

## REPORT

# 'Wiggles and rhymes': Developing a parent and infant music therapy group at a hospice for children with life-limiting conditions and their carers

**Helen Mottram**

Haven House, UK

**Maeve Rigney**

Haven House, UK

### ABSTRACT

Paediatric Palliative Care (PPC) is a relatively new and often misunderstood medical speciality. In contrast to adult palliative care, which has its foundations in oncology care, PPC focuses on enhancing quality of life for children and young people with life-limiting (LL) and life-threatening (LT) conditions. PPC embraces the whole family by offering care and support in the weeks, months or even years leading to a child's death and beyond. PPC services are offered through various statutory services as well as voluntary organisations such as children's hospices. In the UK, over 50 children's hospices provide short breaks and respite care, including symptom management and therapeutic support, placing a strong focus on high-quality, family-centred care.

Music therapy has been a core family-centred holistic care service at Haven House Children's Hospice since 2010. The service aims to address the unique and individual needs of the child as well as support the psychosocial and emotional needs of the family. This report highlights the development of the music therapy service within an expanding organisation over the past eight years and describes the introduction of a new parent-infant music therapy group, 'Wiggles and Rhymes'. The rationale and perceived benefits of offering therapeutic group work in a children's hospice are presented, with a focus on the ways in which the diverse needs of this clinical population were met within the sessions.

### KEYWORDS

Paediatric Palliative Care (PCC),  
parent-infant music therapy,  
group work,  
children's hospice,  
family-centred care

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### AUTHOR BIOGRAPHIES

**Helen Mottram** has worked as a music therapist with children and families for ten years. She currently works in a children's hospice with children with life-limiting and life-threatening conditions and within a neonatal unit with premature babies and their families, using music to support bonding and physiological changes within the babies. She also works in an NHS inpatient unit for women with postnatal depression who are hospitalised together with their babies, providing group, individual and family sessions to support relating and attachment and improve mental health. [[helenmotttramusictherapy@outlook.com](mailto:helenmotttramusictherapy@outlook.com)] **Maeve Rigney** qualified as a music therapist in 2008 and has gained clinical experience with both adult and paediatric populations since then. As the lead music therapist at a children's hospice until recently, Maeve has a particular clinical interest in the role music therapy can play in enhancing quality of life for children with life-limiting conditions and their families. Maeve is also a qualified neurologic music therapist and her current work focuses on neuro-disability and multidisciplinary work in a range of rehabilitation and community settings. [[maeverigney@gmail.com](mailto:maeverigney@gmail.com)]

## INTRODUCTION

With increases in references to Paediatric Palliative Care (PPC) in medical and nursing literature, UK national bodies such as The National Institute for Health and Care Excellence (NICE) provide guidelines for the planning and management of end-of-life care for infants, children and young people. In addition, media attention –such as that focused on the recent ‘Charlie Gard’ case– has meant that PPC has become a more recognised medical subspecialty and one that is seen as vital by many. This report is intended to provide an outline to PPC as an approach, focusing particularly on the role a children’s hospice plays in supporting children, young people and their families who are affected by life-limiting and life-threatening conditions. We outline the role that music therapy has played at one particular children’s hospice in the UK and the rationale for developing a specialist music therapy group to support young infants and their primary carers. By sharing two case studies from our clinical work with this group, we outline the perceived value that this type of innovative working had on a group of infants and their families and the wider impact that this had on the support they received from other PPC services.

### Paediatric palliative care

Paediatric Palliative Care (PPC) is an active and total approach to care, from the point of diagnosis or recognition of illness, through the child’s life, death and beyond (ACT, 2011). In the UK, there are over 49,000 children and young people with life-limiting and life-threatening conditions (Fraser et al., 2011). A vast range of illnesses and symptoms are seen within this population, from neonates to young adults, all with a varied and complex illness trajectory. Life-limiting conditions (LLC) are defined as illnesses for which there is no reasonable hope of cure, and from which children and young people will die. Life-threatening conditions are defined as illnesses for which curative treatment may be feasible but can fail (ACT, 2011). Children’s hospices care for and support children and young people with diverse and often rare conditions. Most commonly seen are congenital diseases (41%) and neuromuscular conditions (39%) (Spathis et al., 2012).

