

Communicating Lily's Pain:

parents and professionals working together

Summary Report 2019-2020

Background

Children with profound cognitive impairment experience a higher number of pain episodes than their healthy peers and often experience frequent and significant pain. Although the evidence base is growing, they are vulnerable to poor pain assessment and management. The complexity of their children's healthcare needs, alongside the fact that their children's pain behaviour and expressions are different to typically developing children, can create communication difficulties.

This resource translates research findings into materials that parents and professionals can use to improve pain management wherever children with profound cognitive impairment are receiving care (in their homes, in hospital, at school or in hospice or respite care).

How did we develop the resource?

This resource was developed in collaboration with parents, clinicians, and other stakeholders. The script for the animation and the content for the information sheets draw on key quotations, and tone, mood and emotion within the stories told by parents and professionals. A team (researcher, professional writer and animator) collaborated with parents to generate an animation that related the story in a way that would engage both parents and professionals. The same collaboration occurred in the development of the information sheets. A parent of a child with complex health needs provided the voiceover.

The resource was funded by WellChild and has been endorsed by the Royal College of Nursing.

What does the resource consist of?

This free and downloadable resource consists of an animation and information sheets. The animation was launched ahead of the information sheets.

The animation

The animation focuses on the Lily and how her mother tries to assess and manage her pain and what support she needs from health professionals when Lily's pain gets out of control.

The information sheets

The three information sheets are aimed at parents, professionals and educators. They provide detail about the types of pain children like Lily experience and provides



guidance about how to assess their pain and includes what the most important things are to do, what assessment tools can be used, and what resources are available.

How have we ensured impact?

From the inception of the idea for the resource, the intention is for it to have impact and to become embedded into the care of children with profound cognitive impairment. We have used online survey, small discussion groups, postcards and other methods to enhance and measure impact.

On the journey to creating the resource

Funding was gained from The Arts Council and Junctures (via [30Bird](#)) to develop artistic interpretations of the research findings. This resulted in performances called **The Mother of All Pain**

- Carter, B. & Young, R. (2018) The Mother of All Pain. ArtsEqual, The Festival of Ideas, Edge Hill University in conjunction with 30Bird. 13th June 2018.
- Carter, B. & Young, R. (2018) The Mother of All Pain. Junctures², Cambridge Junction, in conjunction with 30Bird. 24th March 2018.

Via websites and social media and linking with children's charities

The resource is hosted on the Edge Hill University website as well as having links to it via the WellChild website. It is being promoted through [WellChild](#). It is also hosted on [Figshare](#) (the University repository)

Via workshops, festivals, networks, conferences and publications

It has been presented at the Science Festivals

- Carter, B., Young, R., Meehan, E. The Mother of All Pain; a feral adversary. Festival of Ideas 2019. Exchanges: Creativity-Community-Curiosity. Health Research Institute. EHU.

It has formed part of the Somatic Practices and Chronic Pain network meetings and core materials

- Carter, B. Assessing Pain session at Somatic Pain and Pain Workshop, Coventry University, 5-6th February 2020. Funded by AHRC.

It was presented at the Virtual Physiotherapy Conference UK, 13th November.

- Carter, B., Young, R., Munro, J. Using an animation to enhance parents and professionals' communication and assessment of pain in children with profound cognitive impairment.

Abstracts had been accepted for papers to be presented at conferences (e.g., British Society of Pain, IASP, RCPCH) in Spring and Summer 2020 but COVID-19 meant that the conferences were cancelled although the abstracts were published.

Selected publications include

- Carter, B. (2020) Animating children's pain research: using arts-based approaches to disseminate knowledge and mobilise emotions. Advancing the Science and Practice of Nursing. *Nursing Standard*. pp48-51 <https://journals.rcni.com/nursing-standard/feature/animating-childrens-pain-research-using-artsbased-approaches-to-disseminate-knowledge-and-mobilise-emotions-ns.35.10.48.s31/full>.

