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# The emotional impact of cancer on children and their families\*

Anthony Lee and Jane Elfer

College London Hospital (UCLH) is part of the Department of Child and Adolescent Psychological Medicine, which also comprises teams of clinical and systemic psychologists and child and adolescent psychiatrists. With two other child and adolescent psychotherapists and a child and adolescent psychotherapist in training, we provide a psychoanalytic psychotherapy service to children and their families and to young people referred from within the hospital. We dedicate a significant proportion of our time to work with the young people who are treated in the teenage and young adult service, as well to the many young children who are treated here for their cancer in the paediatric service. A high proportion of children with brain tumours come to UCLH for radiotherapy treatment.

In this chapter, we consider aspects of our experience of working closely with children with cancer. Through case material and with reference to the literature, we will attempt to construct a narrative around

<sup>\*</sup>Throughout, unless referring to a specific case, we denote the masculine for the child, the feminine for the therapist, and use the term "parents" to refer to any adult or adults who may care for the child.

the emotional impact of cancer on children and their families. It is an account drawn from our close observations of the children and their families and from our countertransference responses from being in their company.

#### The emotional impact of cancer

A diagnosis of cancer immediately raises consummate anxieties both conscious and unconscious, around loss, dying, and death. This is in stark contrast to the more ordinary anxieties—and joys—around a child growing up that are associated with his emerging bids for independence. Children diagnosed with cancer may find themselves relying on their parents physically and emotionally in ways that may have been more typical of when they were younger. This may be the case for any child with a serious or disabling illness, but the anxieties surrounding thoughts of loss, death, and dying, bring a quality of omnipresent terror that can have profound effects on the child and his family. The diagnosis, the shock, the urgency of the treatment, the demolition of ordinary life is traumatising; the resultant uncertainty maintains the traumatic state and may leave the child and his family undefined, disorganised, and profoundly distraught.

For each family member, such trauma is met with the erection of powerful defensive structures, where the full impact of the shock is mitigated to prevent a collapse into despair and dread. Thus, for example, the child with cancer may appear oblivious to his illness and be thought of by others as "brave", "coping amazingly", "so grown up", but at other times seen as fretful, and clingy, frightened and terrified, and at other times unreasonably demanding furious and angry. The sibling may at times tenderly temper his needs in consideration of his brother's or sister's and parents' states; at other times be distant and withdrawn. The parents may find themselves in a surreal and exhausting "going through the motions" state, which serves to hold them together to do what needs to be done, but which from time to time is punctured by the horrifying reality of what is happening. Both children and parents will, in their own ways and with varying degrees of success, attempt to restrain themselves to protect the other—at other times not. Within the family, one person's shift in state of mind will affect all the others. The ongoing dynamic inevitably leaves everyone feeling at times wrong-footed, inept, and insensitive, guilty, and angry. It can lead the family members feeling

at times dejectedly disconnected from one another. This complexity is in part explained by the fact that despite "cancer" being the common source of cataclysmic upheaval in the family, each family member will react uniquely to the trauma, both from moment to moment and in terms of their anticipation of what the future might bring.

#### Projective identification

Melanie Klein (Klein, 1974) showed how the infant, at a time in his development when he has limited capacity to integrate his experiences, instinctively deals with early anxieties and overpowering impulses by splitting off such experiences and projecting them into his parent. Betty Joseph (Joseph, 1993) writes that in its most primitive form "... projective identification is the attempt to get back into an object—to become, as it were, undifferentiated and mindless and thus avoid all pain" (p. 178). Projective identification continues to be used as a psychic defense, though to a lesser degree and for other purposes, as the child develops and grows. Wilfred Bion (Bion, 1959) felt that the process could also be understood as a means of communication, whereby the child casts the parts of his experience and inner world that are un-processed and un-digestible into the other—to have these parts received, processed, and returned in a form that makes the experience bearable and meaningful.

Irma Pick writes that the projective identifications have powerful effects on the recipient—the function of this process is to evoke a reaction: "... in so far as we take in the experience of the patient, we cannot do so without also having an experience. If there is a mouth that seeks a breast as an inborn potential, there is, I believe, a psychological equivalent, i.e. a state of mind which seeks another state of mind" (Pick, 1988, p. 35). As child psychotherapists, we must not only allow time to process these projections, but remain conscious of and process our own reactions to them. Given the inherent drive in all of us to move from discomfort, the child psychotherapist will come up against forces from within the child as well as herself, to enact—to avoid pain.

