

Being a pain conduit: interpreting and advocating for another's pain

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Expressing pain

- “Pain defies language”^[1].
- Communication about pain (clarity of expression and explanation) ‘impossible’ for most people.
- Especially difficult for children with limited verbal and other means of expression.
- Usual pain cues can be masked or unavailable.
- Challenging for parents and professionals – a form of ‘Chinese whispers.’



Parents as conduits

- Parents develop insight and expertise^[2]; but typically developed on their own.
- Parents use their bodies to sense their child's pain through touch, interpreting posture, tension and difference.
- They learn to know their child's pain, through feeling their child's body.
- Parents become conduits for the internal experience of their child's pain and use this knowledge to advocate for their child.



Barriers to advocacy

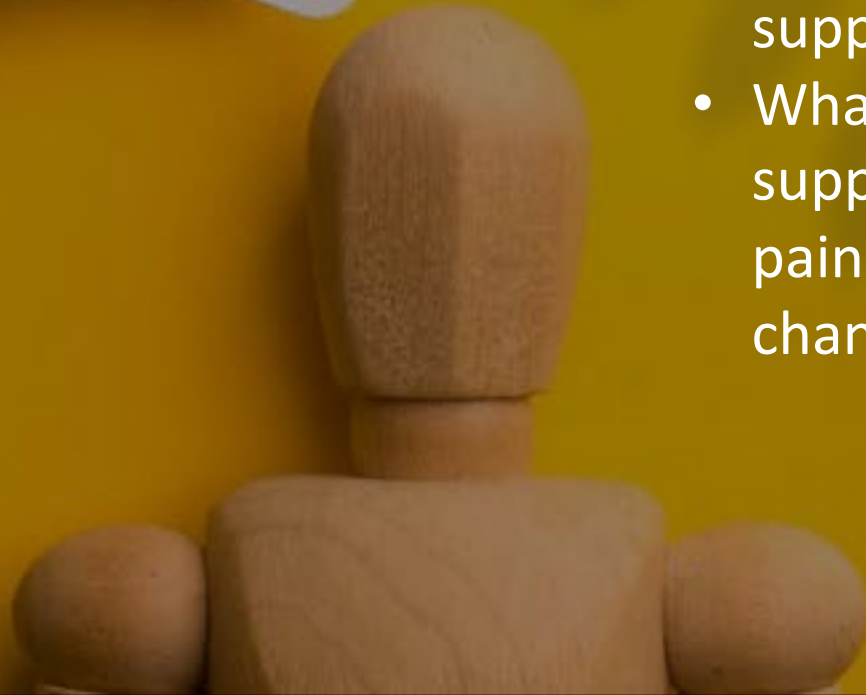
- Parents then have to present their understanding of their child's pain to professionals.
- Translating 'something felt' into language.
- Professionals often uncertain^[3]; clinical cues atypical, parents often not listened to or disbelieved^[4].
- 'Communicating Lily's Pain' is an animation that aims to create insight and understanding.



Thoughts and questions



- Are parents/mothers unique in this 'role'?
- Could a 'curriculum' be developed to support 'lay' people to learn?
- What can somatic practice contribute to supporting parents of children who have pain but cannot express it via usual channels?



References

1. Scarry, E. (1985). *The Body in Pain: The Making and Unmaking of the World*. New York: Oxford University Press.
2. Carter B, Arnott J, Simons J, et al. Developing a Sense of Knowing and Acquiring the Skills to Manage Pain in Children with Profound Cognitive Impairments: Mothers' Perspectives. *Pain Research and Management* 2017;2017:2514920. doi: 10.1155/2017/2514920 [published Online First: 2017/03/26].
3. Genik LM, McMurtry CM. Reflections and considerations for knowledge translation efforts on pain training for caregivers of children with intellectual and developmental disabilities. *Pediatric Pain Letter* 2020;22:4.
4. Carter B, Simons J, Bray L, et al. Navigating Uncertainty: Health Professionals' Knowledge, Skill, and Confidence in Assessing and Managing Pain in Children with Profound Cognitive Impairment. *Pain Res Manag* 2016;2016:8617182. doi: 10.1155/2016/8617182 [published Online First: 2016/12/21]
5. Communicating Lily's Pain Animation
<https://www.youtube.com/watch?v=nH3BKpGxzw4>

