**Illness and the One-to-One Encounter**

**Brian Lobel and Emily Underwood-Lee**

*We enter the room of a parent/carer and her 18-year-old child. Her child, who lives with complex medical needs, is about to transition to adult care after spending his whole life receiving paediatric care from Great Ormond Street Hospital. We are dressed in costumes related quite literally to self-care and relaxation: fuzzy slippers, colourful bathrobes, eye masks perched on our foreheads. We begin our performance/questionnaire which, despite our costumes, raises no red flags; this mother is used to being asked questions by medical staff she has never met and will sometimes never meet again. She slowly realises that the questionnaire is fun, funny, and art-y, and very quickly says ‘I don’t have very much to say…’ about what it means to be a parent/carer of a child at Great Ormond Street, what it means to care for herself alongside caring for her child, what it means to relax, dream, and vision new futures.*

*‘I don’t have very much to say’ she says… and then she speaks, uninterrupted, for forty-five minutes.*

In this chapter we argue that there are useful parallels to be found between one-to-one performance and the medical encounter and that, by bringing this often avant-garde performance form to the hospital space, there is much to be gained for audiences/patients, institutions, and artists. Ultimately, we argue for a care-filled and compassionate ethical encounter that opens up new possibilities for one-to-one performance as part of the arts and health exchange. We consider the benefits of one-to-one arts encounters within the hospital space with particular reference to our *Kicking Up Our Heels* project - performed for parents/carers in 2018 and 2019 at Great Ormond Street Hospital, London (GOSH) - alongside *Footwashing for the Sole* (2009)*,* a one-to-one performance by Adrian Howells. We have used the term parent/carer throughout to indicate the many routes by which we might come to be in a parental role for a child.

*Kicking Up Our Heels* was evaluated and reflected upon in 2020 by creative facilitator Anna Ledgard, who described the project formally as:

Artists Brian Lobel and Emily Underwood-Lee invited Parents & Carers to take part in a playful performative ‘survey’ about how they nurtured and looked after themselves whilst caring for a child in the hospital. In their responses parents were encouraged to get beyond the notion of the ‘good parent’ who subjugates their needs for those of their children. The responses were used by Emily Speed to design a permanent artwork, *Cocoon*, which was installed at GOSH in February 2020 and was accompanied by a paper booklet *You are Doing a Great Job*, which incorporated ideas and activities offered by parents to improve their own and others’ wellbeing (Ledgard, 2020).

For our ‘playful performative survey’, dressed in colourful bathrobes and fuzzy slippers, we asked parents/carers survey-style multiple choice questions about how much time they practiced self-care, walked in nature, slept, and so on, knowing that most answers to the questions would be ‘Not at all!’ With a gentle wink and a shared understanding of how little they take care of themselves when their child is sick, we then asked them more open-ended questions about their own rituals, advice, and dreams of spaces that would enable more self-care. Ranging from five to forty-five minutes, the performances were attended by Brian and/or Emily, creative facilitator Anna, the parent/carer, and – more often than not – their child, either actively listening, or contributing, or laying asleep. Though not always strictly ‘one-to-one’, the intimate interaction was much more akin to one-to-one performance than any traditional stage show, and it is through the lens of one-to-one performance that we examine the piece here.

# **Arts, Health, and Parents**

The existing literature on the impact of parental mental health on the wellbeing of children is considerable (Barlow et al, 2014), although there is less literature specifically engaging with the needs of parents/carers whose children are undergoing hospital treatment. In their review of the literature on psychological interventions for parents/carers of children with chronic illness, Christopher Eccleston et al note that the data linking parental psychological health to paediatric patient outcomes is slight and has not been consistently replicated (2019: 26). Emily Law et al note that, although difficult to prove causality, there is significant literature that demonstrates indirect links, specifically in relation to ‘child mental health, behavior, and medical symptoms’ and suggest that children’s treatment should always be designed with a view of the needs of the whole family (2014: 880).

