients had MBO
- 3 patients were chemo naïve
- 9 had TPN
- Other interventions
(ryles tube, abx, ascites drainage, surgical intervention, RIG, venting gastrostomy)



Results: Outcomes

- Cycles completed ranged from 1 cycle to 6 cycles
- 4 Patients (40%) received a single cycle only
 - Outcomes following this varied (d/c home, stayed in hospital)
- Measuring effectiveness of chemo was out with the scope of this service evaluation
- At time of initial data analysis (Oct 25) **8 patients had died**

- Average length of survival from starting palliative chemo 56 days
- Average length of survival from stopping palliative chemo 29 days

But did the chemo change the survival???



Healthcare at its best
with people at our heart

Results: Outcomes

	Mortality from first day of chemo this regime (n=8)	Mortality from last date of chemo (n=8)
Died within 7 days	n=0 (0%)	n=1 (12.5%)
Died within 14 days	n=1 (12.5%)	n=3 (37.5%)
Died within 21 days	n=2 (25%)	n=4 (50%)
Died within 28 days	n=3 (37.5%)	n=5 (62.5%)
Died within 60 days	n=4 (50%)	n=6 (75%)
Died within 90 days	n=6 (75%)	n=8 (100%)
Died within 120 days	n=8 (100%)	n = 8 (100%)

Update at time of presenting.....

90% of participants had died
= 10% survival at 1 yr for patients receiving IP Palliative Chemotherapy at NCCC for recurrent Ovarian Cancer



Results – Outcomes

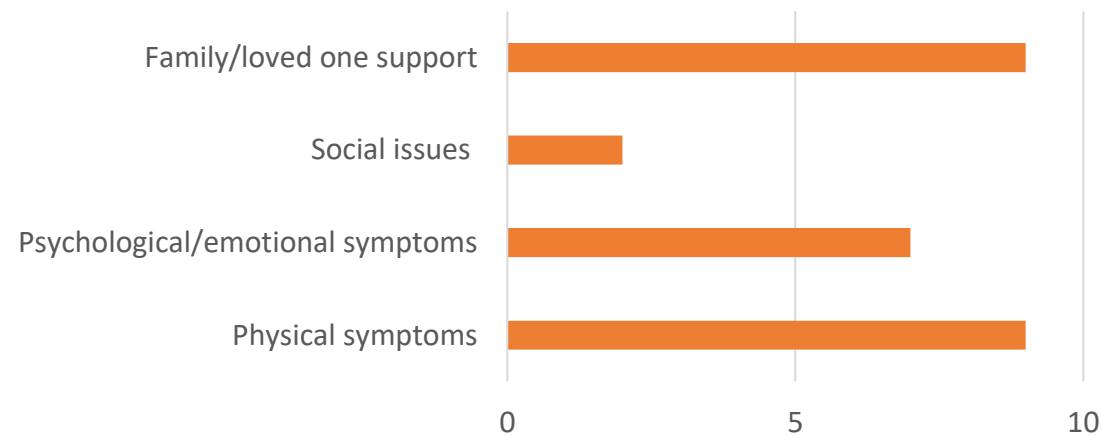
- 2 patient were still alive at time of initial data analysis (Oct 25)...
- **Patient 9.5, admitted for conservative management of SBO** (gastrograffin, bowel rest, dexamethasone).
 - Example of good TEP (DNACPR) in place and bespoke management plan which included continuing chemotherapy (completed Aug 25)
 - Remains on Letrozole. Never known to PCS. Recent surgical intervention for BO.
- **Patient 15.8, Admission Jan 25 for management of ‘malignant stricture and reactive gastropathy’**
 - biopsy proven and likley drug induced. Managed conservatively with TPN and antiemetics. PCS input for nausea (seen 14 times over 29 day admission).
 - Chemo stopped Oct 25 – for BSC, GNCR 18/1 says pt deceased



Results – Symptoms and PCS input

- 9 patient had been referred to PCS
- Primary referral reason: pain, nausea or both

PCS Support (n=9)



	This group	NCCC caseload*	PCS caseload*
Av. duration on caseload	27 days	10 days	8 days
Av. Number of PCS contacts	17 contacts	6 contacts	5 contacts

*(Taken for NUTH PCS annual report 24/25)