According to the World Health Organisation (2014), “Worldwide, over 20 million people are estimated to require palliative care at the end of life every year. The majority (69%) are adults over 60 years old and only 6% are children”. A systematic review of PPC (Knapp et al., 2011) found that almost two thirds of countries in the world have no known PPC service provision. PPC aims to support the child, and the child’s family, who may feel vulnerable as they carry the responsibility of being long-term caregivers to their loved one. Therefore, PPC should be family-centred and tailored to meet the unique needs of each child and family that it supports (Hill & Coyne, 2012) and have its foundations in a holistic approach to care (Muckaden et al., 2011). The authors write that:

When the hope of cure and prolonged survival dwindles, families and care givers may face tremendous stress. Care at this stage requires a holistic approach to the patients’ and families’ physical, emotional, and spiritual needs. (Muckaden et al., 2011, p. 52)

The impact of this care and support can determine how well equipped a family can feel to face the hardship often associated with caring for a child with a LL or LT condition. Parents often become experts in managing their child's condition through necessity rather than choice, and siblings "often manage a delicate balance between protecting their unwell sibling, their parents and themselves" (Malcolm et al., 2011, p. 2). Positive health approaches look at and build on the strengths and networks of families. In palliative care this approach is particularly pertinent in developing and enhancing quality of life. Guidelines by NICE on end-of-life care for children outline the importance of using music, play and art with this population as a way of encouraging self-expression in a creative and independent way (Smith, Stone & Mavahalli, 2016). Music therapy is recommended as part of paediatric palliative care treatment (Widdas, McNamara & Edwards, 2013) and can contribute towards promoting quality of life for families with a child with a life-limiting condition (Sheridan & McFerran, 2004).

## Haven House

Haven House is a children's hospice in North East London. It was founded in 2003 and has supported over 1000 families during this time. At the hospice, children and young people benefit from day and overnight stays including nursing care, symptom management, step-down care following a hospital admission and various play activities, as well as end-of-life and bereavement care. In 2014, Haven House established their Holistic Care Centre where children and young people can access a range of therapeutic support including music therapy, physiotherapy and yoga. Parents and family members can access pre- and post-bereavement counselling, family and sibling support, as well as a range of complementary therapies including reflexology and massage.

## Music therapy

In 2010, a music therapy post of five hours a week was established. Since then this has grown to a seven-day-a-week post of 49 hours, covered by four therapists. Music therapy is now a core hospice service, funded through specific grants via named donors as well as generic hospice fundraising revenue. Referrals are taken for individual or family input, and music therapy groups for inpatients and family group sessions are offered at weekends and during school holiday periods. Music therapy is also part of the 'Hospice at Home' project for children and young people at the end of life, or those who are too unwell to leave their homes to access hospice services on site. In 2017 a new neonatal music therapy project was developed at a local Special Care Baby Unit, and a therapist travels weekly to deliver sessions there.

## Parent-infant support

As Winnicott stated, "a baby cannot exist alone" (1964, p. 16), describing how wherever there is a baby, there is also a carer. The importance of these early relationships has been shown time and time again (Ainsworth, 1962; Bowlby, 1995; Gerhardt, 2015). Challenges may arise in this bonding process however, when a baby is born with a life-limiting condition or with complex medical needs

(O'Callaghan & Jordan, 2011). A parent may experience a tremendous sense of uncertainty and grief, and begin to mourn the loss of the 'normal' or healthy child they may have hoped for.

Caring for a child with a LLC can have a significant effect on a family system, creating everyday challenges and experiences of loss and isolation. Some children with LLCs will have had developmental difficulties identified in utero, where mothers are then offered the option to terminate their pregnancies, sometimes well into the third trimester. Other mothers experience seemingly normal pregnancies, with difficulties only evident at birth, or present following a birth trauma and subsequent acquired brain injury in the baby.

Twin pregnancies pose particular risks in this respect, with a significant number of children at Haven House forming half of a twin set, often as the sole surviving twin or, alternately, with a living, healthy twin sibling. Most children with LLCs using hospice services spent their early days, weeks or even months requiring neonatal special or intensive care. This involves periods of tremendous uncertainty around the outcome for the baby – whether or not they will live, and if so with what difficulties. Families often feel disempowered as they hand over the care of their baby to medical staff; unable to feed, change or hold them when they like. The impact of this can be long-lasting; Pierrehumbert et al. (2003) found that 41% of mothers whose babies had spent time in a NICU showed symptoms of PTSD, which were still evident 14 months after birth.

