



Charlotte's Hospice Stay: Time for Play

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Objectives

At the end of this chapter, you will be able to:

- Reflect on the complex emotional needs of a child with a life-limiting illness and their family.
- Develop a basic understanding of holistic play development, core conditions of play and principles of CCPT.
- Review strategies for supporting a terminally ill or dying child and their family through play, using knowledge of holistic play development, core conditions and CCPT principles to inform practice.
- Self-reflect on the important role the reader holds within their practice and the future relationships they form with this demographic and their families.
- Consider self-care strategies to support emotional wellness when providing end-of-life care.

When reality is painful and a child's future not bright, we may sometimes be tempted to feel that it is kinder to leave a child in a state of not being able to think... This would be to deny the very humanity of the child and their right to a full life, whatever it may hold and however brief it may be.—McMahon [1]:165

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Introduction

A life-limiting illness can be defined as a condition or disease which has no reasonable expectation of a cure and is fatal [2]. The premature death of a child can be caused by a range of different diagnoses, some of which are related to congenital abnormalities, muscular disorders, organ failure, metabolic conditions, severe multiple disabilities or neurodegenerative and neurological conditions [3]. An illness may oscillate between being perceived as chronic or life-limiting, depending on numerous factors which determine the clinical course of the condition and the prognosis. Such factors can vary greatly depending on the cause, stability, predictability and complexity of the illness. These characteristics can determine whether the life-limiting illness is degenerative or immediately threatening and how demanding or restricting it can be for the child [4].

With technology and modern medicine continually evolving, children who might have died from a particular illness decades ago are now more likely to live healthier, productive lives [5]. However, depending on the diagnosis and prognosis of the child's illness, they could be faced with significant healthcare treatment over varying periods of time and sadly, eventually their own death. With the medical profession actively working towards the prevention and cure of childhood illness, a reduction of the physical, social, and psychological impacts is also a high priority [6]. When children have been diagnosed with a life-limiting illness, a holistic approach to their health care is necessary to ensure that both their pain is controlled and symptoms are managed, but also their emotional well-being is addressed [7].

The diagnosis of a life-limiting illness can result in the child and their family experiencing a range of stressors, particularly in relation to how their illness is managed [5]. Locating adequate health care and support services for long-term management may contribute to the stress experienced, along with factors such as financial burden, uncertainty of the future, and a subsequent increase in family tension. Living with a life-limiting illness can result in the child not being able to utilise their natural coping behaviours, due to experiencing high levels of stress, pain and anxiety [8]. As each experience of physical illness will vary, the provision of appropriate support should be unique to the needs of the child and all involved with supporting the child to enhance the likelihood of coping, understanding and adjustment.

Upon diagnosis, most children with a life-limiting illness will be admitted to hospital and then will intermittently return for medical treatment throughout their lifetime, depending on the illness, condition or disease [9]. Some may even attend a children's hospice for occasional respite or end-of-life care. Anxiety, tension, medical procedures, financial strain, uncertainty, and reliance on support services or other personnel are just some of the experiences that may have a negative individual or collective impact [5].

With a limited number of children's hospices Australia-wide and many children geographically dispersed, there is a need for paediatric palliative care services to improve the quality of life for children experiencing life-limiting conditions and their families by providing specialised support in the home or hospital [10, 11]. This chapter will draw on the author's own research, professional experience and

relevant literature to determine how therapeutic play or CCPT can be effective, holistic, safe and supportive for children living with a life-limiting illness. It will also explore how the therapeutic relationship is of importance when supporting the child and the family unit. Whilst this chapter will be focusing on the therapist's role in the context of a children's hospice, the reader is encouraged to reflect on the role that they hold within their current practice and how they can apply this knowledge to further enhance the relationships and quality of life of the children and families that they encounter.

A Progressive Brain Tumour—Charlotte's Experience

Charlotte, a 7-year-old Australian girl, with a progressive brain tumour, woke as her family pulled up in the driveway of a place she had not visited before. Charlotte's parents and brothers did not talk very much during the drive so she knew they were worried and sad. Charlotte noticed that she was also feeling nervous because she was not sure what to expect. She had heard about this place called a children's hospice and wondered whether it would be like her experience of being in the hospital. In the hospital, there were lots of people constantly coming and going from her shared room, her surroundings were not familiar, and her family could not be together all the time. Charlotte felt her heart race and a heavy feeling in her stomach, she really hoped she would like it here because she knew things were getting very tough for her body. The simplest things she used to find easy to do, such as breathing, talking, remembering things and walking, were becoming increasingly more challenging as her condition deteriorated further. A friendly nurse came to greet Charlotte and her family in the car park and Charlotte was transferred to her wheelchair. She took some deep breaths as she was wheeled through the doors and into the lift with her family. Her Mum reassuringly rubbed her arm, and the lift made a 'ding' sound. The first thing Charlotte saw as the doors opened were lots of children's photos and artworks on the walls—it already seemed like a special place where so many children had already been, and this comforted Charlotte a little.

