available on skin changes in people with darker skin and we consulted the Ubele Initiative.

**Results** Preliminary searches found few articles covered descriptions of skin changes at the end of life and contained outdated terms. No studies described the appearance of skin in people with darker skin at the end of life. Information about skin changes relevant to end of life care in people with darker skin found in resources from Wounds UK, National Wound Care Strategy, Mind the Gap and UK Sepsis Trust was used to update resources and website information which were reviewed by experts by experience and professionals.

**Conclusion** There is a significant lack of robust evidence, information, and guidance on changes of skin tone in people with darker skin at the end of life. There is a need for co-produced, evidence-informed practical guidance for healthcare professionals and informal carers supporting people at the end of life.

**Background** Service user involvement in design, implementation and evaluation of services is becoming increasingly commonplace (Omeni, Barnes, MacDonald, et al. BMC Health Serv Res. 2014;14, 491). Research also shows that service user involvement has a positive impact on the organisation and the service users (Gordon, Franklin, Eltringham. Res Involv Engagem. 2018; 4, 11; Minogue, Bonez, Brown, et al. Int J Health Care Qual Assur Inc Leadersh Health Serv. 2005;18(2–3):103–12).

**Aims** To evaluate and understand what matters to the families, what families with children and young people with life-limiting conditions need to live the best life they can, and what role do the children’s hospices in Wales play in providing this support?


**Results** Hospice services provide essential support to families and are the main places that families access the support they need. Access to respite/short break care is essential to family coping and wellbeing. Complexity of condition has an impact on care and family life. Support for young people leaving hospice services is lacking and there is a need for bereavement support and counselling.

**Conclusion** Children’s hospices in Wales are often the only places where families can access the tailored support that they need to care for their child. Including families in service design, implementation and evaluation at all levels is crucial to providing excellent services.

**Background** With more children with life-limiting conditions surviving into adulthood (Jarvis, Roberts, Flemming, et al. Pediatr Res. 2021; 90(6): 1120–1131) approximately 25% of the overall children’s hospice caseload was of transition age. Families expressed how challenging and stressful this period was, both practically and emotionally. A significant need to transform support was overwhelmingly apparent, particularly in the absence of a national framework alongside a lack of investment and resource. It also became clear there is disparity between services available to a young person (aged 18) in a children’s hospice compared to accessing services from an adult hospice.

**Aims** To build a transition service informed by a steering group involving hospice Clinical Services Leads and representation of families, to facilitate and inform a review of the current offer of support; to ensure quality improvement and equity of service, with an identified caseload. To review multi-professional approaches and service availability within differing referral criteria.

**Methods**
1. Extensive research and information gained from the National Institute for Health and Care Excellence, Together for Short Lives and Hospice UK, alongside the lived experiences of families.
2. Development and implementation of unique Transition Framework.
3. Restructure and recruitment of designated posts.
4. To work collaboratively with adult services.

**Results** Contacting families to provide bespoke support has been key to understanding the needs of families, putting the voice of the young person at the centre. Creating opportunities for peer-to-peer support and developing these support programmes has been invaluable in connecting families, through hybrid engagements and collaborative working.

**Conclusions** Transition support has been transformed, with increased understanding of legislation, defined support service offer and enhanced communication with social and health providers. Needs of young people have been identified, and support given to all family members moving into adult services. Access to psychosocial Family Support defined after young person’s 18th birthday with start of transition plan in place from 14 years old.

**Background** You may have special memories from a school trip, whether a first stay away or trying something new. These opportunities are crucial for siblings living with a young person with a serious or life-limiting condition. For the past two years, we have organised a three-day residential for siblings transitioning to secondary school. The need greatened after the pandemic with lockdown affecting the mental health of those living with siblings with disabilities, who have missed out on important opportunities to meet others.

**Aims** The focus was to provide a fun space, create new friendships, meet others in similar situations and build
resilience. Additionally, siblings would learn more about the wider services the children’s hospice provides.

**Methods**

An appropriate adventure park was sought, criteria were set, challenges assessed, and skillsets of staff and volunteers, cross-departmentally, were identified to best support siblings who often had additional needs. Evaluation of the work was significant and impacted on subsequent trips.

**Results**

Children’s self-esteem and confidence increased, improving their emotional well-being whilst being in a digitally-free environment. They built lasting relationships and continue to connect within the sibling support programme. Meanwhile, families were able to have a different focus including self-care and dedicated time with their other children. Those with socioeconomic disadvantages could participate through practical support offered. Staff and volunteers experienced morale boosts after a period of reduced face-to-face trips.