There is also a growing field of literature informing us that access to and participation in the arts is effective for improving wellbeing. Daisy Fancourt and Saoirse Finn conducted a review of over 900 articles examining the benefit of arts and health and found that engagement with the arts is effective for both prevention of ill-health as well as promotion of health-improving behaviours, and for the management and treatment of health conditions. They identified claims for psychological, physiological, social, and behavioural benefit from engagement with the arts (2019: 3). In a modest study undertaken with participants in a ten-week arts on prescription programme, Anita Jensen and Wenche Torrissen found a specific link between aesthetic engagement and mental health improvement. Although the study only worked with seven participants, we are particularly interested to note that it considered the role of aesthetics where many other studies struggle to differentiate whether positive outcomes are a result of social engagement, movement, or community building which occur within an arts encounter but could also be found in many other community classes or social, physical, or cultural settings. Jensen and Torrissen state:

Although more research is needed to explore the complex connections between aesthetic engagement and wellbeing, this study has shown that aesthetic engagement can create deep emotional experiences that can change the distribution of the sensible in ways that have a significant impact on people’s lives and wellbeing (2019: 246).

In the context of the United Kingdom, the 2017 report ‘Creative Health: The Arts for Health and Wellbeing’, commissioned by the All Party Parliamentary Group on Arts and Health, noted that there is inconsistent evidence linking the arts with health outcomes , and highlighted the research challenges of proving a causal relationship between arts participation and health and wellbeing benefits (2017: 11). However, with this caveat in mind, the ‘Creative Health’ publication still reports that participation and engagement with the arts can improve health and wellbeing significantly:

[participation in the arts can] stimulate imagination and reflection; encourage dialogue with the deeper self and enable expression; change perspectives; contribute to the construction of identity; provoke cathartic release; provide a place of safety and freedom from judgement; yield opportunities for guided conversations; increase control over life circumstances; inspire change and growth; engender a sense of belonging; prompt collective working; and promote healing (2017: 21).

We knew that parents’ mental health was critical for enduring their own experience while parenting a child undergoing treatment at the hospital; we knew that, in turn, this would have a significant impact on the care they were able to provide to their child; we knew that parents’ mental health and resilience could be improved by engaging in arts activities; and we knew that at the point that we entered the hospital, parents/carers were not attending arts events. These assertions provided the starting point for our *Kicking Up Our Heels* project created for GOSH Arts, the arts programme at Great Ormond Street Hospital. Though the GOSH Arts team, over the years, had repeatedly provided events specifically designed for parents/carers and also staged a range of events that parents/carers could participate in with their children or with staff from the hospital, we were told that parents/carers were very reluctant to attend anything that forced them to leave their child’s room. Both the authors of this chapter, Brian and Emily, also had lived experience of hospital treatment for young people - Brian as a young adult cancer patient undergoing treatment for metastatic testicular cancer in the early 2000s (whilst living with his parents), and Emily as the mother of a child undergoing treatment for Acute Lymphoblastic Leukaemia between 2011 and 2015. It was in 2018 that we, Brian and Emily, began conversations with Caroline Moore, then Arts Manager at GOSH Arts, in order to think about how we might be able to provide bespoke arts encounters for the parents/carers of children being treated at GOSH.

# **Parents**

Influenced by Sara Ruddick’s call to think of mothering not as a biological state but as a way of thinking and doing (1989), we define parenting as the work done by anyone in a position of care for a child, regardless of their route to nurturing. Ruddick, in her seminal book *Maternal Thinking*, asks us to imagine mothering not as the biological production of a child but as a way of thinking and acting that emerges from love. Ruddick is clear that, although this way of thinking maternally arises from biological mothering, it is not limited to biological mothers, or indeed to biological fathers, and nor do all biological mothers feel love towards their child; instead, maternal thinking can be carried out by anyone and maternal actions can be directed towards anyone (1989). In this way, maternal thinking can be extended not just to children by parents/carers but towards whoever needs our love and care. Virginia Held extends this thinking towards action and ethics, articulating that ‘care is both a practice and a value’ (2006: 42). It is not just in what we believe, but how this is enacted, that care is made manifest.