As they entered the corridor, they were welcomed with a play space, which looked like there were lots of options of things to play with and do. The nurse introduced Charlotte to the Child Life Therapist/ Play Therapist, Lexi, then continued to show her where her room was going to be. Charlotte could not believe it! A whole room all to herself with an adjoining room where her family could also sleep. She noticed on her door there was a specially crafted name sign, on her bed there was a cosy quilt, and, on the shelves, there seemed to be lots of things that she really enjoyed, like art materials, books to read and a variety of games. Charlotte looked out the window and beyond the sunny balcony she saw some beautiful trees, a garden and the sea in the distance. The pit in her stomach seemed to have eased and this place began to feel a little more like home... In the days and weeks that followed, Charlotte's parents and brothers did not leave her side. They spoke of all kinds of things—recalled memories, shared photos, videos and laughed together. They also made plans of what things they could do during their stay, such as visit the beach,

eat ice cream, make family artworks, spend time in the garden, listen to music and play together as a family. Charlotte knew she was dying and tried so very hard to be brave and strong for her family, but sometimes she just felt like crying. Inside, Charlotte felt really scared because she was so sick, in pain and completely exhausted. She desperately wished things were different. Something that helped with these big feelings, was spending time with Lexi. Lexi always came up with fun ideas of what Charlotte and her brothers could do, which also gave her Mum and Dad a much-needed break. The more time Charlotte spent with Lexi, the more Charlotte felt safe and knew she could genuinely show all the different sides to herself. This meant, as things became physically more challenging for Charlotte when her condition deteriorated further, there was not an expectation ‘to do’ lots of things or feel certain ways, but Lexi could ‘just be’ with her when needed—something that helped Charlotte feel deeply cared for, comforted, understood and accepted, particularly when words became too difficult to form.

Child-Centred Play Therapy

The Child-Centred Play Therapy (CCPT) approach has proven to be an effective intervention for children of different developmental stages, client groups and cultural backgrounds [12]. It has long been known that the theoretical understanding behind CCPT is to enable the child to use their innate ability to strive towards growth, maturity and acceptance through self-directional play [12–14]. With consistent and repeated exposure to sensitive attunement and core therapeutic conditions such as empathy, congruence and unconditional positive regard, a mutually respectful, accepting, permissive and safe relationship evolves between the therapist and child over time [12, 15]. These facilitating elements of the relationship are the main causation for change and growth to occur within the child throughout the therapeutic experience, enabling an experiential, intuitive learning and acceptance of the self to evolve [14].

Whilst living with a life-limiting illness, the child will have a range of emotional needs related to the loss of a fully functioning or physically healthy body, their identity or the experience of vulnerability and dependence on others. Where these children often experience fewer opportunities for self-directed play and control over their lived experiences, CCPT offers them a space to freely lead, set the pace of their sessions and develop mastery [1]. With repeated opportunities for self-awareness and self-developed skills, this supports the process of self-actualisation to occur as it enables the child to completely trust themselves and their feelings, which leads to an overall feeling of peace within [16]. With an understanding of the core conditions and main beliefs that underpin the process of CCPT, the reader can reflect on how they build relationships, engage with children in their care, support children through play experiences and improve outcomes for the children and families they work with.

It is thought that to provide an appropriate and effective therapeutic experience, the therapist should carefully consider the unique needs of each child, regardless of their reasons for referral [5]. Depending on the child’s communicative or physical

abilities, such as whether they are non-verbal, experience physical limitations or are immobile, therapist expectations and certain adaptations to the therapeutic space and sessions may be necessary [8]. Considering how the space is set up and organised is important to ensure everything is accessible, appropriate and practical for the child, such as ensuring all play items are clearly visible, providing options where play experiences can be brought to the child, and flexible seating or enough room for those in wheelchairs to move freely or fit under tables with ease. The therapist should also be mindful of confidentiality and sensitive to the porous nature of hospital rooms, open play spaces or various areas within the hospice. The lack of privacy may cause the child to feel inhibited, vulnerable or exposed within their therapeutic play process and may also have an impact on the relationship [14]. Acknowledging the space limitations to the child can help create a feeling of containment within the therapeutic relationship.