## PARENT-INFANT GROUP WORK

### Addressing a need

For children who go on to be diagnosed with LLCs, parents' feelings of grief, trauma and loss often need to be side-lined as families quickly learn to adjust to the complexities of living with a child with significant medical needs. Endless appointments, rounds of medication and tube and gastronomy feeding often have to be juggled with caring for other children. Hinjosa et al. (2012, p. 500) describe how family caregivers of children with life-threatening illnesses are impacted by "higher levels of burden, uncertainty, greater depressive symptoms, poor quality of life, poor health, and increased mortality". Being offered the services of a hospice and all that they can provide, at this point in time, can ignite a mixture of feelings in families. Some, so focused in the moment and day-to-day care of their sick child, can struggle with the connotations of the term 'hospice' and its associations around dying. They may continue to hold onto hope that their child will recover, or that a cure can be found, and not wish to even consider a service that suggests otherwise. Others understand that a children's hospice can offer services that compliment, add to or top up statutory ones, and are keen to utilise these.

### Literature review

Very little has been written about group family music therapy within a children's palliative care setting. Mayhew (2005) describes her work with a group of bereaved siblings within the context of a children's hospice, and Schwarting (2005) writes about the open music therapy groups that are

commonplace in British children's hospice settings, however neither of these pieces of work involve parents or the wider family. Several music therapists have written about their work with multiple parent-child dyads in group settings in other contexts, including with marginalised families and communities (Nicholson et al., 2008) and vulnerable families at risk (Kelly, 2011). Shoemark (1996) and Burrell (2011) describe their work with groups of families in community-based early intervention settings.

Much notable research into the efficacy of family interventions in group settings comes from the Australian *Sing and Grow* programme. Abad and Edwards (2004), Abad and Williams (2007), and Williams et al. (2011, p. 76) describe how their Sing and Grow Programmes aim to "enhance parenting skills, improve parent-child interactions, provide essential developmental stimulation for children, promote social support for parenting and strengthen links between parents and community services". The programme involves ten weekly group sessions of multiple parent-child dyads and targets families with children aged three and under, and has also been expanded to include children with disabilities (Williams et al., 2012). The format has inspired other music therapists to devise short-term programmes. For example Cunningham (2011) describes 'Musical Beginnings'; a ten-week music therapy programme which supports positive relating between teenage mothers and their new babies, and was based on the 'Sing and Grow' format and structure.

A number of paediatric music therapists who focus their work on parent-child interactions have written about these interventions (Flower, 2014; Oldfield & Bunce 2001; Oldfield & Flower 2008; Shoemark 1996; Shoemark & Dearn, 2008;). However, it remains evident that limited clinical work and research has been documented on the role music therapy can play in supporting the parent-child dyad in PPC, despite a strong and apparent need for specialist support for this population, particularly in the early days following a diagnosis.

Hinojosa et al. (2012) describe the uncertainty frequently felt by parents, who are rarely medically trained, in their ability to care for their extremely sick and medically complex child at home, and the increased stress and anxiety this uncertainty can cause within families. McFadyen (1994, pp. 121-122) describes how for some women, "the ability to be a Mother can be invalidated in their own eyes if the baby is very small, fragile, or otherwise disabled". A bereaved father at the hospice described his pride on receiving the results from his son's autopsy, where it was described that all his organs were a good weight, heavier than you would expect for a child of his age. He seemed to take solace in the healthiness of his son's perceived size and strength, even in death. In cases of disability or sickness at birth, the neonatal period can be accompanied by a pervasive sense of loss of a phantasy perfect child, as well as a sense of failure, as both a woman and a mother (McFadyen, 1994).