Rethinking parenting to extend beyond the biological acts of birth and caring for ‘our own’ children in this way is radical and political. It allows us to extend our thinking about parenting beyond the biological parent, and more usually the biological mother, to think of the wider relationships we might encounter and experience as family, and the infinite ways that family and community might be constructed and queered. In the UK, where the *Kicking Up Our Heels* project took place, we may come to be the primary care-giver for a child through legal, biological, or medical routes generally recognised by institutions, or we might come to be responsible for a child through our networks of care including chosen families, extended families, and infinite other constructions, or what bell hooks might term our ‘kinship structures’ (2000: 37). At GOSH, we encountered people acting in parental roles who had come to that position in myriad diverse ways including through friendships and through extended family relationships such as siblings, grandparents, aunts, uncles, and so forth. Further, when we begin to think about parenting as taking care and responsibility for another, we see many staff working within the hospital setting as in a parental role including play workers, translators, porters, nurses, radiologists, and many more. Thinking of parenting in this way enabled us to work with anyone within the hospital who wanted to engage in an encounter with us. This meant that we initially worked with 100 family or kin of young patients of GOSH, but then extended the *Kicking Up Our Heels* project to provide a workshop at the annual GOSH staff conference in order to work with those staff members who also provide care and felt the desire for a space in which to reflect on their own needs.

# **Care**

If we accept our proposal to redefine parental roles as being care-full of another, then we are required to consider exactly what is meant by care. Joan Tronto has made in-depth studies of what it means to care and how care is a political act. She helpfully articulates this: ‘Care requires not only nurturing relationships, but also the physical and mental work of taking care of, cleaning up after, and maintaining bodies’ (2013: 2). This definition of care is particularly helpful for our needs in this chapter as the parallels between caring as a parent/carer and caring as a member of staff within a hospital become immediately apparent. Tronto expands on her conception of care to note that it is a public value and that this is central to society (ibid: 18). Following Tronto, and in parallel with medical literature that notes that those whose wellbeing and mental health needs are not being met are less able to care for others (Cameron et al, 2020: 766), we can argue that without good care no-one can flourish, including those who are required to give care professionally or in parental roles. Here we are again reminded that if parents/carers and staff within the hospital are not cared for, they will be less able to care for their children/patients, and physical, psychological, and emotional outcomes will be worse for everyone.

Tronto notes several key aspects of care including: ‘caring about’, ‘caring for’ and ‘receiving care’ (2015: 7). ‘Caring about’ requires that we are attentive to the needs of others, be those others in our immediate circle, in our wider societies, or those other global citizens with whom we share the planet. ‘Caring for’ requires that we take responsibility for enacting care in whatever way we find it is required, and further requires us to be aware of the competencies and expertise that we may or may not have and that are needed for various caring roles. The consideration of caring competencies is particularly important when considering care for a child in hospital; for example, there are some acts that a parent/carer who is not trained in nursing will simply not be able to do. Erin A. Brown et al note the centrality of caring for parents/carers in our attempts to provide better care to children in hospital in their review of ‘parental moral distress’. In particular, they note that in hospitals parents/carers may feel unable to care or doubt their own ability to care for their children because they are unable to carry out some of the new tasks that are required in order for their child’s needs to be met:

parent moral distress may be one or more negative self-directed emotions or attitudes that arise in response to a situation in which important parental roles are perceived to be threatened or their ability to enact important roles is stymied (2018: 828).

They note that ‘[w]hen we care about parents, we impact the children in their care’ (ibid: 834). Tronto’s final category of care is ‘care receiving’, which calls us to be responsive when we accept care and to identify and articulate our care needs. Tronto argues that caring for, caring about, and receiving care create an unending cycle where care is always circulating, repeating, and being reinvented (2015: 7). *Kicking Up Our Heels* adopted the philosophy that although the need to give care is infinite and can never fully be met, care is not finite or limited; instead, when we are all cared for then our capacity to care also increases.

