

# A Long and Winding Road:

## *Music Along with Children with Cancer Through their Journey*

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### Abstract

The WHO defines pediatric palliative care as a global model of attention to children with a disease that limits and/or threatens their life and their family life. This care should start with the diagnosis, even if this doesn't imply a bad prognosis in a short time. It's a comprehensive care strategy and philosophy and a life-affirming approach.

The music therapy approach is focused in helping children to walk through their disease contacting them with health, with empowerment, with life. Making music in different moments and scenarios, along with a supportive and empathic relationship, helps them find joy, meaning and hope.

This paper will show different moments of this journey, and will try to convey the intensity and the richness that, as music therapists at the Pelluffo Giguens Foundation since 1999, we receive as music therapists sharing musical experiences with these children.

**Keywords:** Cancer, Pediatrics, Music Therapy, Music, Journey

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## Introduction

While working on the title of this paper, I became aware of the dimension of my own journey as a music therapist. The roads I have taken have also been long and winding. They have brought me here, more than 10.000 miles away from home, to a situation I never dreamt of: being part of this conference and presenting my humble experience in working with children with cancer before such a qualified audience. Just amazing!

I would like to share with you the peculiarities of my work with these Uruguayan children, which are, of course, dyed with the colors and sounds of the culture I come from.

Uruguay is a small country, rather well-known lately because of football and famous football players. I am from Montevideo, it's capital city, where almost half of the population of the country lives I have been a music therapist for almost 20 years, and ever since the day I chose music therapy as a profession, my job has involved working for the spreading and acceptance of music therapy in the country and for the creation of a music therapy training course as part of college education, what we achieved three years ago. This is why our work has always been focused on assistance. We will not have researchers until the end of next year, when the first class of music therapy students graduates. These new professionals will allow us to give a big qualitative leap.

Despite this complex reality, it has been 13 years now since the Oncology Pediatric Center of the public hospital of Montevideo opened up its doors to music therapy, inviting us to be part of its team of professionals. This center provides health care assistance and social support to children from all over the country for free and with the support of the Peluffo Giguens Foundation, has led Uruguay to being the Latin American country with the lowest cancer mortality rate for children under 14 years old. The Center shares the "palliative care philosophy", proposed by the World Health Organization: a global model of attention to children with a limiting or threatening disease, starting with the diagnosis, even if this doesn't imply a bad prognosis in a short time. It is a comprehensive care strategy and, above all, a life-affirming approach.

I firmly believe in human musicality – the idea of **Homo Musicus** proposed by Zuckerkandl- which I first heard from Dr. Clive Robbins, when we were blessed by his visit to our country eight years ago. *Man as musician; the being that requires music to realize itself fully*; musicality as an essential attribute of the human species. This is what inspires me each time I introduce myself to a child arriving at the hospital. My purpose, my intention, will be to use music as a means for his betterment, by helping him to get in touch with his musicality, with his musical being.

The children we work with are very different in terms of personal features, age and socio-cultural background. Throughout their journey, they need to face a lot of hard issues, such as:

- The moment of diagnosis
- Different stages of treatment
- Invasive procedures all along their treatment
- Surgery
- Pain suffering and management
- Chemotherapy side effects, as nausea and vomiting
- Hair loss and other body changes
- Management of other patient's death
- Relapses

In this particular context, singing, improvising and musicing in different moments and scenarios along with a supportive and empathic relationship helps to find joy, meaning and hope. I share Rudy Garret's ideas about music as a means and as a medium. He states that *the motivation for children engaging with music has to be the musical activity in itself*. The flexibility and richness of the musical experience will facilitate participation. Eventually, almost every child will respond to the invitation to meet in the music. In this encounter, in this relational dynamic is where the work will take place, where we will always find something unpredictable and surprising.