## Wiggles and Rhymes

The 'Wiggles and Rhymes' group developed from an increase in referrals to the hospice for children under the age of two. These were often families who had become accustomed to caring for their child, but frequently still held hope of, if not recovery, then at least developmental progress. As described above, music therapy is a well-established service at the hospice, with parents often requesting and participating in it but being reluctant to engage further in hospice services. We

introduced *Wiggles and Rhymes* as a closed group with a fixed number of parent-child dyads, in order to address this increase in referrals as well as to offer an opportunity for parents to support each other and to increase their confidence in using other hospice services.

An initial pilot group was established in the spring of 2017, run jointly by two music therapists. All children aged 0-2 currently referred to Haven House were invited to attend. We stated that the purpose of the group was to engage in an experience with their infant that was fun and that would support their development, as well as provide an opportunity for them to meet other families. The music therapy sessions were 45 minutes long and 'stay and play' sessions were offered afterwards as an opportunity for parents to chat over a cup of tea while engaging in a creative play activity with a member of the care team. This was also an opportunity for families to become familiar with the wider hospice environment and to learn more about the care services on offer, as some of these families had not accessed support at Haven House before. The aim of the group was to meet and hold in mind the parents' and children's needs equally.

The pilot became an established group that ran for a year, with eight different children attending at various times across the year. Some families attended for the duration of the year, others attended for a shorter period, and one attended just once. Thirteen adults also attended at different times, including parents, grandparents, great-grandparents, older siblings and an uncle.

This group came to a natural ending as children moved on to start nursery or school, and a second group was proposed. Due to time constraints the format changed to a short-term structure, with ten sessions on offer, and new membership, targeting children aged three and under who were not yet at statutory school age but who would benefit from a group experience.

## Aims of the group

Over time, we consolidated our aims for both groups to include:

- Promoting attachment between parent and child
- Facilitating new ways of parent-child communication and relating
- Addressing the developmental needs of the infant by stimulating and encouraging the development of new skills
- Empowering and enabling the parent to interact with their child
- Offering a supportive environment for the sharing of experiences

## Structure of sessions

The sessions followed a structured format. Parents would support their children on mats and beanbags on the floor whilst the therapists sang hello followed by warm-up songs with actions, during which the parent would facilitate their child's movements and gestures to the music. This would usually be followed by an opportunity for the children to choose which song they would like to hear next using objects of reference related to the song, such as a toy spider for *Incy Wincy Spider*, for example. A minority of children were able to choose and reach for objects, but we persisted in including this choosing time as part of the session, to encourage the idea that communicative intent

may present itself in different ways. We would rub the textured objects on the hands and arms of the children, looking for a movement, glance or vocalisation to indicate a preference. We were keen to model to parents the importance of appropriately stimulating their baby regardless of their life expectancy and degree of disability.

There would then be an opportunity to play instruments. A mixture of activities were on offer including passing an instrument around to take turns, all group members playing the same instrument and an option to make choices of different percussion instruments. All activities would be accompanied by a song related to the activity, with a mixture of familiar and new songs on offer, in order to develop a parent's confidence to sing already-known songs to their children as well as expanding their repertoire with new ones. The therapists would take it in turns to lead the activities, with the non-leading therapist moving between the parent-child dyads to offer some more individualised support and interaction.

The tempo of the sessions would be paced to match the needs of the group, but would usually involve increased action and activity in the middle before a 'warm-down' activity towards the end, involving a slower, less percussive combination of song and instrument such as the wind chimes or ocean drums. The sessions would end with a goodbye song to each child in turn, after which the therapists would be available to answer any questions the parents might have, before escorting them through to the Stay and Play.

## CASE STUDIES

With an indication given as to the rationale and development of the sessions, this section of our report focuses on two particular infants and their parents who attended *Wiggles and Rhymes* for a period of time. These case studies highlight their clinical and psychosocial needs, and how the group supported them in similar and different ways and the clear benefits received by both.

### Anna<sup>1</sup>

Anna was three years old, and had been one half of an identical twin set. Their mother, Monika, experienced a healthy pregnancy, attending the fortnightly scans that are commonplace in twin pregnancies. A week before her final scan the babies suddenly experienced twin-to-twin transfusion, where the majority of nutrients are redirected by the placenta to one twin. The effects of this can be catastrophic for both twins – in this case it was Anna's twin who received the sudden influx of nutrition and, unable to cope, died in utero. Monika discovered this at her final scan a week later. Anna was born at half the weight of her sister, and suffering a myriad of complications, including chronic kidney disease. She spent several months in hospital and experienced a severe kidney infection. Her heart stopped for four minutes, causing what was thought to be irreparable brain damage. McFadyen (1994) describes how intrauterine death involving one twin is rarely mourned in the way that a single miscarriage or stillbirth is, and that there is "little opportunity for grief" (p. 152) when there is a live baby fighting for survival, but that the loss is often felt later on.