# **One-to-one Performance**

One-to-one Performance, as we are exploring it here, relates to a form that has emerged from live art, fine art, and performance art traditions. In the one-to-one event, a performer and audience member have an intimate and interactive encounter designed by the performer for an audience of one. Rachel Zerihan usefully sums up one-to-one performance in her guide for the Live Art Development Agency: ‘One to One’ or ‘One on One’ or ‘Audience of One’ are all terms used to describe a performance that invites one audience member to experience the piece on their own’ (2009: 3). She then explores the dynamics of one-to-one performance, noting that it demands a rethinking of roles and power: ‘questions around one’s individual role in the performance’s agency - in terms of cultural politics, erotic encounters, sacred moments, therapeutic interactions and risky opportunities - are brought to the foreground’ (2009: 3).

Adrian Howells (1962-2014) was a one-to-one performance practitioner who brought major critical and popular attention to the artform. His body of work - which includes work as both himself and the alter ego Adrienne - often used quotidian scenarios to enable profound, unexpected, and revelatory encounters with audiences/strangers. These are described by Deirdre Heddon and Dominic Johnson:

Whether spooning an audience-participant on a bed, or bathing, feeding, or holding one, washing one’s hair or feet, Howells’ encounters were rigorously planned and simultaneously, forcefully open to negotiation, challenge, and change (Heddon and Johnson, 2016: 9).

In *Footwashing for the Sole*, Howells, in his own words, ‘simply washed, dried, anointed with oils, massaged and kissed the participant’s feet’, and the performance, including the conversation surrounding the act of footwashing, provides a useful parallel to the encounters we created within *Kicking Up Our Heels* (explored later) (2016: 189). In particular, Howells noted that *Footwashing* was designed to create and hold space for audience members:

My intention was that during the foot washing and drying I would facilitate a minimal, spoken exchange […]. This silent time was also intended to provide opportunity for internal contemplation and self-reflection. I sought to shift the focus and attention away from the experience being about me and my inclination (Heddon and Howells, 2011: 7).

Using *Footwashing* as an example to think through care and the one-to-one encounter, there are a number of distinct elements of one-to-one that are worthy of critical attention:

* *Multiplicity of Audience and Audience Experiences***:** While, in traditional theatre settings, we appreciate that every audience member has a subjective experience with a piece of art, with one-to-one performance, this is more true than ever. If Howells were performing *Footwashing* six to ten times a day, each of these performances, and each of these audience members’ experiences, would be different.
* *Limited or expandable duration and quantity of performances***:** If a one-to-one performance is twenty minutes or an hour for one person at a time, there will obviously be a limit to how often this work can be produced, and how many people can see it. Because of the open-ended nature of our *Kicking Up Our Heels*, there is a natural emotional and physical limit to the amount of people we could perform with/to, just as with Howells. Thinking through emotional and physical capacity for holding space was critical.
* *It is not for everyone*: There are some elements of one-to-one performance that will intimidate or put-off audience members immediately upon hearing about them– particularly working and living in Britain where a one-to-one interaction with a stranger is many Brits’ worst nightmare. This will always be the case and is notable for when we think about whose voices are present, whose are absent, and who took themselves out of the performance/encounter of *Kicking Up Our Heels* before it even began.
* *Score and Improvisation:*Most one-to-ones are built around the idea of a theatrical ‘score’, rather than a script. Because the audience will change, because the performer will get tired, because the day will get long, and so on, one-to-one performers often forego having absolute control over what happens or what is said, in favour of having an outline, both of texts and of actions, which provides touch points or milestones for the performance. Inside of this, audience responsiveness can guide the performance in one way or another, all of which contributes to the liveness and intimacy of the form.
* *Active participation of the audience:*Going hand-in-hand with a reflection on score/improvisation, the active and activated participation of the audience is often a critical feature of one-to-one performance.