**Conclusion**

Feedback demonstrated that the trip allowed siblings to gain independence and provided space to explore emotions with new friends who they otherwise may not have met. The residential will be repeated for a new cohort with venue improvements and activity adjustments to further develop sibling support.

**Conclusions**

The interdisciplinary model of music therapy and physiotherapy provided opportunities to simultaneously address several aspects of holistic care. The group enabled peer support and provided a gentle introduction to hospice services, enhancing the experiences of children and their families.

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**WRIGGLES AND RHYMES: A MUSIC AND MOVEMENT GROUP FOR YOUNG CHILDREN RECEIVING CHILDREN’S PALLIATIVE CARE AND PEER SUPPORT FOR THEIR FAMILIES**

Caroline Anderson, Jane Field. Bluebell Wood Children’s Hospice, Sheffield, UK

10.1136/spcare-2023-HUNC.155

**Background**

Families of young children with life-limiting or life-threatening conditions encounter many stark challenges, including limited or delayed communication resulting from the child’s medical condition which may affect bonding between parent and child, or lead to experiences of frustration or isolation. Families may withdraw socially, avoiding playgroups and other opportunities to build peer networks. The music therapist and physiotherapist at Bluebell Wood Children’s Hospice sought to ameliorate some of these issues through a music and movement group.

**Aim**

To provide children under five with tailored opportunities to develop movement and communication skills within the motivating context of music-making, to facilitate peer support between families, and to provide a welcoming introduction to the hospice.

**Methods**

A pilot demonstrated the group was feasible. The group was run over six weeks, three times per year. Data was gathered over five years (2018 – 2023) including attendance records, clinical notes and evaluation forms completed by families. The efficacy of the group was evaluated using all different sources of data, identifying trends in attendance and popularity of the group, parents’ perceptions of the group, and any unanticipated findings.

**Results**

The parents gave highest scores for all aspects of the group: activities, leaders, setting, pace. They expressed that they appreciated opportunities to spend time with other families, with whom they recognised shared experiences, and indicated that they would be more likely to use other services provided by the hospice following this first contact.

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**SAFEGUARDING CHILDREN, YOUNG PEOPLE, AND ADULTS; WHEN GOOD ENOUGH, ISN’T GOOD ENOUGH. INNOVATIVE APPROACH WITHIN A CHILDREN’S HOSPICE**

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10.1136/spcare-2023-HUNC.156

**Background**

Safeguarding was held and managed by a small, senior team, which led to increased risk and reduced knowledge, skills, and confidence within the workforce.

**Aims**

There was a thorough review of the safeguarding policy, procedures, training, attitudes, cultures, systems, and processes to upskill the workforce across all departments. We needed to become more transparent and multi-disciplinary in our approach (Department for Education. Working together to safeguard children: a guide to inter-agency working to safeguard and promote the welfare of children.2018).

**Methods**

- Introduction of a Named Nurse for safeguarding with extensive experience to re-design and lead the changes.
- Updated and index linked policy, reviewed by an external, independent safeguarding professional.
- All staff and volunteers receive a level of training appropriate to their roles.
- Internal training updates.
- Staff newsletter updates.
- Quarterly Safeguarding Assurance Committee meeting chaired by a safeguarding Trustee and attended by representatives from all departments across the organisation.
- Adult safeguarding e-learning for all staff.
- Regular audits.
- Safeguarding supervision expectation, with senior staff receiving external supervision. Discussed at all routine 1:1 meetings.
- Six Safeguarding Leads, contactable for all staff and volunteers.
- Monthly meeting to discuss current cases and staff are encouraged to attend to observe or to present cases. Internal referral process in place.

**Results**

Training evaluations, staff feedback and a recent mock CQC inspection have highlighted that staff and volunteers understand their roles and responsibilities, know who to contact and are raising concerns early and appropriately. We have seen an increase in advice being sought by non-care teams, such as retail, and voluntary services. Staff report they have an increased confidence and feel able to raise and review concerns.

**Conclusions**

We completely re-designed how safeguarding works within our organisation, with all staff and volunteers believing safeguarding is everyone’s business. Staff have the training, skills, and confidence to identify and manage safeguarding concerns in a more transparent and autonomous way which in turn, is making us a safer organisation.