#### A child with cancer

Louis looks small and frail, but his rage was huge. He shouts at his mother and hits her with his small, balled fists. He did not want to go to radiotherapy. His mother patiently crouches down to speak to him. She gently encourages him to go down to the machine.

The machine is very large. It looks like the receiver of an old-fashioned telephone. It moves around the patient on the bed and pinpoints the beams to the diseased area. Radiographers help Louis to climb onto the bed and carefully adjust the height of the bed.

Louis has a brain tumour. He must lay very still, in exactly the same position each day, five days a week for six weeks. In order to do this he must have a head mask made—it is green with small air holes and a large hole at his mouth. The mask is screwed tight onto the bed to prevent any movement so the beams can be directed precisely at the tumour. Louis' mother helps and encourages him. The radiographers move around adjusting and correcting both the machine and the bed until all is set. They tell Louis and his mother that they are ready, and she says she will begin to count. Louis, now calm, puts his thumb in the air. He is six years old.

Everyone leaves the room. Louis, alone in the centre and fixed to the bed, stays in contact through the reassuring voices of his mother and the clinicians. The corridor from the room is long and winds round, back to the control room. This is because light travels in a straight line and the radiotherapy rays are of course dangerous. A warning sound begins. Once in the control room the mother and the clinicians can see Louis on the television screen and they speak to him through a microphone. "Okay Louis we're starting now!" The machine begins. Louis, like all the children before him, will feel and see nothing."Okay Louis, a little noise now! The machine is just moving round!" The thumb appears again, and Mother, who has been counting loudly for him, says "You're doing great Louis!" and resumes her counting. The machine moves across Louis. There is a flurry of movement as the clinicians run down to make small adjustments and then return to the control room and the radiotherapy continues. After a while: "All done Louis! We're coming down!" The treatment is finished for the day. Louis is freed from the confines of his mask and helped down from the bed. Mother congratulates him and tells him the number she had reached. It is about the same each day. "Well done!" she says and hugs him. He wriggles free and rushes to a sticker chart behind her. There are stickers ready for him and his drawing of a football pitch denotes how many "fractions" or treatments he has left.

This is a small part of Louis's treatment. He has had major surgery to remove the brain tumour—or as much as is safely accessible. Now six weeks of daily radiotherapy lie ahead of him to eradicate the remaining growth, to be followed by months of chemotherapy. This will make him sick, vulnerable to infections, and, for a time, hairless.

The journey is long and arduous for Louis and for all his family. The medical staff can also find it painful to subject children to such harsh treatments. (JE)

A diagnosis of cancer may follow on from a period of unexplained illness, where in the first instance aches and pains are treated with conventional, well-intended interventions to provide relief. Once a diagnosis of cancer has been confirmed, however, a specific treatment pathway is set out—depending on the nature of the cancer and its site. Children may often find themselves in a position of working to learn and understand about their illness during what is generally a massively disruptive period in their lives. In addition, they will be living in the company of parents who are themselves working to deal with the abject terror of such a diagnosis for their child. In essence, the child's world is turned upside down: what may once have been a life with a reasonable degree of certainty and order becomes one of huge uncertainty and disorder.

Amy, a bright and sensitive thirteen-year-old, had been experiencing increasingly severe headaches. It reached a point where she could no longer concentrate at school. The pain relief prescribed for migraine had little effect. Mother took Amy to the Accident and Emergency Department (A&E) at a weekend, where a scan showed the presence of a brain tumour. Amy's mother, a single parent of two children, was deeply distraught. Following immediate surgery, Amy underwent a lengthy period of daily radiotherapy.

Amy's consultant referred her to the service as he felt that Amy had become increasingly withdrawn. In the sessions that took place in the radiotherapy department, prior to her radiotherapy, Amy spoke of knowing the name of the cancer she had—a grade 4 glioblastoma—but not daring to look it up on the internet to find out what it meant. She lived in a pocket of frozen terror—not wanting to know, not wanting to ask questions, yet consumed by uncertainty.

