

4. The relationship between parents and clinicians is critical to the care of seriously ill children. A breakdown in the relationship can have lasting consequences for both families and clinicians. <u>Through our research, we have identified key factors that bear on the success of consultations and the maintenance of the essential relationship between parents and clinicians as well as factors leading to a breakdown of the relation^{34,35,36,37}.</u>

We have disseminated our results in major journals and at major conferences leading on to incorporation into medical and nursing education and training both within PPC and across paediatric specialities where seriously ill children are seen (e.g. oncology, cardiology, intensive care).

5. Advance care planning (Do Not Attempt Resuscitation Orders, Ambulance directives, plans and preferences in place of care and place of death) is widely endorsed by policymakers and institutions; how ever, parents are often resistant to engage in such discussions. The result is that parents are distressed by being confronted with issues which they find painful to discuss, and clinicians feel inadequate in the performance of their job.

Our research uncovered the bases for such resistance and proposed solutions based upon an approach to advance care planning not as the completion of an agenda but as the sensitive, individualised initiation of the exploration of painful but unavoidable issues^{38,39,40}

Because of our unique relationship with the clinical team, there was not the usual time lag between such discoveries and implementation in practice and education. Having the results immediately and directly from the academic researchers, not having to wait until publication (often a year or more between submission of an article and publication), the clinical team was able to alter practice and incorporate the findings into education and training including their well evaluated oversubscribed simulation course on end-of-life care.^{41,42}

6. Prognostic information about seriously ill children is challenging for clinicians to reveal and painful for parents to receive. Yet it is something that many argue is something parents must know in order to make informed decisions about their

provide any or even adequate prognostic information. They report further that what information is given is poorly understood by parents. <u>Our studies of the actual on</u> the ground conversations between oncologists and parents of children with high-risk brain tumours (audio-recorded and transcribed verbatim) at diagnosis has revealed that an essential issue for parents is not the lack of information or poor information, but rather how to apply complex, often general and statistical information to their specific, unique situation³⁶

100. We are currently analysing consultations as the disease progresses and will, as is our practice, propose clinical guidance based on our findings.

There are indications that our findings apply to clinicians and parents of children with other illnesses including complex cardiac condition; those in intensive care or

awaiting transplant. Part of the work of the PPC Team is helping the parents to understand prognostic conversations and their impact on decisions going forward.

7.

shows that most parents and children welcome the opportunity to participate, and some report benefits from their participation.

¹ Feudtner C, Rosenberg AR, Boss RD, Wiener L, Lyon ME, Hinds PS, **Bluebond-Langner M**, Wolfe J. Challenges and priorities for pediatric palliative care research in the US and similar practice settings: report from a pediatric palliative care research network workshop. Journal of pain and symptom management. 2019 Nov 1;58(5):909-

¹⁶ Patel B, Downie J, Bayliss J, Stephenson A, Bluebond-Langer M. Long-term daily administration of aprepitant for the management of intractable nausea and vomiting in children with life-limiting conditions: a case series. Journal of Pain and Symptom Management. 2021 Feb 13.

¹⁷ **Oostendorp LJ, Rajapakse D, Kelly P,** Crocker J, **Dinsdale A,** Fraser L, **Bluebond-Langner M.** Documentation of breakthrough pain in narrative clinical records of children with life-limiting conditions: Feasibility of a retrospective review. Journal of Child Health Care. 2019 Dec;23(4):564-78.

¹⁸ Greenfield K, Holley S, Schoth DE, **Bayliss J**, Anderson AK, Jassal S, **Rajapakse D**, Fraser LK, Mott C, Johnson M, Wong I. A protocol for a systematic review and meta-analysis to identify measures of breakthrough pain and evaluate their psychometric properties. BMJ open. 2020 Mar 1;10(3):e035541.

¹⁹ Craig F, Henderson EM, Patel B, Murtagh F E M, Bluebond-Langner M. Palliative: date from kinded in a fight a fight in people with stage 5 chronic kidney disease. Pediatric Nephrology. ative

recommendations for future inquiry and policy. Palliative Medicine. 2013 Sep;27(8):705-13. DOI: 10.1177/0269216313483186.

³² Bluebond-Langner M, Beecham E, Candy B, Langner R, Jones L. Problems with preference and place of death for children too. Bmj. 2015 Nov 19;351:h6123. DOI: 10.1136/bmj.h6123.

³³ Papadatou D, Kalliani V, Karakosta E, Liakopoulou P, Bluebond-Langner M. Home or hospital as the place of end-of-life care and death: A gro
-making. Palliative Medicine. 2021
Jan; 35(1):219-30.

³⁴ GibJEm0 G[G)4(ibJEm0 G[Mg2 8er DT/F1 9.96 Tf1 0 0 1 186.65 720.46 Tm0 G[2)-10(015)]TJETQq.86 7)]TJETQq0.0000BT67F32 8.4

⁴⁶ Day E, Jones L, Langner R, Stirling LC, Hough R,

⁶² Kaye EC, Gattas M,
7
Baker JN. Longitudinal investigation of prognostic communication:

cancer. Cancer. 2020 Jan 1;126(1):131-9.

⁶³ k V 7 - # h ses to prognostic disclosure at diagnosis of a child with a high-risk brain tumor: Analysis of clinician parent interactions and implications for clinical practice. The role of reflection in dealing with uncertainty. Pediatr Blood Cancer, 68: e29057. https://doi.org/10.1002/pbc.29057.

⁶⁴ Marron, J.M. (2020), Communicating uncertainty: A step in the right direction? Pediatric Blood Cancer e28849. https://doi.org/10.1002/pbc.28849.

Bryan G, Bluebond-Langner M, Kelly D, Kumpunen S, Oulton K, **Gbson F**. Studyin interactions with clinicians: Identifying methods fit for purpose. Qualitative Health Research. 2019 Feb;29(3):393-403.