- Carter, B., Arnott, J., Simons, J., Bray, L. (2017) Developing a sense of knowing and acquiring the skills to manage pain in children with profound cognitive impairments: mothers' perspectives. *Pain Research and Management*. Volume 2017, Article ID 2514920, <https://doi.org/10.1155/2016/8617182>
- Carter, B., Simons, J., Bray, L., Arnott, J. Navigating uncertainty: health professionals' knowledge, skill and confidence in assessing and managing pain in children with profound cognitive impairment. *Pain Research and Management*. Article ID 8617182, <http://dx.doi.org/10.1155/2016/8617182>
- Carter, B. Communicating Pain: The Challenge of Pain Assessment in Children with Profound Cognitive Impairment. *Comprehensive Child and Adolescent Nursing*. 43(1): 10-14. <https://doi.org/10.1080/24694193.2020.1715105>

Via Awards

It was submitted in February 2020 for BMA Patient Information Award. However, due to Covid-19, the awards were postponed until 2021.

Evidence of impact

To date, we have reached hundreds of professionals across the UK, Ireland, and the rest of the world including people working in primary, secondary and tertiary healthcare, schools and other settings. Conversations have occurred with professionals from many different disciplines including doctors, nurses, specialist pain teams, hospices, paramedics, GPs, school nurses, practice nurses, and teams working specifically with families with children facing the same sorts of challenges that Lily's mother faces.

Creating impact: parents and families

Since most of their care is delivered by their parents we have worked hard to ensure that we have reached out to parents and families.

Primarily this has been done via WellChild as well as via social media. We have also engaged with parents through workshops and meetings.

We can track impact through feedback from parents. Many parents are sharing the resource with other parents and with their care teams.

"Oh this has well and truly left me in tears. Here's a video that actually confirms what us parents have known all along... "we just know." I can relate to this on so many levels. I'm going to share it with my daughter's palliative care team at the hospice so they can use it in their teaching. Thank you so much for sharing this x"



This is brilliant and heartbreaking, we are going to Sheffield Children's Hospital Autism and LD summit to advocate change around exactly this and other things, could I share the video? xx

The *** nurse at Norfolk and Norwich hospital was really excited by the video

Creating impact: professionals

Another impact audience includes health professionals who are providing care to children like Lily.

The work underpinning the animation and the animation has been shared with professionals in the UK, New Zealand, Australia, USA and other parts of the world, through professional networks and via social media. We have presented at conferences and pain education events. The response has been positive with plenty of interest being shown in the resource.

Some of the impact is perhaps 'soft' impact where we have evidence that it is changing people's understanding of the challenges parents face and helping professionals to understand how they can improve their pain care by entering into dialogue with parents.

Other impact is evident in the commitment to use it within practice.

Yes, share it with my clinic in San Francisco and will share with State program next week

Too many professionals still restrict their scope of knowledge to medical 'investigations'. This film is eloquent testimony to what parents know. I hope it will convince those clinicians who don't listen to parents that it's time for them to try it. And the film can help parents to feel empowered to ask – even demand – that clinicians listen to them. I imagine the parents of a chronically ill child keeping this film on their phones and asking a clinician to take two minutes to watch it. Those two minutes could be a turning point in that clinician's life.

Creating impact: educators

The third key impact audience are those people in Universities, clinical and community settings who are involved in delivering education to health professionals.

Positive feedback shows that individual

I am a children's pain nurse and would like to use this in my teaching sessions to other nurses to get them to reflect on the care they give and then hopefully we can improve how we care for children who cannot communicate their pain.

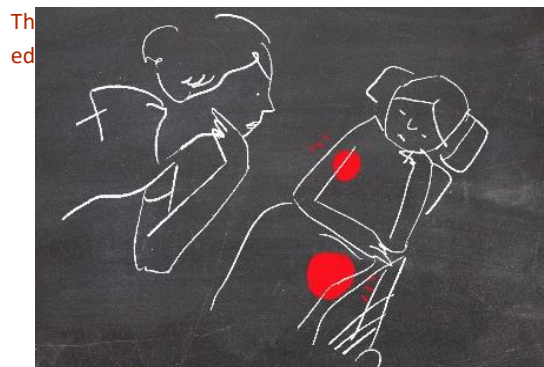
practitioners and educators are using the resource in their teaching.



It has already made a difference. Provoked an emotional response. Made me reflect on families that I care for and reminding what is important to them in the assessment and management of their child's pain. I have shared with my colleagues.

As a children's nurse of 30 years I am experienced in this area but feel that this video says it all in a few minutes and in a lovely thought-provoking and appropriate way.

Definitely - about to email the link to my Journal club - with Child Development therapy team!



RCN Endorsement



The resource was endorsed by the RCN on 3rd June 2020.

Receiving this endorsement means that the resources meet the Royal College of Nursing's quality criteria for professional standards and are fit for national and UK nursing practice.