

# COFFEE AND CHAT:

**A Good Death: supporting life limited children, their family, and friends.**



# Aims today

- Hear from colleagues working with life limited CYP and their families
- Build knowledge and confidence
- Nurture new relationships with each other
- Chance to think about our collective role in supporting life limited children, their families, and friends.

# Our time together today

Why are we here?	<b>Nicky Wood</b> Transformation Lead Women and Children's Commissioning, Surrey Heartlands
Surrey context Child death reviews	<b>Clare Kemp</b> Specialist Nurse Child Death Reviews, Surrey Heartlands
Caring for families at Shooting Star	<b>Tracie Lewin – Taylor</b> Nurse Consultant Paediatric Palliative Care Shooting Star
Helping families of seriously ill children keep moving forward	<b>Vanessa Riding</b> Bereavement Manager Momentum Children's Charity
Break out rooms	All
Reflections back together	All



# Break out hosts

Zoe Pizzie, Director at Jigsaw Southeast.



Helen Alderson, Clinical Service Manager  
Children's Community Nursing Service.



Sarah Nash and Yolandi Johnson, Assistant Heads  
Pond Meadow School, Guildford.



# Nicky Wood

Transformation Lead  
Women and Children's  
Commissioning  
Surrey Heartlands  
Integrated Care System



## Our children, young people and families speak of the need for support in life, to enable a good death.

Each person in the family is an individual and that they all have differing experiences and needs.

Today we want to raise awareness of the needs of our life limited children and young people and their families, and the support is available. Enabling compassionate practice and holistic care in life and death.

### Spud's Story

Humairaa, affectionately known as Spud and her family were introduced to Shooting Star Children's Hospices in 2005. Tamaana her sister says "Spud's needs are very complex, she's on a ventilator, she's got diabetes and epilepsy and, due to the cerebral palsy, she's immobile and unable to talk, but she has the biggest character – anyone who knows her will tell you that,"

"Her care is 24 hours a day, including night-time feeds and having to turn her every two hours as she can't turn on her own. Thankfully we have got nurses that come in sometimes, but obviously the other times it's mum and I sharing it."

"Shooting Star Children's Hospices helped us – not only by looking after Spud, so we could have time with mum.... a lot of the time people ask how the parents are, but people don't imagine how it impacts siblings."

"I feel I had 15 mothers at the hospice – it's the simple things that make it the best, just being a friend, like a family member, being a shoulder cry on – that's the greatest gift that Shooting Star Children's Hospices has ever given us. Having someone on our side."



Questions?