And it is this final element, the activated participation of the audience enabling the show to exist, which is of particular interest in this study. Heddon et al remark on activated participation: ‘Crucial […], then, are the practices of exchange between selves enabled by One to One work’ (2012: 121), while Zerihan et al posit ‘the co-presence of performer and spectator … often refigures the ‘audience’ as participant or collaborator’ (Zerihan et al: 101).

The audience member must be prepared to offer themselves in a reciprocal encounter with the performer, some of which may provoke or challenge in unexpected ways (see Ursula Martinez’s *Confront the Cunt* (2004) or Kira O’Reilly’s *Untitled Action for Bombshelter* (2003) as two such examples).[[1]](#endnote-1) Though not all one-to-one performances require the active and engaged participation of the audience member, most of these works place audiences in a position that often feels much more vulnerable than a traditional performance encounter, during which we can disappear within the crowd of the audience. But just like vulnerable audiences, the performer of one-to-ones must be willing to expose themselves to and be reliant upon the audience member in an utterly co-dependent encounter. This is not an equal encounter: the performer has designed the encounter, knows what to expect, is the ‘professional’ in the situation and in whom the audience member must trust. Instead, we might conceive of one-to-one performance as an asymmetrical or unbalanced yet mutual encounter. Adriana Cavarero discusses the option we all have when placed in a relationship of dependence to reach out to our other with the intent to either nurture or harm and positions care as a particular inclination towards a vulnerable other (2011: 202). Cavarero notes that, in a maternal encounter, the mother must literally lean over or reach out towards the defenceless, and often naked, infant child. Reaching out can be either benevolent or malicious and can be comforting or destructive; we can reach out to caress (as Howells does in *Footwashing*), or we can reach out to hit. Caring as an inclination towards a vulnerable other is inherent in both the one-to-one performance and the medical encounter.

*Kicking Up Our Heels* was a project for parents/carers by performers within the space of the hospital. All of these ‘actors’ (that is the parents/carers, the hospital as institution and the staff that make up that institution, and the performer working on the project) are in a relationship of both power and care. As outlined above, care here is a complicated notion encompassing parental care for the child, the work of ‘caring professionals’, and the caring responsibility that must be taken on by a performer for the audience that they are engaging with. Each of these relationships requires us to put ourselves in a direct and unequal relationship with another - the parent/carer enacting power over the child, the hospital staff in a position of power over the patient and their family, and the performer asking an audience member to enter into an unusual encounter - one where the performer is in control and knows what to expect while the audience member does not. When applied to both one-to-one performance and more traditional acts of care within the hospital setting, we must be particularly alert to the inequalities at play. As Tronto highlights, we must pay attention to the aligned but distinct aspects of caring about and caring for. In order to engage in caring encounters responsibly and productively within the hospital space, these encounters must be governed by an ethics of care. We perform our care in the actions we make (that is, the daily things we do) in the hospital space as well as performances (in the theatrical sense) that make up the principal method of the *Kicking Up Our Heels* project. When Nicholas Ridout proposes that the central question is ‘how shall I act?’ in his discussion on the ethics of performance, we see a double meaning – ‘what actions shall I make?’ and ‘what theatrical performance shall I do?’ (2009: 63).

To make performance that is ethical we must consider the audience member as someone for whom the performer has a responsibility and who should be taken care of, just as the hospital professional must be governed by robust ethical thinking in their own encounters within their working lives. Amanda Stuart Fisher highlights the potential synergy between ethical performance and ethical care, arguing that an analysis of care is essential to understand performance and also that an analysis rooted in performance studies can be a means of understanding the ‘artful, aesthetic, rehearsed and performative’ elements of performing care, enacted by those in social and medical settings (2020: 3). Elsewhere, James Thompson has noted that both care giving and socially engaged performance are aesthetic encounters that require attentiveness and craft (2020: 44). Through performance, we were able to offer an opportunity for both parents/carers themselves, and for all those individuals that make up the institution of GOSH, to pay careful attention and to reflect upon the parents’ need for care within the hospital space.