Results – Treatment Escalation Planning

7 (70%) patients had DNACPR in place (during NUTH IP stay)

4 lead by Oncology consultant

1 each lead by Oncology Registrar, Other reg , PC Consultant



Results – PPC/PPD

- 5 patients (n=10, 50%) had PPC/PPD discussions documented

Of the patients who has died at time of data analysis...(n=8)

- **N=2 (25%)** achieved PPD (1 x home for 1 day, 1 x hospice for 1 month)
- **N=3 (37.5%)** had a PPD identified but not achieved
 - Hospice but unsure if care needs could not be meet + rapid deterioration
 - STGH but decline too rapid to facilitate transfer
 - Carlisle NH but decline too rapid to facilitate transfer
- Those who did not
 - ‘Too early’ or discussions not felt to be appropriate at that time

Dilemma : Discussions PPC/PPD ‘too early’ but ‘rapid decline’



Confidence

Concerns about **getting it wrong** (topic nature, past experience)

Won't/don't have discussions (focus on treatment, lack of skill?)

Cancer Language/ Expertise

HCP need **to be seen to be 'fighting cancer'** for patients

Want to focus on immediate issues and new lines of treatment

Oncologist/Patient **close relationships**, sense of '**patient ownership**', valued by people with cancer.

'Toxic' Optimism

Overestimate prognosis in those who have acute admission.

Tend **not to share prognostic information** even if they 'know' it's unlikely to go well (to pts and HCP)

Conversation Timing/ Triggers

Have responsibility to have FCP discussions at acute admission

Do it **when appropriate**
Triggers: DP on scans, lack of further treatment lines



Conclusions

- High mortality and short survival (in most cases)
- Some exceptions – why decisions around pall chemo for this group needs to be carefully considered on individual basis
- High stakes (high risk but ?high reward in relation to survival, but at what cost (poor QOL, in hospital, intervention dependant)

- Project results shared with gynae-oncology team + more widely in the region
 - Weekly catch up for this IP group (Onc, PCS, AHP)
 - ? Role for patient-reported outcome measures to better capture priorities
 - ? Use of patient developed supportive written information

Goals for this work ongoing:

Better integrate early holistic support and advance care planning

- 'hoping for the best, planning for the worse'
- Standardising FCP discussions for this group of patients
- ?who takes the lead on this....shared collaborative approach



Thank You

Any Questions?

hannah.billett@nhs.net



Healthcare at its best
with people at our heart



**North East and
North Cumbria**

**NEXT:
Sara Heary**

CHIPS Team: Looking after ourselves in our work

Dr Sara Heary, Clinical Psychologist

Dr Linzi Smeaton, Clinical Psychologist
and Family & Systemic Psychotherapist



Our plan for the next 20 minutes.....

- Why it is important to look after ourselves in this work?
- Share the staff support which we offer in the CHIPS team.
- Highlight some feedback from the team.
- Ensure everyone is aware of where they can access further support.



The cost to caring

- There is a cost to caring. We professionals who are paid to listen to the stories of fear, pain, and suffering of others may feel, ourselves, similar fear, pain and suffering because we care.

Charles R. Figley, Ph.D.



The cost to caring

- Whilst stress is a common and normal response to feeling threatened or under pressure, that can help us be motivated to achieve and meet the demands of daily life, chronic stress can lead to burnout
- We know that chronic stress and burnout are particularly common in health professionals
 - Research shows that NHS staff are 50% more likely to experience chronic stress - a known contributing factor to burnout
 - Burnout is a feeling of physical, mental and emotional exhaustion (NHS, Every Mind Matters)
 - Factors such as staff shortages, high workload, and pressures to maintain high quality patient care all contribute to burnout in NHS staff (NHS employers.org)





- Burnout
- Compassion fatigue
- Grief
- Trauma
- Moral injury/distress

CHIPS Psychology priorities

- Psychology staff joined the team in July 2025, and a key need identified was access to 1:1 psychological support for staff members.
- This aligns with national guidance, which states that paediatric care services should ensure psychological support for healthcare professionals (NHS England, 2023).
- NICE (2016) includes recommendations for professionals to talk about their thoughts and feelings with colleagues when a young person or child is approaching end of life or has died.

How heavy is a glass on water?



Reflective spaces – putting the glass down?