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<sup>1</sup> Names have been changed to protect the individuals' identity, and informed consent received for the writing of the case studies presented here.

Anna's parents lived in a very deprived part of London, and shared a house with other occupants. They had just one room in which to care for their extremely sick baby. They had family abroad but no family and few friends in the UK. Anna's father went back to work, leaving Monika to manage the unending task of trying to keep Anna alive and in reasonable health. Their weeks were punctuated by frequent trips to hospital and endless outpatient appointments as the doctors tried to maintain her kidney function.

Anna's family were referred to the hospice for emotional support and respite care. On coming to look around, Monika cried at the sight of older, profoundly disabled children in wheelchairs. Clearly struggling with the enormity of her child's needs, and not ready to be around other parents or children, they were referred for individual music therapy and ten sessions were initially offered for Anna and Monika to attend together. Anna's portage worker (a home-visiting educational service for pre-school children with SEND and their families) attended the sessions on Monika's request and her familiar presence seemed to ease Monika's anxiety around being somewhere new. Anna presented as a very pretty child, small for her age, who smiled frequently to her mum's softly spoken words of constant reassurance in her native tongue. As language was a barrier to the interactions with the therapist, the music acted as the primary means of communicating, and Monika quickly found instruments, soft puppets and scarfs to use to engage gently with Anna, who was held tightly by her throughout the sessions. Sessions were used to work on providing Anna with opportunities to experience new ways of interacting, with the therapist's role to validate her reactions and responses to the music and instruments that were used. The early sessions felt full of sadness, with Anna and Monika often crying softly together in their tight embrace as the therapist offered them a sense of holding and containment via the music. As Monika's confidence increased weekly she seemed to attend with a greater sense of enthusiasm and hope for what might be gained from the sessions. Anna seemed to pick up on this and began to smile, vocalise, open her hands and become more open to the music in the room. This led to playful and upbeat interactions between the trio. Mum expressed her joy in these interactions and at the end of the block of sessions wrote to the therapist to say how much they had enjoyed their time in music therapy, and enquired about continuing.

Whilst on the waiting list for further music therapy input, Anna was referred for a monthly therapeutic yoga group at the hospice. Monika later expressed her anxiety about attending with other children with disabilities; but at home, alone and isolated, she decided the benefits to Anna were such that she needed to overcome her reticence. Following the yoga group, she spoke of how she had seen Anna responding to the other children, turning her head and vocalising, and asked if there were any more opportunities for other groups. Thus they were referred to *Wiggles and Rhymes*.

During a pre-group home visit the therapist found Monika to be tearful and seemingly still extremely traumatised from their experiences surrounding Anna's birth. She described how Anna's twin sister's heartbeat had stopped in utero, saying 'it happened at home', and seeming to feel as if she should have somehow known and been able to do something about it. The two could be observed to be extraordinarily connected, almost bound by an invisible umbilical chord. Monika was attentive to her daughter's every movement, sound, cry and gesture, scooping her up and speaking to her gently in their own language, and Anna responded to her with smiles and vocalisations.



McFadyen (1994, p. 152) describes how surviving twins can often be treated as a “very special and precious child”, and this seemed undoubtedly to be the case with Anna.

In the early sessions of *Wiggles and Rhymes* Monika seemed shy and a little wary of the other group members. She sat on the floor with Anna in her arms. The therapist introduced her to another mum and they quickly discovered they shared a language. This seemed to help, and she relaxed a little, conversing quietly with the other Mum. The hello song started and Monika immediately seemed transformed by the music (a gentle lilting melody in 2/4). A state of calm seemed to come over her as she began to rock Anna gently in time. She quickly learned the words and sang along quietly. They moved through the sessions together, interacting and participating. Monika had an innate sense of rhythm and used this to interact with Anna. She supported her movements and actions on the instruments, and grew more confident in requesting different kinds of instruments, including an African thumb piano, showing it to Anna and playing it gently for her.