# Clare Kemp

Specialist Nurse  
Child Death  
Reviews, Surrey  
Heartlands



## Surrey Context Child Death Reviews





## Child Death Review (CDR) Child Death Overview Panel (CDOP)

**Jamie Carter** (Wed)- Designated Dr for Child Death Reviews

**Noreen Gurner-Smith** (Thurs-Fri)

Designated Nurse for Child Death Reviews

**Suzanne Huddy**

Named Nurse for Child Death Reviews & Health Lead for ICB Joint Agency Response

**Natalie Price, Anna Chai & Clare Kemp**

Specialist Nurses for Child Death Review

**Nicola Mundy**

Child Well-being Professional & Lead for Learning from Child Deaths

**Emily Welch / Anna Miles**

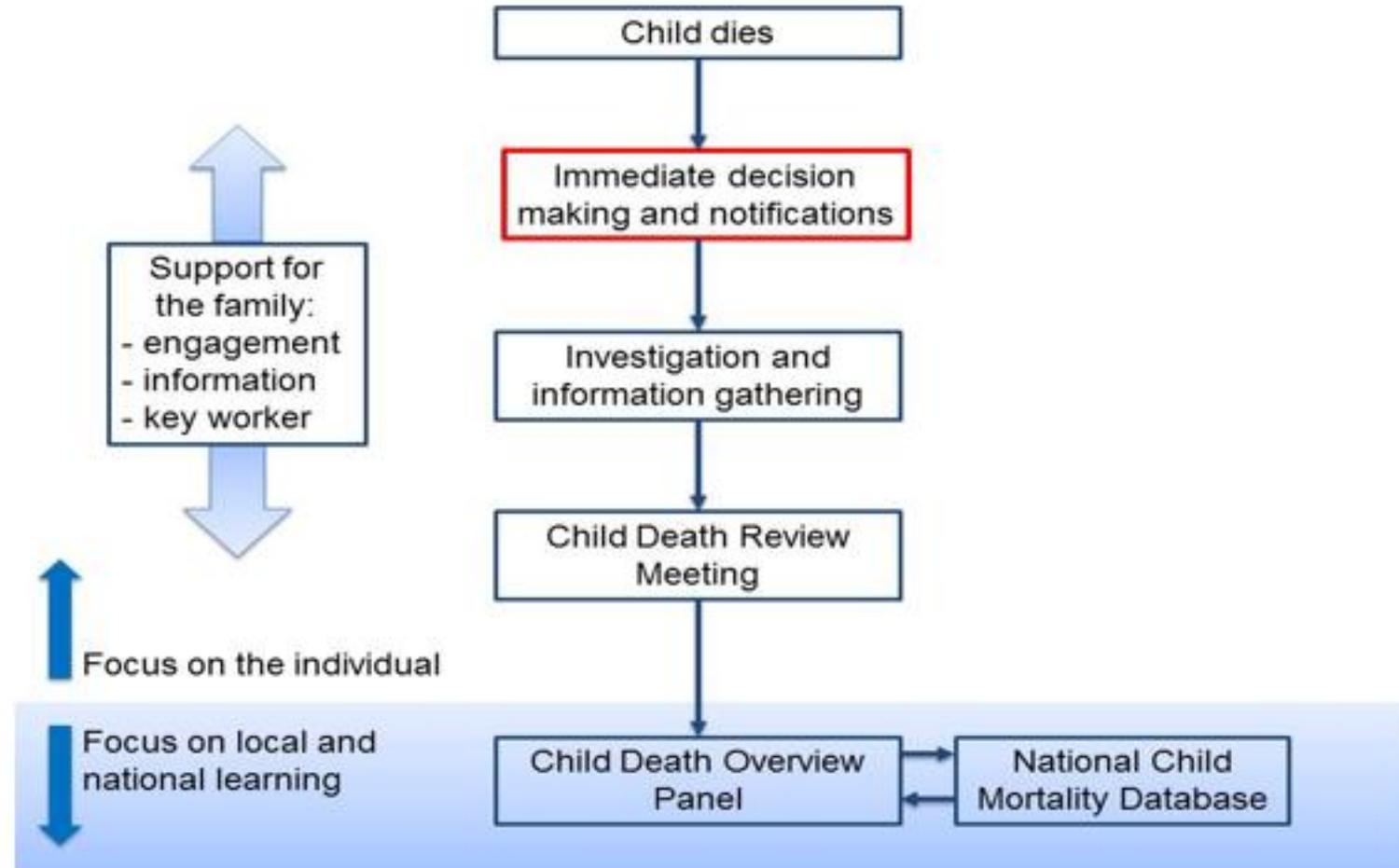
CDOP Co-Ordinator





- Since 1 April 2008 Local Safeguarding Children Boards have been required to review the deaths of all children in their area.
- The purpose of the Child Death Review process is to collect and analyse information about the death of each child who normally resides in Surrey with a view to identifying any matters of concern affecting the health, safety, or welfare of children, or any wider public health concerns.
- The overall purpose of the Child Death Review process is to understand why children die and put in place interventions to protect other children and prevent future deaths







## What we do

- **Complete the Child Death Review (CDR)**
  - Joint Agency Response
  - Joint Home Visit
  - Information Sharing and Safety Planning Meeting / Phase 1
  - Report for Pathologist, Coroner and Police Investigation
- **Child Death Review Meeting**
  - Voice of the family
  - Feedback
- **Child Death Overview Panel (CDOP)**
  - Liaise between services





## What we do

- **Support the family** (7 days a week)
  - Child Death Review Process
  - Act as the statutory ‘Key Worker’
  - Local Child Safeguarding Practice Review
  - Inquest