- ‘a form of in-depth thinking about work activity with the aim of developing as a practitioner’ (Kurtz, 2020, p. 3)
- A way of trying to make sense of the uncertainty in our workplaces and the courage to work competently and ethically at the edge of order and chaos...””(Ghaye, 2000, p.7)
- Rees (2013) interviews
 - Reflective practice can be effective in ‘dispersing the emotional load created by caring work’ (p. 51)
 - It can enable a making sense of ‘the personal emotional challenges...encountered in practice, to acknowledge the emotional labour of nursing, and establish for themselves, how engaged or human they wanted to be in it’ (p. 51)

CHIPS team reflective spaces

- There are many different models of reflective practice, we draw on multiple models but usually has the following structure and aims:
- 1 hour long
- Attendance is voluntary
- Confidential space
- Usually 2 people facilitating, sometimes 1
- A focus on exploring emotions and making sense of experiences
- An aim of fostering resilience through sharing thoughts and feelings about a patient death or a distressing event at work
- It is NOT group therapy or clinical supervision
- The focus is NOT problem solving or lessons learnt

Reflecting team “Ping Pong”

- Based on family therapy ideas (Andersen, 1995).
- During the main part of the session we positioned ourselves as part of the group but took a listening position.
- Then move to sit separately from the team for a “reflecting team” conversation.
- Come back together as a whole group to reflect on the session.



Feedback from team

“Space to reflect on impact of working within complex systems, teams and families”

“Their presence simply encourages conversation Ping Pong is SO insightful”

“Useful emotional safe space as per normal with psychology. We always value these sessions ideas for future also helpful”

“You are so insightful and clever in your use of questions to facilitate discussion in the team. I appreciate how asking about how we deal with challenges moved the conversation onto a more positive and constructive tone”

One to one reflective spaces

- 1 hour long
- Attendance is voluntary
- Once every 2 months (flexible to needs)
- Confidential space
- Usually 2 people facilitating, sometimes 1
- An aim of offering a confidential space to talk about the emotional impact of your work
- It is NOT therapy

Feedback from CHIPS team

Psychological Safe Space

Participants found the reflective spaces provided a psychologically safe and confidential environment to discuss professional and personal challenges that allowed for reflective thinking and perspective taking. It was seen as a highly efficient approach providing significant personal and professional benefits relative to the time required.

Culture and Flexibility

Having reflective spaces as a normalised part of the team culture made staff feel comfortable attending without judgement. Staff noted the importance of having embedded psychologists in the team who can offer flexible support as needed by the team within a busy workplace. Being able to cancel or rearrange sessions was also appreciated.

Impact on wellbeing

The sessions have been helpful for emotional processing and allowing staff to make sense of complex or distressing experiences. This positively contributed to management of personal and professional boundaries.

Feedback continued

"Space to talk about things I wouldn't necessarily wish to discuss with the rest of the team."

"Good way to prioritise thinking about home and work boundaries when 2 worlds collide and help make sense and give perspective on difficult situations."

"I find them very supportive and useful for my wellbeing."

"We are very fortunate to have the opportunity to have 1:1 reflective time with our psychologists, and it is so valuable given the intensity of the work we do."

Limitations

- The evaluation is based in a small sample of respondents ($n = 6$) which limits the generalisability of the findings.
- Feedback was collected through voluntary responses which means there is a chance of self-selection bias, as those with positive experiences may be more likely to participate in the study.
- Not all staff take part.

Signposting

- <https://northeastnorthcumbria.nhs.uk/here-to-help-you/health-advice-and-support/staff-wellbeing-hub/>
- <https://checkwellbeing.leadershipacademy.nhs.uk/>
- <https://www.nhs.uk/every-mind-matters/>
- Individual Trusts occupational health or other wellbeing offers
- PNA's

Our favourite quote.....

“If staff can’t be supported to look after themselves, they’re going to fall apart. And if staff fall apart, the families will fall apart too.”