Being in Amy's presence at this time, I found myself wanting to hold my breath—not daring to know. This primitive form of psychic protection adopted by Amy and projected out, served to evoke trepidation, anxiety for what being curious might reveal. The regularity of meetings helped to provide some certainty wherein I learned of Amy withdrawing from her friends so she did not have to face their questions, and withdrawing from her mother to protect her from even more distress.

After some four weeks, Amy reported in her session that she had searched on the internet to find out about her tumour. She had discovered hundreds of sites—some hopeful, others not. We sat in silence for a while. She eventually said that her cancer was a very aggressive type. She wiped the tears that streamed down both cheeks. After another period of silence, she asked me what she should do. I spoke about how she had felt she had to manage all by herself, but could now begin to think about turning to others. I said she was overwhelmed with what she had found out on the internet and that maybe it was to her consultant she should now turn. (AL)

#### The nature of trauma

We describe as "traumatic" any excitations from outside which are powerful enough to break through the protective shield. It seems to me that the concept of trauma necessarily implies a connection of this kind with a breach in an otherwise efficacious barrier against stimuli. (Freud, 1920)

Wilfred Bion described the role played by the parents in offering protection to the developing ego through their capacity to help the baby manage overwhelming emotional experiences through containment (Bion, 1967).

Melanie Klein has described an aspect of projective identification concerned with the modification of infantile fears; the infant projects a part of his psyche, namely his bad feelings, into a good breast. Thence, in due course they are removed and re-introjected. During their sojourn in the good breast they are felt to have been modified in such a way that the object that is re-introjected has become tolerable to the infant's psyche (Bion, 1962, p. 90).

Bion wrote, for example, of the terror that can engulf an infant if the mother is unable to contain her child: the experience of hunger can be felt by the infant as a terrifying pain that has no end. The mother who can help her baby to bear the wait for a feed can, over time, support the internalisation of a world that has order and is predictable and which supports the formation of a protective shield. In this way, the child is felt to be more able to deal with future adverse experiences.

When the ego's protective shield is broken through or shattered, the person is exposed not only to an external environment that feels unsafe, but an internal sense of disorder and chaos. The degree of devastation may be so complete that the traumatised person collapses completely. In most situations, however, the ego works to form a semblance of cohesion from the fragments. While cohesiveness is reinstated, the capacity to think is profoundly affected. The person traumatised may adopt a cognitive concreteness, that leads to the formation of a rigidly structured "traumatic organisation"—a "second skin" (Bick, 1968; Bick, 1986) that is defensively formed to encase the shattered ego. This organisation serves as the base for re-enactment of the trauma and thus impairs the ability to learn from experience (Bion, 1962).

Louis came into treatment with me for weekly psychotherapy after his period of radiotherapy. He attended regularly. Indeed, he missed only one session because he felt too ill to attend. Often he looked pale, and in the time after radiotherapy his radiated skin was burnt and sore. His scar from the surgery was prominent too. It induced in me a sense of pain and horror that such a small body should endure such hardship.

Initially, because Louis was exhausted by his treatment, he sat at the small table in the room and drew endless football pitches. He drew them carefully and when he made a mistake there would be sharp intake of breath and he would rub it out ferociously. I found myself at first commenting on the two sides battling it out—his team Liverpool and the opposing side, Newcastle, fighting for control of the ball. My mind whirled with the idea of a tumour and the fight to beat it. If I ventured a comment about this, he would just shake his head.

These drawings went on for some time. I found my mind going vacant at such times. I began to wonder about the safety of rules and regulations, of him needing to keep everything the same in

the face of such horrible things. Over time, I noticed that Louis' drawings began to evolve—he began to depict places that required colour and imagination. He drew a farm and a jungle, asking me to help to colour in the sky or grass. I spoke about the life that he had lived previously—full of colour and interest. He would not respond to these thoughts—would not even look at me—but he would continue to work industriously. (JE)

Being with Louis and seeing the impact the cancer and the treatment was having on his small body evoked in the therapist a sense of injustice. Older children will often verbalise how unfair it feels—what did they do that was any different to their friends? Louis' recurring drawings of a football pitch served to numb and deaden any thinking, with his effort more directed at getting the perfect football pitch, though the therapist finds a battle between life and death playing in her mind. Over time, the rigidity of Louis' defences lessened and he was able to bring variance into his drawings. Further, he turned to the therapist and invited her to become involved, thereby enlivening the space between them. In the therapist's experience, Louis was becoming more expressive, and she had a sense of a child re-emerging.