## E CDOP Forms A and B

- Notification of Child Death Form A (required within 24 hours of death)
  - Direct link with NCMD for National monitoring
  - Demographic information
  - Parents phone number
  - Basic overview of what happened
  - Suspected cause of death (Can MCCD be issued?)
- 
- Reporting Form B
  - Nominated person and agency completing form (Hospital Safeguarding Team)
  - Involvement with the family/service provision
  - Background information of family – medical info, safeguarding, birth, social factors
  - Full demographic – siblings, other significant family
  - Home environment
  - Parenting capacity
  - Unusual or concerning observations





## Learning and Thematic Reviews

### Key Points

Between 1st April 2018 and 31st March 2022, Surrey Child Death Review Partnership were notified of 323 deaths, of which 233 were neonates or children who would normally be resident in Surrey, this compares with 299 deaths of which 219 were children who were resident in Surrey during the previous four-year period.



### [Child Deaths - Surrey Safeguarding Children Partnership](#)

In Surrey the Child Death Review Partnership have produced thematic reviews on our leading causes of neonatal and child death. It is important that the 'opportunities not to be missed' identified in these reports are embedded into systems and practice within Surrey.

[Child-Death-Review-Partnership-Neurodisability-Thematic-Review.pdf](#)





## Modifiable factors

- Smoking is the single most important modifiable risk factor in pregnancy. Smoking is associated with a range of poor pregnancy outcomes including miscarriage, stillbirth, premature birth, neonatal complications, low birth weight and sudden unexpected death in infancy.





## Impact of deprivation on child death

- Of the children who died, the death rate of those children living in 'the most deprived or next most deprived quintiles' (the poorest 40% in Surrey) is double that of the death rate of those who were living in least deprived quintile (the wealthiest 20% in Surrey).
- The data shows that over an 8-year period there is a statistically significant difference between the rate of child deaths in Woking and the rate of child deaths in Elmbridge. There is also a statistically significant difference over a 4-year period between the average Surrey child death rate and the rate for Woking, which is statistically significantly higher.





## Impact of ethnicity on child death

- The data follows the pattern of the last 4-year report, where the recording of ethnicity of children suggests that the pattern of deaths does not match the ethnic distribution within the live Surrey population.
- Twelve percent of infant deaths in England could be avoided if all infants in England had the same risk of death as White infants. In an English data report the National Child Mortality Database found that deprivation was not associated with the overall patterns seen.





**For more information:**

Please email me at: [clare.kemp6@nhs.net](mailto:clare.kemp6@nhs.net)



Questions?



# Tracie Lewin- Taylor

Nurse Consultant  
Pediatric  
Palliative Care –  
DipHE, BSc  
(Hons), MSc, Non  
Medical  
Prescriber



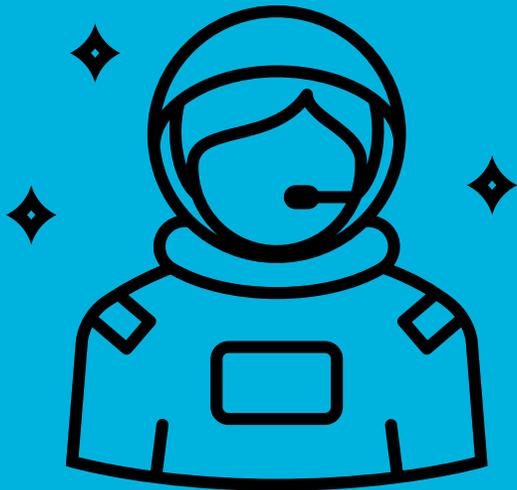
## Paediatric Palliative Care:

Supporting children and their  
families through life



# Shooting Star Children's Hospices

## Paediatric Palliative Care



**Shooting Star**  
Children's Hospices

# Background

- There continues to be a rise in the number of children with life-limiting and life-threatening illnesses in England and it is predicted that this will continue to increase (Fraser et al 2021)
- This growth demonstrates the need for palliative care teams to work with service providers to strive for the best possible care delivery to this complex patient group
- The World Health Organization (WHO 2012) highlights a difference in the delivery of palliative care services between that of adults and children suggesting that paediatric palliative care should begin once a child has been given a life limiting or threatening diagnosis, irrespective of whether treatment is received or not
- This care can span over a long period of time. With improved healthcare and technology, services are seeing children that would have previously died, have repeated admissions and present complexity to care delivery