References

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Rees, K. (2013). The role of reflective practices in enabling final year nursing students to respond to the distressing emotional challenges of nursing work. *Nurse Education in Practice*, 13 48-52



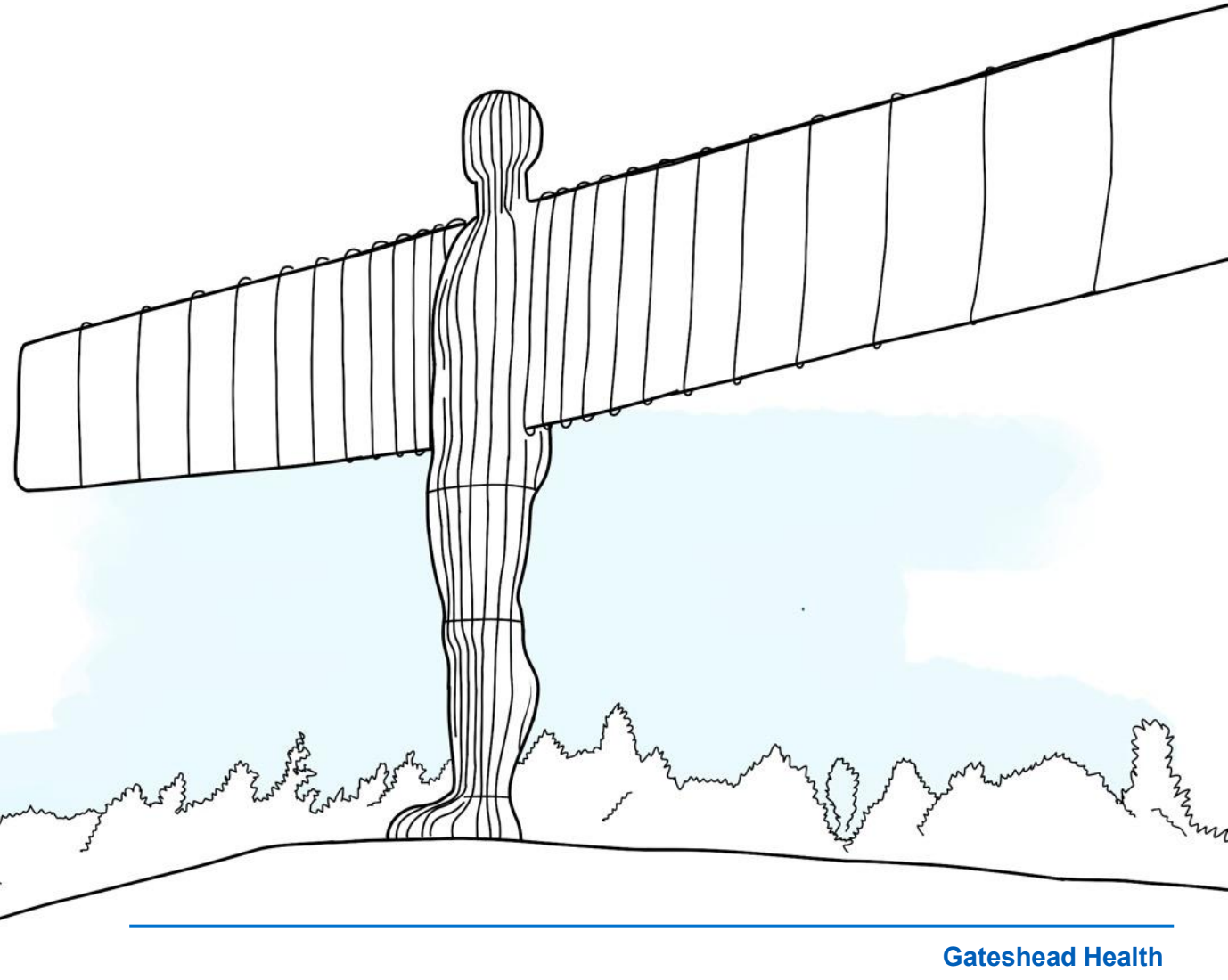
**North East and
North Cumbria**

**NEXT:
Catherine Pye**

Transitioning from Children's to Adult Services in Gateshead

Catherine Pye, Community Children's Nursing Team

15th September 2026 NENC Palliative and End of Life Care Event



Background and Initial Development

Historically, as a team, we have had relatively few children reach the age of transition to adult services. Thankfully, advances in medical interventions and improvements in the quality of care mean that more children with life-limiting conditions are now living well into adulthood. This has highlighted the need for a more structured and proactive approach to transition planning.