The block of sessions passed quickly. Attempts by the therapist to bring words of their own language into the sessions were met with a little shyness and awkwardness; however, Monika formed a firm friendship with another mother, exchanging numbers with her at the end, and asking to be considered for further groups in the future. She appeared more confident and self-assured, and it seemed that, as she held Anna, both physically and mentally, the framework of the sessions and the music within them, held her.

## Joshua

Joshua was a first and much wanted baby. Like Monika, Joshua’s mum, Karen, had also experienced a healthy pregnancy. It was only at a private clinic that a 3D scan detected a cleft lip. Such private clinics aren’t linked into any National Health services, and cannot advise on any signs of disability or abnormalities that they see; they can only give parents the scan picture and advise them to consult their midwives. Karen went back to her hospital for further scans, and a condition where the forebrain fails to divide into two halves, causing defects in the development of the face and brain structure, was detected. Karen was offered a termination at 33 weeks, which she declined.

Joshua spent a short time in hospital before being discharged home. His cleft lip, and subsequent cranial facial bone structure, left him prone to chest infections and to generating large amounts of mucous that he was unable to clear by himself. At two years old his eyes remained almost completely closed and he was unable to sit unaided or hold his head up.

Joshua’s parents were keen to access music therapy at the hospice, feeling that music was the only thing that Joshua responded to consistently. Joshua attended a number of individual music therapy sessions when he was nine months old. Karen and Joshua’s dad, Mark, often attended together with him, and both relished the sight of Joshua becoming more stimulated by the music, as outside of sessions he often presented in a sleepy or passive state. In discussion with his parents, the sessions aimed to promote Joshua’s participation and his motivation to explore his environment. Both Karen and Mark supported him very gently but with much encouragement and praise and, together with the therapist, worked through song and sound to bring Joshua into a more alert and active state where he could demonstrate his likes and dislikes more clearly, and share a meaningful interaction with his parents.

As a nursery worker, Karen understood the importance of play and music in early childhood and it became apparent by their regular, consistent and eager attendance that music therapy sessions played a significant role in their lives with Joshua. Karen often spoke of the times between sessions when she sang to him, and his positive responses to this. As their block of sessions drew to a close, it was felt that group work could continue to support Joshua's development and the progress he had made, as well as offering his parents an opportunity to meet other families and become familiar with the wider hospice and the services on offer.

Joshua was a regular attender at *Wiggles and Rhymes* from the beginning. In the early sessions he spent a lot of time sleeping, and Karen later voiced that she felt it was avoidance on his part. Gradually he began to stay awake for longer periods, and would kick his legs rhythmically. Mum would affix bells to his ankles and the therapist would match the sound he made. Exercises in his physiotherapy sessions, running concurrent to music therapy and taking place at the hospice, improved his posture and range of movements; and some of these were incorporated into the music therapy sessions, put to music. Joshua started to gain more control over his arm movements. He was highly motivated by the wind chimes, and his ability to make sweeping movements across them with his arms increased. He started to use his voice to vocalise; small sounds at first then later louder and more forceful. Both parents were quick to respond, echoing his sounds back to him and interpreting them as communicative.

A change in group membership, with a new, particularly lively, vocal little boy joining the sessions, demarked another change in Joshua. He was immediately responsive, turning his head to watch him and often seeming to vocalise in response to him. The two would appear to exchange sounds, sometimes even coughs! Joshua became increasingly active, kicking his legs forcefully and, when left unattended briefly, managing to turn himself almost full circle on his mat by the force of his kicking. His parents developed a strong sense of pride in what he was achieving, bringing other relatives to the sessions to observe him. It was clear that the group was a place where Joshua was making progress. Music seemed to form part of his identity; with Karen describing proudly how she took him to her brother's passing-out parade from the army, and how he had cried when the marching band finished, saying, 'He loves his music!'