# What can the hospice provide?



# Categories

<b>Category 1</b>	<p><b>Life-threatening conditions for which curative treatment may be feasible but can fail.</b></p> <p>Access to palliative care services may be necessary when treatment fails or during an acute crisis, irrespective of the duration of threat to life. On reaching long-term remission or following successful curative treatment there is no longer a need for palliative care services.</p> <p><i>Examples: cancer, irreversible organ failures of heart, liver, kidney.</i></p>
<b>Category 2</b>	<p><b>Conditions where premature death is inevitable.</b></p> <p>There may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities.</p> <p><i>Examples: cystic fibrosis, Duchenne muscular dystrophy. Spinal muscular atrophy</i></p>
<b>Category 3</b>	<p><b>Progressive conditions without curative treatment options.</b></p> <p>Treatment is exclusively palliative and may commonly extend over many years.</p> <p><i>Examples: Batten disease, mucopolysaccharidoses.</i></p>
<b>Category 4</b>	<p><b>Irreversible but non-progressive conditions causing severe disability, leading to susceptibility to health complications and likelihood of premature death.</b></p> <p><i>Examples: severe cerebral palsy, multiple disabilities such as following brain or spinal cord injury, complex health care needs, high risk of an unpredictable life-threatening event or episode.</i></p>



## Referral criteria

Babies, children and young people with life limiting or life-threatening conditions who are unlikely to reach their 18<sup>th</sup> birthday

Families must reside within the SSC geographical area or not have access to a children's hospice in their locality