For parents dealing with their own horror, it is often hard to find the right words to speak about what is happening to their child. How can parents who themselves feel uncontained be expected to contain their child? Ahmed was three years of age when he was referred to our service—a small child with a brain tumour. His restless and aggressive behaviour was making it almost impossible for staff to manage him and to give him his medical treatment. Ahmed required daily radiotherapy for six weeks, which meant for him a daily general anaesthetic.

I met Ahmed in the playroom. He was in his father's arms and holding a large toy elephant. Without warning, he hit his father hard in the face with the toy. His father looked shocked and pained, but said nothing to Ahmed—not reacting or acknowledging the attack. At that moment, one of the doctors arrived and asked to speak to his parents. Ahmed was put down to play. He rushed about the room, as if in a panic—pulling toys out, hardly looking at them and casting them aside. He seemed not to have noticed his parents having left the room. I sat on the floor and began to

take out some more of the toy hospital equipment—bandages, the stethoscope and syringes. I took some toy animals too—horses, giraffes, zebras, and lions and began to "play hospitals". After a few minutes, Ahmed joined me. He seemed interested in my play and listened to me as I spoke with sympathetic tones to the sick animals; watched me use the stethoscope to listen to their hearts and give them injections. Ahmed bandaged one of the animals and lay them all down as though they were in a big ward. He nodded as I stroked them and continued to speak softly about them. Ahmed's parents returned and he resumed his whirlwind, manic rush around the room.

I asked to speak with Ahmed's parents and discovered that they had not spoken with Ahmed about him being so unwell and the need for the treatment. They felt that he would not understand and would only be made afraid. They had tried to distract him with new toys, but his behaviour had changed completely from a sweet lively boy to an aggressive, angry child who lashed out at every opportunity. They were heartbroken, and believed that it was the brain tumour that had caused his change in character. They felt Ahmed would never be the same again. The consultant had confirmed that Ahmed's behaviour was unlikely to be caused by the tumour, given its location. I worked with the parents to think of a way of speaking about what was happening in a manner that Ahmed could engage with and understand. I spoke of how the current situation was much more frightening for Ahmed, as he had no idea why he was in hospital. He was being treated by strangers, who at times had to do painful things to him. He was also at times witness to his parents looking upset and afraid. I suggested that the wild behaviour exhibited by Ahmed might be linked to their feelings of fright and uncertainty. I helped them to acknowledge the importance of reinstating the more ordinary boundaries that could contain Ahmed's unmanageable feelings.

Over the next six weeks, Ahmed's parents worked with me, and Ahmed began to understand why he was in hospital. He settled down and managed his daily treatment without further difficulties. Ahmed's mother had found the support so helpful that I was able to refer her to a local team for continuing help. I recently learned that Ahmed had started nursery and that he had settled well. (JE)

Ahmed was only three and his parents feared that they would lose their only child, despite reassurances from their medical team that Ahmed's tumour was treatable and that he had a good prognosis. The parents felt that it would be best to hide the "truth" from Ahmed in the belief that he was too young to understand. However, they came to acknowledge that their sense of events was also coloured with their fantasies, and how their son, bathed in their anxiety, felt alone in his fear. With no one to contain his fear and anxiety, he resorted to a muscular defence, becoming overactive and aggressive as though trying to keep fear at bay and to crush any sense of feeling small and vulnerable. The psychotherapeutic work provided them with a containing space to allow them, in turn, to contain their son.

Children below the age of ten may have only a limited understanding of their cancer diagnosis. Naturally, like Ahmed, they will look to their parents to make things right for them—to take their pain away. Children will naturally have a sense of things not being right and some may possibly know more than their parents can bear to acknowledge. The sense of the child protecting their parents was evident with Jake, who was five years old.

Jake had had many treatments. Lying in his hospital bed, he asked me to watch a DVD cartoon. He did not want me to watch it all, just a short sequence. It was an unsophisticated cartoon about some animals on a farm:

One of the daddy animals had defended the farm from a ferocious pack of wolves and in doing so had been killed. The young son of the father was bereft and in his grief returned to a spot where days earlier he and his father had happily played together. He had recalled their closeness and their joy in each other's company and had smiled.