Another structural consideration for the therapist is to be flexible to the child's needs with each encounter, as some children may require a shorter time with the therapist or may not be able to attend a session at all. This could be due to the ill child being physically unable to sustain a longer session if experiencing physical or mental exhaustion, feeling unwell or experiencing discomfort and pain. However, once children are engaged in play, they are often in a state of flow, where the positive feelings aroused can balance the negative feelings associated with the discomfort or pain they are experiencing [17]. With a holistic understanding of play developmental stages and considering the child's needs and capabilities, the therapist may find that they need to be more directive in some circumstances, such as presenting suitable options to the child using visuals that represent various attachment, somatic sensory, rhythmic, embodiment, projection and role play options for the child to select [18, 19]. Through aiming to acknowledge and attend to the minutest indication of interest and communication such as eye movements, symbols, signing or mirroring, the therapist is also able to establish a connection and maintain the therapeutic relationship [1].

The therapist's choice of materials also needs to be considered and adaptable to the environment that the child is in, particularly if they are in isolation, confined to a bed or require sessions in an alternate setting, such as within the hospital, hospice or home. The provision of carefully chosen toys and materials that are of a sensory, nurturing, real-world, aggressive and creative nature are encouraged as these can further support the child's emotional release, expression, thought processes, and behaviours related to their imminent death [14]. Providing unstructured play materials can also further assist with alleviating the child's anxiety and provides opportunities for regressive play, which can help to soothe and relax the child [1]. A thorough understanding of various types of play, sensory regulation and the developmental needs or interests of the child can further support the child during their stay or in moments of distress, difficulty or pain. Some strategies for consideration could include:

- Breathing, i.e. blowing bubbles, a pin wheel or using 'big belly' breathing with the support of a toy, expanding sphere or shape breathing.

- Physical touch, i.e. comfort positioning, paediatric massage, attachment-based play experiences, sand play, tactile toys or engaging with a therapy pet.
- Sight, i.e. toys that light up, visuals, pictures, bubbles and puppets.
- Sound, i.e. singing familiar songs or musical instrument play, reading children's literature or guided visualisations, tracking and reflecting.
- Smell, i.e. diffusers, mists, essential oils or bringing nature indoors with leaves and flowers.
- Taste, i.e. cooking experiences, eating familiar or comforting food, or drinking cold water (if child can eat or drink orally).

There may also be various spaces, activities and experiences that will enable the therapeutic relationship to be transferred to different contexts, such as a multi-sensory room, lounge room, garden, or a nearby park. Following a child's lead with their interests or wishes within or beyond the hospice grounds can facilitate normalisation, enhance the quality life of the child and help create lasting memories for the family as a whole.

Case Vignette—Charlotte's Experience

When a child, such as Charlotte, lives with a life-limiting illness, they may be affected in a range of ways and varying degrees of severity due to the impact that the illness has on their general health, appearance, mobility, lifestyle and social interactions [20]. Often an ill child can experience a loss of self-control, powerlessness or inadequacy as they are forced to manage daily treatments or numerous medical procedures. This may consequently cause depression, anger, resentment, anxiety or behavioural problems to emerge and can impede aspects of their development or their level of independence [6]. Physiological or emotional regression may also be a challenge, particularly for toddlers or during adolescence, as the loss of newly acquired or firmly established developmental skills need to be re-learned or re-experienced [21].

Niethammer [21] suggests that the illness and the proposed treatment plan should be explored openly with the child in a developmentally appropriate manner. Such consideration to their present understanding, ensures active involvement in the decision-making process occurs. Attempts to protect children from their illness or pending death is thought to be ineffective and potentially harmful, as an ill child is able to respond to their own internal and external cues [22, 23]. CCPT provides a platform for the child to openly explore their treatment plan, condition and potential outcomes in a developmentally appropriate way. Research has been conducted on the various phases that a child will experience during the course of their illness. Depending on their experience, it is believed that each child will process a range of information, issues and tasks during the pre-diagnosis, acute, chronic and terminal phases of their illness [23]. The ways in which a child manages or expresses their wishes, emotions and thoughts surrounding their life-limiting illness can have an overall effect on their self-concept and can be less or more challenging depending

on the child's age, what is communicated to them, their level of cognitive understanding and the longevity of the illness before it leads to death [21]. As death is an abstract concept, each child will make sense of their own mortality differently depending on their age or stage of development, revisiting or reforming their understandings throughout their life if the illness is prolonged. To support children with making sense of this complex understanding, they should be provided with opportunities to connect through play as this can naturally offer non-verbal and verbal ways to explore and enhance their understanding of their past or present circumstances and the uncertainty of their future [16].