Take referrals below age 18 only but can under hospice until 21years



**Shooting Star**  
Children's Hospices

# In house



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Assessed night stays

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GP 24/7 service

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Emergency/ crisis respite

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Symptom management stays

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EOL care



**Shooting Star**  
Children's Hospices

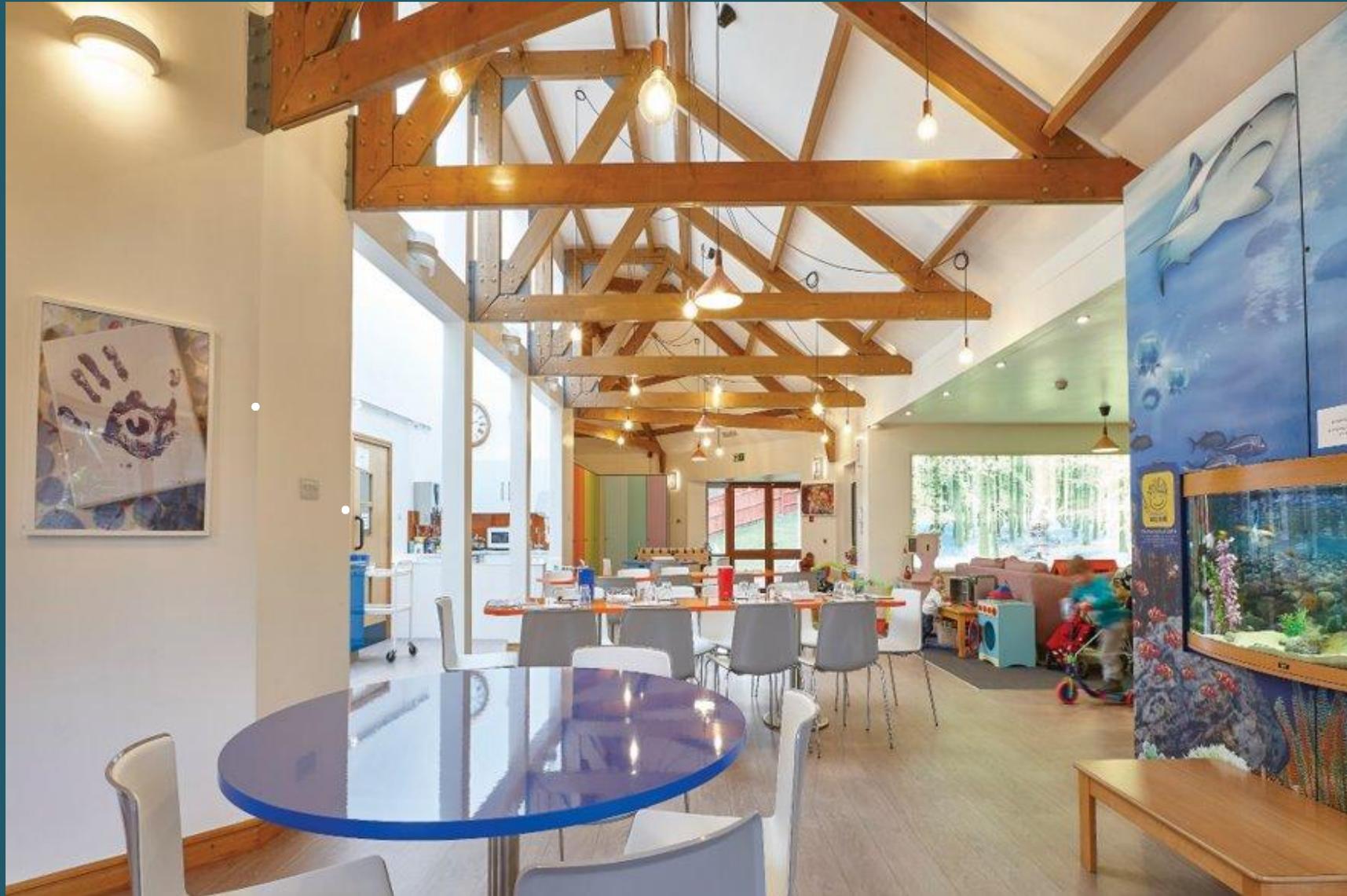
# Shooting Star Children's Hospices

Shooting Star House



Christopher's





**Shooting Star**  
Children's Hospices



**Shooting Star**  
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**Shooting Star**  
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## Community



Initial assessment



Interventional based support  
at home



Support with end of life care  
at home



24/7 on call rota for end of life  
care



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## Psychosocial



Team of mixed professionals e.g. therapists, counselors, physio, Family Support Workers



Support for families – emotional and practical



Offer services both in and out of the hospice setting



Specialist bereavement offer



## SPACE team



Lead by a consultant with speciality training in paediatric palliative medicine



Team consists of specialist nurses, doctors, specialist pharmacist



Offer services both in and out of the hospice setting – perinatal through to 21 years



24/7 on call service



Provide support with symptom management and end of life care



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Children's Hospices

# Introducing palliative care

- Being open and honest
- Explain benefits of involving wider professionals
- Be clear with language used with families about diagnosis / prognosis
- Understand parental concerns

Thank you – any questions?

Registered Charity No. 1042495



Questions?



# Vanessa Riding

Bereavement  
Manager  
Momentum  
Children's Charity



Helping families of seriously ill  
children to keep moving forward





# momentum

children's charity

Helping families of seriously ill children to keep moving forward

# How Momentum Children's Charity started



Bianca Effemy founded Momentum in 2004 while she was a Paediatrics receptionist at Kingston Hospital

The ethos was always, and still is, paving the way to support each family with personal touches.

No family should cope alone



# Hospital partnerships

The work we do with families, all starts with a referral being made to us from one of our partner hospitals:

- 1: St Peter's Hospital, Chertsey
- 2: Kingston Hospital
- 3: St George's Hospital, Tooting
- 4: Royal Surrey County Hospital, Guildford
- 5: Epsom Hospital
- 6: East Surrey Hospital
- 7: Royal Alexandra Children's Hospital
- 8: Worthing Hospital
- 9: The Royal Marsden



We are Smokefree  
Thank you for not smoking  
at our Hospital

FRESH AIR  
HEALTHIER  
GREENER  
CLEANER  
SMOKEFREE



momentum  
children's charity



**Each family are assigned a family support worker who will reach out to the family in the community too. They will be there to help every step of the way, for as long as we are needed, offering comprehensive support.**

We offer Creative Therapies to our Echoes sibling  
Including music, art, play and drama.

These sessions can help with:

Creating a safe space for a bereaved sibling to talk  
about their person.

Expressing feelings of sadness, anger, guilt, joy, anxiety,  
Working through difficult feelings in a safe, unpressurised way.