At this point Jake turned to me to ask what I thought. I was full of sadness and a powerful sense of imminent loss. I said that Jake was letting me know how very sad it is when someone you love dies and how it was important to know that we always have those we love in our minds and in our hearts. He smiled at this in a way that conveyed a sense of relief. He turned off the television.

Jake was to go home the next day and we said our goodbye. He left me a drawing saying "I love you". Some weeks later he died

and I felt that whilst we had not been able to speak directly about his knowledge that he would die, I had understood his hope that people who we love will remember us. (IE)

#### Working with trauma

For most children with cancer, and as was evident with Amy, there may be an unsettling state that exists in them of both wanting to know and not wanting to know. The general drive to avoid discomfort unconsciously elicits in the other an urge either to reassure or the opposite—to adopt a defensive stance whereby the depth of the terror is denied. In either case, the complex state being experienced by the child is not being acknowledged. Therapeutically, the ambivalence communicated calls for the presence of a mind that can remain aware of the dissonance created from the flow of disparate projections. Attuning to the child in this manner offers a deeper understanding of their internal struggle.

I felt that it was my commentary that Louis held on to, and so as well as speaking of what he was doing in a factual way, I weaved in the emotional charge stirred in me to bring into what I said something of what his play might mean. As Louis became stronger, he explored the room and began to play with the doll's house and the domestic and wild animals. In each session in this period, Louis carefully lined up the animals outside the doll's house—with all of them looking in. I was taken with a sense of being seized upon, invaded—an image of Louis having brain surgery—a forming sense of this most inner part of the self being looked into. I wondered about Louis feeling looked into, that he was letting me know that he felt he had no privacy. He started to place the baby animals on the backs of the adult animals. I had a sense of the smaller animals getting a better view, and I wondered if he felt able to see things more clearly with the help of Mrs. E.

Shortly after, the animals began to enter the house and jump on the dolls. I described the attack and how frightening it was. There seemed to be no escape. I linked this to times when he may have been frightened and felt there was no way out. Louis listened in his way, without looking at me or acknowledging what I had said. The animals stopped invading. A mother bear and father bear and their two cubs were picked out from the animals. The cubs

magically flew around the room and had adventures climbing on the computer, landing on the door handles or light switches. As I commented, Louis maintained his silence, but seemed to attend closely to my words, in particular to the descriptions of the emotional states of the two cubs—fear if they fell, excitement when they could fly, anger when they fought, pleasure at returning to the mother and father bear. I spoke of the competition between the two cubs, especially when one fell and the other seemed triumphant. I wondered aloud about Louis' own feelings towards his sister.

Although Louis said very little, he was always keen to attend his sessions. His mother said that he looked forward to coming each week. As his treatment progressed, he became weaker and more tired—an inevitable consequence of the onslaught of the chemotherapy. Despite his physical state, in a session at this time Louis turned every piece of furniture in the doll's house upside down. He turned to his box and began to turn all the toys within this upside down. He turned the small table and chairs over. He looked at me and asked if he could turn the big chairs over too—and the doll's house. Over the course of the session, Louis had turned everything that he could upside down. I said that he was letting me know what his life was like, what had happened since he had been taken off in the ambulance.

His reaction on finishing this upside down world, was one of absolute delight. He asked if he could show his mother. At the end of the session he pulled her and his sister into the room. Mother was rather amazed. I said that Louis was perhaps showing us how upside down the world was for them all. Louis seemed proud and pleased and repeated this play during subsequent sessions. (JE)

Louis conveyed a sense of needing to be held by the concrete presence of the therapist—through her words that followed him. The therapist provided a curiosity and interest, which contained Louis and allowed him to explore the room and to use the toys to communicate to her. At each stage in his play, the understanding by the therapist seems to allow further elaboration, thereby gradually elevating the depth of the communication. The repetitive lining up of the animals, turning them all to look towards the house, seemed to show that Louis felt safe to bring the confusion he was experiencing, and evoked in the therapist a sense of intrusion, being looked into. The animals, domestic and wild,

enter into the house and jump on the dolls within. The therapist felt the attack and reflected this back, making links to Louis' own angry feelings. Placing the baby animals on the backs of the adult animals seemed to convey Louis seeing what he could not see before—leading towards an understanding and clarity through the help of the therapist. Through this understanding, Louis seemed to link with something more connected to his external world, with the bear family representing his family and, through the play, his exploration of the close relationship he held with his sister.