# **One-to-one medical encounters**

Victoria Bates and Sam Goodman discuss the history of the medical humanities, particularly noting that the evolution of medicine and the arts are inextricably interlinked. The result of this interwoven development, they conclude, is the ‘socially contingent nature of both the arts/medicine relationship’ (2013: 6), the need to take a ‘broad approach’ when we think about what might be considered for inclusion in a discussion of the arts and medicine (ibid: 5), and that ‘the relationship between medicine, arts and humanities should be conceptualized in terms of reciprocity and exchange’ (ibid: 5). This is particularly pertinent for us when considering performance. The well- rehearsed arguments of performance studies, that enable us to examine actions and language as a series of performed encounters, lend themselves particularly well to the hospital setting, with its history of the operating theatre as a site of spectacular revelations.[[2]](#endnote-2) Similarly, every medical encounter requires a series of performances from the medic who must act out their reassuring expertise, the nurse who demonstrates compassion and professionalism, the radiographer who is a model of technical competence, and the patient who performs stoicism or humility. These performances of reassuring expertise, compassion, and so on, are in fact so embedded inside the medical encounter that they are formalised in medical education via Objective Structured Clinical Examinations (OCSEs). The OSCE (created in 1975 and developed upon in the last forty-five years) tests medical students on skills related to medical care (drawing blood, reading results, and so on), while also testing them on communication, breaking bad news, taking a history and the like. Drawing on their learning, students navigate these ‘scripts’ and are assessed according to how they hit appropriate milestones during the encounter and acting with courtesy and professionalism. These examinations, and their stature inside medical education and thus medical practice, ensure a level of consistency inside healthcare, and without this series of performances the one-to-one medical encounter would collapse, just as the one-to-one performance encounter could not happen if the performer and audience member did not performatively signal their roles

# **Care in Performance – *Kicking Up Our Heels***

In the *Kicking Up Our Heels* project parents/carers were asked to make actions with us through simple drama exercises and imagination activities, including those examples that we have shared below, that allowed them to make visible both the care they give and the care they receive while also taking time to reflect on the care they might need.

Care towards the other was evident in all aspects of the thinking, action, and values that informed the work we witnessed at GOSH, including the care shown by professional and administrative staff, support and clinical staff, allied health professionals, parents/carers, artists, and others. To act with care is clearly not an alien concept within the hospital; and yet, to show care to the parents/carers within the space was an area that we found to be overlooked, both within the processes and practices of the hospital and by the parents/carers themselves.

Ruddick asserts that, when we act with love, we are rewarded by seeing our child flourish (1989). Conversely, we can act with love and yet the child still succumbs to illness or to social or political events which prevent them reaching their full potential. When this happens, Ruddick notes, we are left with ‘anguish… helplessness and guilt’ (1989: 30). The parents/carers we encountered in GOSH were asked if they wanted to engage in a short performance encounter led by either one or the other of this chapter’s authors to creatively imagine a space where they could be free from any anguish, helplessness, or guilt. We asked them to imagine that we had a magic wand that could ensure they could travel anywhere they wanted, real or imaginary, while knowing that everyone that might need them was safe and happy and that there would be no urgent calls from hospital staff or distressed children. The spaces that parents/carers imagined included:

* It would be a beach, white sand, clear sky, just the noise of the water and maybe family. nearby. Cold drink like a Sprite or 7up. I don’t want any music, just sea and birds.
* A proper bed, a separate room for the patient and family with a nice view.
* A holiday, with the kids. Big villa. Swimming pool. Infinity pool. Peaceful so you can hear the birds. Soothing. No phone charger. Archers & Lemonade. All the alcohol.
* Technology is an escape – I can keep in touch with friends, without having to talk about what’s going on here. Normal life is an escape.
* Home. Most of his life was here in hospital.
* America, for treatment, anywhere for her.