The Plurimodal Approach, created by Diego Schapira in South America, provides an excellent framework within which I can display this philosophy. I find it versatile and very adequate for medical settings, where we need to adapt to different and constantly changing situations. It provides a clear and flexible referential framework, and a broad collection of musical tools, classified around four axes:

1. Working with songs
2. Therapeutical musical improvisation
3. Selective use of edited music
4. Receptive techniques

These musical resources are always available. We can sing, improvise, listen to music, search on the internet, produce a songbook, or whatever musical activity meets the needs of patients. Sometimes interventions aim at helping a child to face and process, through an improvisation, an invasive procedure which causes him a lot of un-controlling fear and distress. Or we can also have a sustained presence during long processes, as for example, with two girls I worked with, accompanying them with songs in various ways, along the different stages of their disease and treatment, all the way from their diagnosis until their death. Other times, interventions are just for the fun of making music together, while stimulating different cognitive and expressive skills of children, or can also be singing along, for example, with a group of mothers and their sick daughters, as a way to welcome an arriving mother with her recently diagnosed daughter...Or these three adolescents, who, while having fun playing together, came up with this combative version of a popular song:

## I Won't Give Up

If I ever I lose all the battles  
If I ever I sleep with loneliness  
If all the doors get closed  
And darkness won't leave me alone

If I ever feel scared of silence  
If standing up feels something hard to do  
If all my memories reveal  
And put me against the wall

I won't give up  
Standing up against everything  
I'll become iron, to harden my skin  
And though the winds of life blow hard  
I'm like the bending reed,  
That always remains straight

I won't give up, so I can stay alive  
I will bear the blows  
And I will never give up  
And though my dreams  
Break up into pieces  
I won't give up, I won't give up

Another piece of music I would like to share with you is the one composed by a 17 year old outpatient with a complex family situation, and an incredible musical talent. I decided to teach him how to play the recorder as a means to have something challenging he could do at home, while providing him with a meaningful relationship. He came back with this music, which he called "Bipolar day." He composed a beautiful melody, with two parts with different beats, which resemble two clearly different moods.

### Singing – Expanding the Senses

Songs carry a message, which acquires a singular meaning for each person. Songs carry a musical meaning, or *musining*, as Ronaldo Millecco says. This word, *musining*, was coined by the Brazilian music therapist Clarice Costa.

Although children do not have the history of songs that we adults have, they quickly embrace the songs they resonate with; they get attached to them, loading them with *musinings*. Songs provide the possibility of getting closer to unconscious contents that eventually contribute to our insight, while stimulating different types of memory. At the same time, they elude defensive or resistant positions.

Hanna, an 11 year old girl, finds a way to ease her suffering as she resonates profoundly with the words of this song. She says: - *I like this song, because, what it says,*

is right. I have bridges with my brother, my sisters, my great-grandmother, with my dog, .....and with my Mom. (She had died a year ago).

### The Bridge

People on one side,  
And on the other side, people  
Who doesn't live here nor there,  
But on the bridge

On one side, work,  
On the other, relatives  
And that string of light  
That crosses continents

The bridge is made of air  
Has no color, is transparent  
The bridge that goes  
From your chest to mine  
Although you are not facing me

### Conclusion

When musicing, there is a relationship of reciprocal benefit, which I find very nourishing for both, the patient and the music therapist. This is the most rewarding aspect of our profession. I feel it's a privilege to be there during those intense, highly emotional moments; to have the possibility of helping a child recover contact with his healthy side – enhanced through his musical being, and receive, at the same time, the joy and the richness of musicing together.

In this comprehensive approach, we also try to be present not only during difficult times, but also to children when they resume their regular lives, providing them with meaningful experiences which will help them get back on track. A group of recovered kids was invited to sing with a local band, called *La Saga*, a song that was composed and specially dedicated to children with cancer.

### I Love You (Yo te quiero)

I want the farthest of your dreams  
The sweetest of your kisses  
'n see you laugh when I laugh

I want to give you everything I've got  
The wildest of my dreams  
'n celebrate I'm with you

I want light in your window  
'n see the morning sun

Protecting us from cold  
Let's go dance and sing together  
Let's be loud

I love you forever, I love you  
'cause I love every little thing in you  
I love you forever, because I love  
Everything little thing in you

1, 2, 3, can you hear me? 1, 2, 3  
Today I will sing a song  
1, 2, 3, can you hear me, again?  
Today my heart will sing for you

2 and 2 is 4, 4 and 2 is 6  
Today I'll give you what you ask for  
6 and 2 is 8, and 8, 16  
I'll sing for you

As Paul Nordoff said, "You will never have more to give a child than what you have within yourself."

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## Appendix

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