When children are placed within a hospital environment for medical treatment of their illness, repeated stays may be necessary and could last a matter of days, weeks, months or even years. Hubbuck [24] identified that some of the biggest anxieties experienced during these stays are usually concerned with the treatment method being painful, frightening or unpleasant. These anxieties, combined with the lack of freedom, self-control and privacy, can be experienced at different intensities, depending on the child's cognitive development and the amount of separation from familiar surroundings [5]. Practical improvements to children's wards or hospitals have aided the accommodation of children's needs, such as admission and treatment preparation, flexible visitation hours, the inclusion of play programs and access to social experiences [9]. Whilst these are valid methods to alleviate anxiety and create a less threatening hospital experience for children, multiple experiences of high stress and painful procedures can cause the ill child to develop mistrust towards medical professionals over time. This is also why the establishment of a safe therapeutic environment and relationship becomes crucial for a child with a life-limiting illness, providing them with a sense of acceptance, freedom of choice, stability and opportunity for mastery [5]. Creating a home-like experience for children and their family within a children's hospice can further support the child and family to experience medical treatment and health care support in a less clinical manner.

It has been found that some children who remain hospitalised for a longer duration may not be well enough to engage in CCPT [25]. There are also some factors that may influence the outcomes of the play-based process such as, prior hospital experience, the child's coping style, timing, parental influence and the developmental stage of the child [26]. Depending on the needs of the child, access to different therapeutic approaches may need to be considered as there may be certain therapies that are more suitable or appropriate. For example, providing Music and Art Therapy within the hospital or hospice setting to children that are physically restricted, severely ill or at the end of their life [27, 28].

The Family Experience

When a child, such as Charlotte, is diagnosed with a life-limiting illness, the entire family unit can be either directly or indirectly affected depending on how the illness is responded to and how much friction or strain is experienced as a result. Changes in parenting, parent-child relationships and hierarchy of family members, may have

repercussions on the children in the family, particularly regarding self-concept, personality, emotional responses or social isolation [4]. If the illness is of life-limiting nature, the heightened experience of unrelenting stress, anxiety and anticipatory grief may impede on the parents ability to cope adequately [20]. Other factors that may also impact the family are the ill child's age, developmental understanding, level of comfortability or pain experienced, the location of the setting and whether there is access to a supportive network [20]. A study exploring the concepts of children with chronic illness conducted by Brewster [29], concluded that the coping style of the family can generally be a predictor of how well the child deals with or manages their illness. It has also been found that familial characteristics such as the ability to problem solve, be expressive, low incidence of conflict and satisfaction of medical care, can all contribute to a greater acceptance of and adaptation to the illness [30].

Understandably, when the ill child becomes the priority in the family due to the high demands of their physical health and emotional wellbeing needs, often the siblings will become unacknowledged and unsupported [31]. This can cause possible resentment, anxiety, guilt, jealousy, anger, loneliness or embarrassment to be experienced [32]. Continual experiences of such feelings can lead to the occurrence of socialisation, maladjustment and underachievement issues [33]. Therefore, opportunities for CCPT or therapeutic play can be helpful for the sibling to process and make sense of their own experiences, emotions and grief. With all these complex systemic factors in mind, a therapist's relationship with the family can play an integral role within the therapeutic process [5]. The therapist can actively support the caregivers to improve their overall understanding of their ill child's and other children's emotions, behaviours and adjustment difficulties, whilst providing insight into how they can best support them all throughout the process.

Systemic Approach to Support the Child and Family

Depending on the needs of the family, relevant and suitable support groups or services may also be offered and accessed additionally to CPPT or therapeutic play. A family-centred approach should be priority and can be achieved through thoughtful consideration of how to meet each member's needs. As there is usually a team of health, social and educational professionals involved with each case, a comprehensive and collaborative multidisciplinary approach is necessary to ensure the lives of the ill child and their family are enhanced. Hospitals or hospices may offer psychological or counselling support, Child Life Therapists, Art Therapists, Music Therapists, family support workers, social workers or community support networks to help the entire family manage the various psychological or practical needs and issues [20]. One way the therapist may work towards achieving a holistic, family-centred approach in their clinical practice is through the provision of Filial Therapy sessions. Filial Therapy can support and enhance parent-child relationships within the family using therapeutic principles such as reflection, acceptance and limit setting [34]. A study conducted by Tew [30], reported that parental attitudes towards

the illness improved and acceptance of the child increased, whilst a decrease in stress was experienced. Results also demonstrated that children within the family also experienced a lower incidence of behaviour problems, anxiety and depression.