## Music, art and play therapy



**momentum**

children's charity



## Echoes family events

Contact with other Echoes families is vital  
Creating a space to chat to others that understand  
Events throughout the year for bereaved siblings, mums, dads



# Mini holidays and respite breaks

Momentum has 3 cabins available to supported families for much of the year. This provides invaluable time away and the possibility of feelings hope



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children's charity



## Boat trips

Moments on the River, our Momentum barge, is skippered by our fantastic volunteers and enjoyed throughout the year for day cruises, overnight stays and Echoes Cruise and Craft events.

A chance of peace, surrounded by nature or one to share memories with others.

- START
- Open padlock to main cabin
  - Switch gas ON - under off
  - under steps into main cabin
  - Switch ON water pump - NAV
  - Check off heating and engine
  - Check water supply
  - Oil level - check with dipstick
  - Holding tank - needs emptying
  - Light Summers in WC compartment
  - Using shore power / run socket
  - Check the floor
  - Charger off
  - Check the bow thruster is ON
  - Switch ON engine with ignition key
  - Check that cooling water is spraying
  - Look on port side
  - Coast off mooring ropes



# Parent buddy & peer support

Recent developments in our Echoes dads support

# Social work programme

Advice and Signposting  
DVL/PIP  
Education  
Blue Badge  
Housing  
Grants/Benefits/Finance  
Employment





# Echoes bereavement support

Thank you for  
listening!

Any questions?  
Comments?  
Reflections?



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Keep in touch!

Vanessa Riding

Bereavement Support Manager

Direct Line: 07385 583248

Main office: 020 8974 5931

  
momentum  
children's charity



Questions?



# Breakout rooms

Room	Focus	Hosts
1	Supporting siblings	<b>Vanessa Riding</b> Bereavement Support Manager <a href="#">Momentum Children's Charity</a>
2	<ul style="list-style-type: none"> <li>Supporting families when a child dies unexpectedly.</li> <li>Statutory processes following a child's death.</li> </ul>	<b>Clare Kemp</b> Specialist nurse child death reviews Surrey Heartlands
3	Paediatric Palliative Care: Supporting children and their families through life	<b>Tracie Lewin-Taylor</b> Nurse Consultant Pediatric Palliative Care <a href="#">Shooting Star Children's Hospices</a>
4	<ul style="list-style-type: none"> <li>Age-appropriate language.</li> <li>supporting parents and family.</li> </ul>	<b>Zoe Pizzie</b> Director <a href="#">Jigsaw Southeast</a>
5	<ul style="list-style-type: none"> <li>What can be offered at home (focus on end-of-life care) – nursing support, charities supporting memory making etc.</li> <li>The voice of the life limited young person (particularly teens)</li> </ul>	<b>Helen Alderson</b> Clinical Service Manager Children's Community Nursing Service
6	Supporting a school community and staff.	<b>Sarah Nash and Yolandi Johnson</b> Assistant Heads <a href="#">Pond Meadow School</a> , Guildford.

# Feedback



Join at [slido.com](https://slido.com)  
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**‘This session has enabled me to make a new connection or hear about a Surrey organisation I was not aware of’.**

① Start presenting to display the poll results on this slide.

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To what extent has this session increased your **KNOWLEDGE** of how to support life limited children, their family, and friends?

① Start presenting to display the poll results on this slide.

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To what extent has this session increased your **CONFIDENCE** in supporting life limited children, their family, and friends?

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**How likely is it that you would recommend our Coffee & Chats to a colleague?**

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**How likely is it that you would recommend our Coffee & Chats to a colleague?**

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**Anything else?**

- **what you need from others**
- **what you can offer (resources, time etc.)**
- **one key action you will take away?**
- **other feedback**

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# Further Support

## **As professionals:**

Jigsaw Southeast's support line 01342 313895 open 0930 – 1230  
Open to everyone including professionals.

## **Personal:**

### **CRUSE BEREAVEMENT CARE: 0844 477 9400**

Cruse Bereavement Care promotes the well-being of bereaved people and aims to enable anyone bereaved by death to understand their grief and cope with their loss.

### **COUNSELLING DIRECTORY**

Stay in  
touch!

<https://surreyyouthfocus.org.uk/events>

<https://surreyyouthfocus.org.uk/bulletins>



# COFFEE AND CHAT:

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