

Book Review

Ludwig, A. (Ed.). (2019). *Music Therapy in Children and Young People's Palliative Care*. Jessica Kingsley Publishers.

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Music Therapy in Children and Young People's Palliative Care provides different accounts of UK-based music therapists working in this field. The book showcases the growth of this niche area of practice, from its beginnings in 1995 with the development of Jessie's Fund¹ (Pavlicevic, 2005).

The foreword is written by Lesley Schatzberger, the bereaved mother of the fund's namesake. Her daughter, Jessica May George, died (aged 9) a few months after an unexpected brain tumour diagnosis. Jessie's legacy has enabled the exponential growth of UK music therapy in this field over the last 25 years. Schatzberger makes a pertinent point that music therapy in palliative care is often considered a "non-essential" service (p.10) despite there being a great need. Therapists develop creative and innovative ways of working with limited resources. There are strong parallels with the experiences of New Zealand music therapists during the recent pandemic lockdowns.²

I felt a sense of familiarity while reading this book, having had the experience of developing a music therapy position in New Zealand's only dedicated children's palliative care service. I thus found myself nodding in agreement to some of the obstacles and critical reflections expressed by the authors.

I thought Anna Ludwig's careful and considered editorial approach was evident. The ten chapters in this book offer diverse perspectives and a range of contrasting, innovative therapy approaches: from delicate, emotive, poignant vignettes to detailed, research-focused, objective accounts. Most of the authors are children's hospice-based music therapists with a wealth and depth of experience. They successfully show the scope of practice,

¹ <https://jessiesfund.org.uk>

² Editorial note, see for example the experiences portrayed in a collaborative article in this journal (Talmage et al., 2020)

such as developing collaborative projects with musicians and community organisations, and creating events and performances.

I identified key themes in the book which stood out for me, when thinking about my experiences and the future of children and young people's palliative care in New Zealand. One of the major themes discussed is therapist competence. The book begins with Ormiston's sensitive account of working closely with young children with high and complex needs, and those with a poor prognosis. I appreciated her gentle, honest process of critical reflection, realising that "we can do a lot by doing very little" (p.28). This helped me to reflect further on my own practice and to reconsider my approach with the individuals I work with. Ormiston advocates working with subtle responses, attuning to clients and families' needs, and looking for potential, rather than focusing on goals. Similarly, in Chapter 6, Vanstone-Howe describes three case examples of music therapists working closely with families and parents. Delicately written, with seamless flow, this chapter makes links to the theoretical underpinnings of attachment theory (Stern, 1977).

Chapters 2, 3, and 8 address the sensitive nature of this work from a community music therapy perspective, through organising concerts or public performances. For example, Ibberson and Gilroy (Chapter 3) often plan events and performances in collaboration with external organisations, in this case, with a ballet company. I had immediate concerns here as I felt community music therapy did not seem to be a good fit for palliative care. Putting music therapy work into the public domain posed ethical challenges, because of the sensitive nature of this work. However, the authors manage to strike a balance between maintaining safe, ethical professional practice and placing the wishes of the child/young person and family at the centre of the care, with clear therapeutic outcomes for all involved.

Chapter 4, by Tsisir and McLachlan, is an in-depth investigation of current service evaluation procedures. The authors indicate the need for more robust evaluation methods to examine the quality and sustainability of music therapy. Squires (2011) and Savage & Johnston (2013) wrote about music therapy evaluation in hospice care in New Zealand, but I was unable to find any literature specific to children's palliative care. Music therapy in children's palliative care in New Zealand is still in its very early stages of development. We need further research and development of practice, in order to establish models of working appropriate to our unique context.

The results of a recent exploratory survey by Hodkinson (Chapter 5) could further inform a New Zealand model of working. Hodkinson discusses the wide scope of practice and varied roles and responsibilities of UK music

therapists. Commonly agreed areas of therapist expertise include flexibility, multidisciplinary teamwork, and an “active and total approach”:

“... an active and total approach to care, from the point of diagnosis, throughout the child’s life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child or young person and support for the whole family. It includes the management of distressing symptoms, provision of short breaks, and care at the end of life and bereavement support.”

(Together for Short Lives³, cited in Ludwig, 2019, p.13)

Another significant theme is an identified gap for those transitioning between child and adult hospice services. Long-term care is typically a focus of hospice care for children and young people, whereas adult services often only provide palliative support during the last stages of life. Methods focusing on empowerment and a sense of identity were identified as being highly beneficial for young adults during this difficult period of transition between services. In Chapter 10, British music therapists Joanne Edgar and Giorgos Tsiris collaborate with New Zealand music therapist Daphne Rickson in a case study, “Moving on with Music”, a therapeutic songwriting project for young adults with life-shortening illnesses.

Many of the authors highlight a general barrier when developing services: the level of need outweighs the available resources. Due to medical advancements, children and young people are living longer, but still face life-limiting or life-threatening conditions. They, therefore, require long term support and continued access to services. In Chapter 7, Ludwig highlights the work of charities and describes the growth of one community-based charity in Scotland, the Team Jak Foundation⁴. Scotland is comparable to New Zealand in terms of population size and having large rural areas. In Scotland, as in New Zealand, many rural communities cannot access specialist palliative care. This charity provides a successful way of bridging the accessibility gap and offering the emotional and social support that children and young people require as part of total care.

What I enjoyed most about this book is its relevance to my own work experiences, and how it displays a broad scope of flexible practice. I particularly enjoyed the different ways of “telling the stories” (p.13), illustrating the high level of flexibility and holistic approach to care that is required when working in children’s and young people’s palliative care.

³ <https://www.togetherforshortlives.org.uk>

⁴ <https://www.teamjak.org.uk>

However, I would like to have also seen the inclusion of work reflecting the UK's culturally diverse population.

This book is highly relevant for music therapists and other professionals who are seeking to develop music therapy services for children and young people with high and complex needs, either under a specialist palliative service or in schools. Hospice-based music therapists in New Zealand need to consider how to develop evaluation services which will contribute to the growth of this significant and fulfilling service in children and young people's hospice care.

Working in palliative care with children and young people is challenging. However there is also much cause for hope. The growth and scope of practice described in this book are remarkable and inspiring. While there is still more to be done, it encourages me to know that many children and families are well supported by music therapists.

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