The upside down world seemed to convey vividly the chaos Louis and his family were all experiencing at that time. His delight—and relief—on constructing this world was palpable. His need to share this vision with his mother and sister may have also been a means of letting them know that this was not unique to him, and that they too may be able to find some relief from seeing what he worked to show. Louis seemed to have genuinely taken in his experience of his therapist, of someone who worked to bring understanding.

In working with children with cancer and their families, we often bear witness to the shock and terror of the evolving trauma. We work to support the family by listening without reassuring; providing a presence for them to express, in whatever form, the myriad of different thoughts and feelings that may arise; to stay with the distressing, painful, and at times unbearable feelings that do not yet have words given to them. We particularly strive to understand the child's perspective and support them by amplifying their communications throughout their medical treatment. Sadly, we also confront the distressing fact that some of our child patients become terminally ill and will die.

Lily is a bright fourteen-year-old. She has lymphoma, which presents as a mass in her lungs. I met her following a shockingly sudden relapse that occurred after a brief period of being in remission. The planned stem cell transplant was suspended. Instead, she had to prepare to undergo further cycles of chemotherapy with a different drug. She was angry with her consultant—who Lily felt had had no right to tell her that she was in remission. I was astounded as to how much Lily knew about the nature of her cancer, about the different drugs. She had a solid belief that she should remain fully aware of all aspects of her disease. She recounted how,

a couple of years back, she circumstantially missed a school trip with her classmates, among whom were a number of good friends. The coach the group travelled in had crashed and all but two of the children had survived. Lily understood that there must have been a reason why she was not on that coach—a purpose for her surviving this tragedy that she was yet to find. In her mind, it was not possible to succumb to the cancer. This belief gave her the strength to look the cancer in the eye, as it were.

I continued to meet with Lily weekly as an outpatient. Though unable to attend school, she maintained her desire to study, to go to college, to go to university. Lily was irritated that this illness was holding her back from her studies—from getting on with what was important. I felt somewhat intimidated by her knowledge and found myself needing to be precise in the words I used. I came to understand that the knowledge functioned as a "second skin" for Lily, for below the knowledge was a dread, as was occasionally evident when her attention was taken by the meaning of aches and pains.

Following the third cycle of the drug she had been on for the past twelve weeks, a scan revealed secondary tumours—the extent of the spread throughout her body was astounding. Lily was told a few hours before I arrived that she was terminal. She lay in her bed in a side room with the lights dimmed. Through occasional spasms of painful coughs and light gasps for air, she told me the sequence of events following her meeting with her consultant. Lily understood that she had a few weeks. She did not blame her consultantshe had done everything possible. There was a long period of no words-just intakes of breath. My throat restricted. I kept my eyes on her face. Lily stared at the ceiling. She turned and, looking directly at me, said that it was just shocking. As she articulated the unfairness, the waste of hope, I could also feel how angry she was. Suddenly, and with no warning, my mind was overwhelmed with a swell of anguish and utter despair. Lily held my eyes. A tear burst from the corner of her eye and fell on the pillow. (AL)

In working with children who are dying, the imperative is not so much to interpret, but to understand through the countertransference and bear the feelings evoked, so that the therapist can maintain her contact with the child and the family.

#### Conclusion

We have attempted to describe aspects of the emotional impact on children with cancer and their families through our work as child and adolescent psychotherapists. As part of the paediatric, adolescent and young adult cancer team, our discipline provides a component of the support that is offered to patients and their families. We work in a flexible manner that can range from single meetings following a child's consultation with their medical team, to more traditional regular contact through in-patient, in-clinic, or out-patient appointments.

At the heart of our thinking is how we work to retain a thoughtful presence in the face of the trauma we witness, in a way that best supports the child and his family through the diagnosis, their medical treatment, and often beyond. At times, we can help by separating out the different emotional experiences, with a view to keeping the family in touch with each other, by working with the whole family or sometimes the parents alone. At other times, it may help the child to feel attended to and to be with a person who is separate from their family, who they do not feel they have to "protect". At all times we endeavour to stay with the painful states if expressed and avoid the imperative to reassure. Our understanding of the emotional impact on the child and the family through these encounters is shared with the multi-disciplinary team to support a broader experience of containment for the family.

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