The family took songs from the sessions home with them and utilised them there to motivate Joshua to move and interact, and bought him some of his favourite instruments from the group for his birthday and Christmas. Parents at the hospice have previously expressed how difficult events that involve present-buying can be, with often no sense of what their child's interests might be, if any, and so no idea of what to buy them. Another family described how they bought their child nice clothes instead as he couldn't play with toys, and that that was their way of spoiling him. The significance of Joshua's parents now feeling that he had interests, and being able to buy him gifts that would support this, seemingly could not be underestimated.

## Reflections

Both families appeared to gain different things from the group setting. Monika clearly benefited from the support of the other mothers, whilst her daughter Anna was able to experience being around other children and adults in a developmentally stimulating and motivating environment. Monika was

able to see this, and it seemed to help allay her fears of being around other children with disabilities. Karen and Mark seemed to take tremendous pleasure in observing Joshua's responses, initially to the music, then later to the other children; whilst they themselves seemed to be held by the structure of the sessions, arranging their weeks around the session times to the point of turning down other interventions so they wouldn't miss *Wiggles and Rhymes*. They later agreed to take part in a fundraising film for the hospice which focused on Joshua's music therapy sessions and how transformative they had been for them as a family. For other families attending the group, *Wiggles and Rhymes* appeared to act as a springboard to accessing other services at the hospice. Families went on to subsequently use both day and overnight respite care, physiotherapy and therapeutic yoga, and to attend the summer family fun days at the hospice. Service-user confidence seemed to increase as a result of their participation in the group.

All parents who attended *Wiggles and Rhymes* were surveyed at the end of the sessions. Feedback was extremely positive; of the nine respondents, all stated that they found the group either 'very enjoyable' ( $n = 8$ ), or 'enjoyable' ( $n = 1$ ). All parents also stated that attending the group had increased their confidence when interacting with their child, that they would sing songs from the sessions outside of the group and that they would attend a similar group in the future.

The positive feedback given from the parents involved highlighted the significance of this group and its potential to aid parent-infant bonding, provide stimulation and a sense of social inclusion and to promote the child's development. Supporting developmental needs, and the idea that a child might make developmental progress when prognosis and life expectancy is poor, had the potential to feel paradoxical, but as the group progressed it became clear that the children were not only responding to the music, but making progress and passing developmental milestones.

Both parents are affected by a child's illness, regardless of living or marital situation, and "parental involvement is amplified, having to respond to the increased needs of the child" (Bailey–Pearce, Stedmon, Dallos & Davis, 2018, p. 1). It is often the mother who provides the majority of care for a sick or life-limited child and becomes the parent who is indirectly "in charge" of the child's care (Yogman & Garfield, 2016). However, with more flexible working procedures in place in some organisations, and the father becoming seen less stereotypically as the 'breadwinner', opportunities are present now more than ever to involve the father in the care of their child (Yogman & Garfield, 2016). As we witnessed with Mark and Karen, *Wiggles and Rhymes* offered an inclusive invitation to family members to attend a group with their child, and the father's participation was supported and their involvement enhanced as much as the mother's.

## CONCLUSION

Haven House has compiled their 'Vision 2020', which sets out a strategy with a plan to support 500 children each year across their respite, end-of-life and community services by 2020. Part of this vision is to maximise a multidisciplinary care approach through the Holistic Care Centre. As such, more family-based interventions and services are being delivered at the hospice through therapeutic and family support services, with the entire family being held at the core of what we offer in the hope that the quality of life experiences can be enhanced by working within this holistic and inclusive framework.

Group work for a specific population in a clinical setting such as Haven House can have enormous benefits. A closed group format in particular can offer a structured framework that is limited in time and allows all participants to live a common experience from beginning to end with the potential for progress and change being explored and maximised by each participant at the same time (Tourigny & Hebert, 2007). A closed group format can create better confidence bonds and provide a sense of security and stability (Douglas, 1991), which we felt was vital to this client group at Haven House who, by the nature of the lives they led, required a consistent and predictable setting and framework within which risks could be taken and explored in a safe way.

Although a vast amount of literature now exists surrounding family-centred practices in paediatric palliative care, there appears to be a lack of literature on the role of music therapy in this field in the UK and Ireland. In 2012, Bunt, Daykin and Hodkinson published a paper that explored the provision of music therapy in Children's Hospices in the UK. They reported that only six of the 22 respondent therapists ran music therapy groups for a specific client group in their hospice, and that working with babies was listed as an area for development in the future.