Therapeutic play opportunities centred around memory or legacy making, can also be an inclusive experience for the whole family, supporting each member to play, connect, express their emotions and make lasting memories together. Such experiences can be facilitated by the therapist in collaboration with the family and can consist of various creative expressions or play. Examples include painting art works as a family, creatively incorporating finger, hand or footprints into art works, collecting items or mementos to include in a family memory box or scrap book, taking or collecting photographs to make a collage, jewellery making, crafting family hand moulds, creating a family story or song, documenting family memories into a journal or simply playing games together. Such playful and connected experiences can be considered stress inoculation for the family, supporting them to process their emotions in relation to the ongoing medical treatment and expected loss [17].

Chapter Summary

Play is viewed as a natural way for a child to gain control of their environment and cope with the stressors that are endured when living with a life-limiting illness [25]. Whether the child is in hospital or a hospice, therapeutic play or CCPT should be considered as integral, developmentally appropriate supports. Playful and creative experiences provide the ill or dying child with coping strategies and opportunities to express their complex emotions in a constructive, symbolic and contained way. Through such a holistic and safe process, along with the establishment of a trusting relationship, the child is also able to use play to express, explore and make meaning of their life experience, internal conflicts, thoughts, questions and misunderstandings in relation to their illness, the loss of a healthy body and pending death [14]. Change can occur in several ways as the child begins to integrate their illness into their life, enabling them to experience acceptance, awareness, control, empowerment and mastery [14, 17].

The therapeutic relationship may need to be transferred between various spaces depending on the needs of the ill child, their diagnosis, or prognosis and when medical interventions are necessary. When working with children who have a life-limiting illness, the therapeutic space can be impacted in various ways and certain factors may need to be considered such as time, maintenance of boundaries, privacy and physical alterations or adjustments. At the heart of an effective therapeutic intervention is the therapeutic relationship. Establishing a strong relationship with the child and family can support the 'therapeutic space' to be transferred to any setting or physical space when needed.

The involvement and support of the entire family is crucial throughout the process, from the initial referral/assessment phase through to the eventual ending and beyond. Adopting a family-centred approach with a holistic consideration of each family member's needs is necessary, to ensure the ill child is not being supported in

isolation. Establishing strong parental relationships is considered critical, particularly as often there is great complexity within the history, background and relationship dynamics of the family. The therapist plays an integral role in supporting the parents or caregivers to see past the physiological issues that the ill or dying child faces and enables them to comprehend the emotional needs that are present. The disentangling of such difficulties within the family enables the caregiver to consider the perspective of the child's experience. Depending on the family's circumstances and needs, additional support services may need to be accessed in conjunction with therapeutic play or CCPT, to ensure a holistic approach is implemented. The therapist may employ additional skillsets such as Filial Therapy when supporting the family, depending on their needs. Provision of such support can assist with the reparation of various relationships and positively alter the dynamics within the family unit. Other psychological or emotional supports may also be offered or provided to support the caregivers and siblings throughout the intervention.

When working with this demographic, the therapist will need to work as part of a multi-disciplinarian team to achieve a holistic approach with the family involved. In doing so, the therapist can be an advocate for the child and family whilst gaining practical skills and knowledge from other professions. Providing an array of creative interventions such as Music Therapy or Art Therapy, in addition to therapeutic play or CCPT, is important and necessary within a children's hospital as each modality can bring different opportunities to the child and family, particularly towards the end of their life. Consideration of the child's unique needs is necessary when determining which therapeutic support would be most suitable. Finally, whilst it is a privilege and can be deeply rewarding work, when reflecting on one's professional role it is important to consider the practice of regular self-care. This may look different for each person, but it is necessary when engaging in such complex and emotional work. The reader is encouraged to consider what is necessary for nourishing their own wellbeing, whether it be attending to your basic needs of adequate sleep, good nutrition, regular exercise or engaging in social interactions, playful or creative experiences, connecting with nature or attending clinical supervision and personal therapy.

Reflective Questions and Activities

- Reflect on your personal experience of death, grief and loss. How could you use this understanding when interacting with and supporting the emotional needs of the children and families in your care? What might be some triggers for you to be aware of when engaging in this type of work?
- With your understanding of the core conditions of play and principles of Child Centred Play Therapy (CPPT), how do you currently convey your personal qualities and provide a safe space for the children in your care? What could you be more mindful of in your practice?
- Consider how you would support a dying child and their family through play. How could you playfully incorporate connection to the senses to ensure the play

is developmentally appropriate for the child, i.e. sight, sound, smell, taste or touch?

- Reflect on your own self-care practices. What do you currently do to ensure you are supporting and nurturing yourself? What experiences would you like to include in your regular self-care practice?

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