These responses reveal not just what these parents/carers want, but also what they are lacking; normality, care, sleep, and peace came out very strongly on the list of the kinds of care that parents/carers need but do not have access to when their child is resident in hospital. In articulating these things, which many take for granted, we are shown a vision of what is denied when caring for a child who is undergoing serious medical treatment. Parents/carers are able to speak from a position of authority about their own needs when sharing these images through engaging in a short interaction – they are treated as the expert on what it is that they desire, and power dynamics are momentarily reversed. We also worked to publicly acknowledge parents’ own expertise by asking them to share advice that they would offer to another parent/carer coming into the space. When parents/carers shared this wisdom with us, we wrote it on an eye mask and offered it back to them; this gifting back of their own advice enabled parents/carers to recognise their own knowledge and also reminded them to show the levels of compassion towards themselves that they might show to someone else. The final ‘You’re Doing a Great Job’ leaflet that was produced as part of the *Kicking Up Our Heels* project was subtitled ‘advice from parents for parents’; again, this was an attempt to acknowledge the parents/carers themselves as experts in their own needs and situation and to attend to the inequalities of power found within the theatrical performance and hospital space.

# **What we learned from one-to-one bedside performances at GOSH**

The nature of one-to-one performance makes it a challenging artform to document (lest you interrupt the one-to-one-ness) and evaluate (unless you capture and quantify each possibility for interaction), but over many performances, patterns and learnings begin to emerge. The learning we have drawn from our series of one-to-one performances, therefore, coalesces around some themes, while other details remain in orbit. The patterns and the outliers are, of course, both interesting to performance studies and healthcare practices. For example, we learned that the ubiquity of hospital surveys, which meant that parents/carers were used to sharing information, made it easier for us as artist/researchers to approach parents/carers. Parents/carers do surveys constantly and feel a drive to contribute to knowledge towards the betterment of the hospital and the affirmation of good practice; because of this comfort, we were probably successful (if we measure success by a parent/carer choosing to engage in an encounter with us) with 80% of the parents/carers that we approached, as reported in Anna Ledgard’s final evaluation of the project (2020). Though the pull of the survey was a gentle way to begin a performance, some parents/carers still chose not to engage with us. Reasons for not participating cited by parents/carers were often related to their child’s needs (or the child’s needs being a convenient excuse when they just did not want to be bothered), exhaustion, not being the central caregiver so they would not want to speak on the subject, personal business, or a desire for rest. We also had to end a number of encounters soon after beginning them, and before the parent/carer was ready to finish, because of medical priorities; for example, when a child was called away for an x-ray or a doctor came for a consultation. The external evaluator noted in her final report:

There was a high take up of parental involvement (80% of those who were approached took part). Most of those who declined did so for understandable reasons (clinical procedures/other visitors etc.). When compared with the uptake of other parental surveys the artistic approach had a considerably higher uptake (Ledgard, 2020).

We leave *Kicking Up Our Heels* with the knowledge that the survey technique is useful and worthy of more attention. Parents/carers desperately want to give feedback to the hospital but are often afraid to be critical or ‘too difficult’ lest it impact on their child’s care. A performance survey might enable a moment to hear this feedback in order that the service can improve for all concerned. A notable example of this is that the findings from the *Kicking Up Our Heels* project were used to inform the development of the physical spaces of the new children’s cancer centre at GOSH. Bringing performance, research, and other engagements to the bedside makes it easier for parents/carers to fit them into their demanding, and often chaotic, days in the hospital, and allows participation where they might not be able to otherwise engage in any arts activity or in the feedback to the hospital that they are so committed to improving and supporting.