We believe that a group like *Wiggles and Rhymes* is an innovative and emerging area of clinical care in a children's hospice. It is our hope that by reporting on the rationale and the setting up and delivery of a closed group session for parents and young children in a children's hospice, more music therapists and healthcare professionals across different disciplines working in this environment will be encouraged to expand the scope of their practice, where the unique and specific needs of this population can be met and outcomes achieved.

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## «Wiggles and rhymes»: Αναπτύσσοντας μια μουσικοθεραπευτική ομάδα γονέων και νηπίων σε μια μονάδα ανακουφιστικής φροντίδας για παιδιά με περιοριστικές συνθήκες ζωής και για τους φροντιστές τους

Helen Mottram | Maeve Rigney

### ΠΕΡΙΛΗΨΗ

Η Παιδιατρική Ανακουφιστική Φροντίδα (ΠΑΦ) είναι μια σχετικά νέα και συχνά παρεξηγημένη ιατρική ειδικότητα. Σε αντίθεση με την ανακουφιστική φροντίδα των ενηλίκων, η οποία έχει τα θεμέλιά της στην ογκολογική περίθαλψη, η ΠΑΦ επικεντρώνεται στην ενίσχυση της ποιότητας ζωής των παιδιών και των νέων με περιοριστικές συνθήκες ζωής (life limiting – LL) και απειλητικές για τη ζωή συνθήκες (life threatening – LT). Η ΠΑΦ αγκαλιάζει όλη την οικογένεια προσφέροντας φροντίδα και υποστήριξη για τις εβδομάδες, τους μήνες ή και τα χρόνια που περνούν μέχρι τον θάνατο ενός παιδιού και πέραν αυτού. Οι υπηρεσίες της ΠΑΦ προσφέρονται μέσω διαφόρων θεσμικών υπηρεσιών αλλά και εθελοντικών οργανώσεων, όπως είναι οι μονάδες ανακουφιστικής φροντίδας (hospices) για παιδιά. Στο Ηνωμένο Βασίλειο, πάνω από 50 μονάδες ανακουφιστικής φροντίδας για παιδιά παρέχουν σύντομες διακοπές και προσωρινή φροντίδα ανακούφισης, συμπεριλαμβανομένης της διαχείρισης των συμπτωμάτων και της θεραπευτικής υποστήριξης, δίνοντας ιδιαίτερη έμφαση στην υψηλής ποιότητας οικογενειακή φροντίδα.

Στο Haven House Children Hospice, από το 2010 η μουσικοθεραπεία αποτελεί αναπόσπαστο κομμάτι της υπηρεσίας για οικογενειακοκεντρική ολιστική φροντίδα. Η υπηρεσία αποσκοπεί στο να αντιμετωπίσει τις μοναδικές και ατομικές ανάγκες του παιδιού, και στο να υποστηρίξει τις ψυχοκοινωνικές και συναισθηματικές ανάγκες της οικογένειας. Η παρούσα αναφορά υπογραμμίζει την ανάπτυξη της μουσικοθεραπευτικής υπηρεσίας στο πλαίσιο ενός αναπτυσσόμενου οργανισμού τα τελευταία οκτώ χρόνια, και περιγράφει την εισαγωγή μιας νέας ομάδας μουσικοθεραπείας γονέων και νηπίων, την ομάδα «Wiggles and Rhymes». Στην αναφορά παρουσιάζεται τόσο η φιλοσοφία όσο και τα αισθητά οφέλη που προκύπτουν από την προσφορά θεραπευτικής ομαδικής δουλειάς σε μια μονάδα ανακουφιστικής φροντίδας παιδιών, εστιάζοντας στους τρόπους με τους οποίους καλύπτονταν οι διαφορετικές ανάγκες αυτού του κλινικού πληθυσμού στις συνεδρίες.

### ΛΕΞΕΙΣ ΚΛΕΙΔΙΑ

παιδιατρική ανακουφιστική φροντίδα, μουσικοθεραπεία γονέα-νηπίου, ομαδική εργασία, μονάδα ανακουφιστικής φροντίδας για παιδιά [children's hospice], οικογενειακοκεντρική φροντίδα