The transition from paediatric to adult services is a complex process that requires effective coordination across health, education and social care. Without a coordinated and well-planned approach, there is a significant risk of gaps in care, which can negatively impact the patient's health, wellbeing and overall experience. A lack of clear planning can also leave professionals uncertain about the transition process, including their roles and responsibilities.

“The transition of life-limited children to adult services is currently a gap described as ‘a cliff edge’ for young people” **(Together for Short Lives, 2026)**

Continued...

We identified a gap in service provision and coordinated an initial fact-finding meeting with the regional *Children's Holistic Integrated Palliative Care Service* (CHIPS) to explore current services and identify areas of need.

During the meeting we identified a patient who was approaching transition age.

We made contact with his Mam and explained that there was currently a gap in the service. We discussed the possibility of involving an expert parent, whose lived experience could help us to develop and shape a transition plan around her child's individual needs.

Thankfully, his Mam was happy to be involved. Her lived experience as a parent has been invaluable throughout the transition journey.

Meet Callum



Callum was born at 24 weeks gestation and, as a result, has Cerebral Palsy that affects all four limbs. He is ventilated 24 hours a day via a tracheostomy tube and requires a gastrostomy button for nutrition.

Callum live at home with his Mam, Sharon, and little brother, Charlie.

Like most 17 year olds he thinks he's the boss and has his Mam at his beck and call. He lights up every room with his beautiful smile. He has a wicked sense of humour; he is mischievous, loving, and communicates with his perfect fluttery eyelashes and great facial expressions.

He has had quite the journey so far and has shown everyone that he is a determined, resilient young man who lives life to the full.

Callum is loved by everyone he meets.

Supporting Callum's Transition from Children's to Adult Services

- An initial transition planning meeting was held at St Oswald's Hospice during one of Callum's respite stays, bringing together Sharon and the multidisciplinary professionals involved in his care.
- The discussion was centred on Callum's individual needs, personal aspirations, and goals for adulthood. Sharon's expertise as Callum's parent provided the foundation for the conversation, ensuring that Callum's voice, preferences, and priorities remained at the heart of all planning and decision-making.
- The meeting identified the adult services that would provide continuity of support, alongside new services that would become involved as part of Callum's transition to adult care.
- This early engagement created a safe and supportive environment for Sharon to share her concerns, explore potential challenges, and begin developing confidence in the transition process.

Understanding Family/Child Priorities

- Where would Callum go if he became unwell? Sharon was frightened about moving away from the specialist consultants who know Callum and his needs so well.
- Would it be safe for Callum to attend an A&E department that he had never been to before?
- Who would provide and manage Callum's medical equipment?
- Who would the new professionals involved in Callum's care be?
- Would Sharon continue to be listened to and involved in decisions, particularly as her legal parental responsibility would look different when Callum turns 18?
- Where would Callum receive end-of-life care if this became necessary?

Responding to Family/Child Priorities

- CHIPS liaised with Callum's local A&E and ITU department
- Paediatric and adult services worked collaboratively and planned transition home visits, inline with NICE guidelines
- Reassurance provided around respite transition. Callum will remain at St Oswald's for respite until he is 25 years old.
- The team supporting the transition discussed and guided Mam through The Mental Capacity Act
- Multiple and ongoing meetings, with Callum and his families concerns at the centre
- Provide Mam with a list of professionals involved and how to contact them.
- Services have agreed that Callum will attend St Oswald's Hospice for end of life care if required.

Embedding a sustainable transition process

Develop and implement a structured CCNT transition pathway, co-produced with key stakeholders including Children's Bladder and Bowel Services, Locality Teams, and the Rapid Response Nursing Team, to ensure a coordinated approach to transition.

Support the education, training, and professional development of staff involved in the transition process, promoting confidence and consistency across services.

Continue to strengthen collaborative working relationships between paediatric and adult services to facilitate seamless transitions and improve continuity of care.

Embed an early transition planning approach, commencing from 14 years of age where appropriate, and guided by the individual needs, preferences, and aspirations of the young person and their family.

Develop a personalised Transition Passport to provide a comprehensive and portable record of the young person's needs, preferences, and care requirements, supporting continuity throughout their transition journey.

Questions?



**North East and
North Cumbria**

**Thank you for joining us today at the
PEOLC Celebratory Event**

Safe journey home!