Another aspect of our performances that may account for our success in engaging with parents/carers, was the role of costume and status. We learned that ridiculous bathrobes and colourful shoes are a way to seem non-threatening and approachable to parents/carers and their children. Further, we found that being honest about our own position in the hospital as people who have a history of receiving care as patients and as a parent/carer of a patient, enabled us to demonstrate that our knowledge was, at least in part, gained from personal experiences and to recognise that parents/carers also have a level of expertise that they can share. Of course, there was not a parity between the parents/carers and us; we were presenting as artists employed by the hospital which brings in a complex power dynamic around roles as well as serving to reassure the parents/carers that we had the necessary level of expertise to manage the performance encounter. Nonetheless, we wonder if these practices around status might also impact hospitals or healthcare practices in some way. To seem lower status, or clown-like, was helpful to break the ice, bring a smile, and get the conversation started in our performance, to bring our own history to the conversation broke down hierarchies of expertise, acknowledging that parents/carers within the hospital bring an expertise drawn from their own experiences.

From *Kicking Up Our Heels* we also learned (or were reminded) that people (parents/carers and children) love receiving a gift as part of the work; our inexpensive customized sleep-masks worked a treat. We learned (or were reminded) that language is always an issue in hospitals – particularly in an international space such as GOSH – but does not affect the ability to communicate about feelings well. We learned (or were reminded) that nearly none of these parents/carers had their first names used in the hospital. They entered the hospital with a sick child and instantly became just ‘Mum’ or ‘Dad’, to professionals and to other parents/carers. And we learned (or relearned) how parents/carers support each other in hospital settings in the smallest of ways that often feel unremarkable in retrospect (‘I poured her a cup of tea’) but life-altering and huge in the moment (‘I will never forget that person who poured me a cup of tea just when I needed it’). All four of these lessons we might have predicted, but we hadn’t, and the one-to-one form of work reminds us of small, individual stories and encounters, and to consistently take in many different people’s journeys in empathic ways.

And finally, we learned and felt deeply reminded that the length of the encounter is not an indication of the quality or depth of the exchange. Some of our sessions with parents/carers lasted well over an hour, some only a couple of minutes, but all parents/carers responded to say they had enjoyed the exchange and had a moment to reflect on their own needs. We are particularly grateful to Anna Ledgard, the external evaluator for the *Kicking Up Our Heels* project, who observed many of the encounters we undertook and was able to follow up with parents/carers about their experiences.

**Final Words**

*We are standing in the corridor after a long day of encounters with parents/carers. Our feet are tired from walking in slippers all day. We are introduced to a parent/carer who has expressed an interest in receiving a one-to-one encounter with us, but we have caught her at a bad time. Her child has just fallen asleep so we cannot go into the room for fear of disturbing them. This is the parent’s only chance to run out and get food. She chats to us for a moment and tells us she has to rush but would like to know more. We briefly explain the project and start a truncated encounter. We ask: ‘Where do you find space for yourself in the hospital?* *’. She replies: ‘I hide in the bathtub. It is child sized so I have to curl up’. The whole event takes less than five minutes. Then she leaves to go on with her day.*

The one-to-one encounter, either performance or medical, is defined in the moment by the people who are engaged in it, both are active participants and, for the encounter to be successful, both must enter into a reciprocal, asymmetric exchange, with vulnerability and care. A successful one-to-one engagement in a hospital setting can enable us to find out much about what is needed, what the experience so far has been, to develop an intimate yet fleeting relationship, and to dream together.

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1. *Confront the Cunt* is discussed in Lobel, B., R. Zerihan, and E. Kartsaki, eds. (2014). *Performing Ethos: Ethics of One-to-One Performance*, a Special Issue of *Performin Ethos Journal,* 3.2., and *Untitled Action for Bombshelter* is documented in O'Reilly, K., (2018) *Untitled (Bodies)*, Live Art Development Agency: London. [↑](#endnote-ref-1)
2. See Michel Foucault’s *The Birth of the Clinic* (1963) for a discussion of the hospital as the site of spectacular revelations. [↑](#endnote-ref-2)