

# SEN

special educational needs

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## New potential: music therapy for juvenile dementia

*Professor Adam Ockelford talks about the crucial role of music in the lives of children with juvenile dementia.*

**D**ementia in children is rare, but when it occurs, its consequences are devastating for the whole family. As with adult dementia, children gradually lose their ability to communicate, to move and to think. For some, the first sign that something is wrong occurs when they go blind, which occurs in a particular condition known as Batten disease.

### The power of music

Among the young people we studied was Laura, for whom the power of music was evident: "Her music therapy sessions have always been rich, emotionally vibrant and creative times," wrote Laura's music therapist when she was 15. "She has been able to use the sessions to express the emotions she is feeling at the time, as well as for the reflection and remembering. It's been good that she's felt able to reflect on her life and singing about the events she can remember. It is the one therapy that she is still responding to with smiles and clear enjoyment, providing a lovely time for the family to have together."

*'It is the one therapy that she is still responding to with smiles and clear enjoyment'*

For most of us, the experience of sound starts in the womb and so our understanding of music can develop before the genetic consequences of conditions such as Batten disease take hold. Music can also be one of the last effective ways of communicating as we near the end of our lives. So, while research into the place of music in all of our lives is important, it is nothing less than crucial for those with childhood dementia, who will lose their sight, their capacity to move and the ability to understand much of what is happening to them. Through all this, it seems, the brain's capacity to engage with music, at some level, remains intact.

*'Music is an indispensable element in the lives and education of people with complex needs.'*

## Research

Until recently there was little academic, evidence-based research in this highly specialised field of disability. Our research, which was supported by an eminent steering group, set out to influence educational and therapeutic practice in the field of Batten disease and beyond. It is part of a wider body of work, undertaken at Roehampton's Applied Music Research Centre, which has forged an innovative approach seeing music as an indispensable element in the lives and education of people with complex needs.

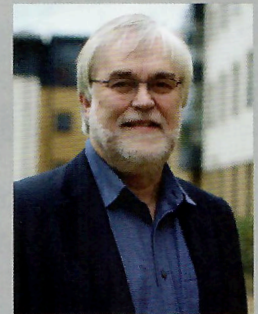
The research project, funded by the Erasmus+ scheme, was the first in a proposed series called 'MIND' ('Music in Neurodegenerative Disease'), and our principal source of evidence was 13 case studies of children and young people in the UK with Batten disease. In addition, we used data from a European survey that examined the educational implications of a variant of the Batten disease known as CLN3, which drew responses from 183 parents and professionals across six European countries. The most striking finding of this survey is that as children and young people with CLN3 grow up, music is perceived by parents and professionals to gain dramatically in importance in their lives. This happens at the expense of virtually all other activities, and particularly those that involve physical participation such as sport and dance. Crucially, our research found some children were able to keep using words for months or even years longer if they were sung rather than spoken.


## Key findings


Our key findings and recommendations suggest that for these children, active engagement in music, including the chance to learn to play an instrument, should be encouraged as early as possible. When children and young people no longer have the physical capacity to play conventional instruments, active participation in music-making should be sustainable through gesture-based music technology. For young people who could once speak, but in whom the capacity to use language expressively is declining, 'micro-songs' (short songs that incorporate functional language) can sustain the capacity to communicate through words longer than would otherwise be the case. Playing, singing and song writing can offer young people a medium through which to access and articulate feelings when other channels of emotional expression are occluded. Favourite pieces of music can be remembered when other forms of recollection diminish, and songs can be used to stimulate the recall of associated memories. Sound and music can be used symbolically to convey information about activities, places and people, potentially supporting children


## About the author

**Adam Ockelford** is a Professor of Music and Director of the Applied Music Research Centre at the University of Roehampton, London



 [ambertrust.org](http://ambertrust.org)

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and young people's understanding, communication and choice-making. Music also has the capacity to aid children and young people in regulating their emotions, and to produce a sense of wellbeing. Music offers a unique form of social activity in which children and young people can engage with family members and friends, even in the most advanced stages of the disease.

## Barriers

However, there are certain barriers that may prevent music fulfilling as complete a role as it could in the lives of children and young people with Batten disease. Music teachers are likely to lack experience of working with blind pupils and so find it difficult to adapt their usual teaching strategies. Teachers and carers who are not music specialists may also lack the confidence to use musical strategies, such as specially created 'micro-songs', that would enable children and young people to sustain communication for longer. Additionally, none of the music technology that is currently available and can be operated through gesture offers a readily affordable solution to accessibility for those with limited movement.

## Micro-Songs

The 'micro-songs', which I first created in the 1990s and developed further for the MIND research, tap into the fact that language and music share some resources in the brain. They are designed to promote the continued use of language when words alone fail. This is achieved by consistently setting key words and everyday phrases to the same fragments of melody, thereby supporting learning and recall in a way that is especially effective in children whose verbal communication skills are limited. The songs are also of potential value to those who are unable to make speech sounds at all, since by reproducing the contour or rhythm of the melodic fragment, its associated word or phrase can be implied and potentially understood.

Map of the 'micro-songs' that were used in the research project.



Among the young people who tried using micro-songs during the research was Lily, who had a strong desire to communicate but found producing comprehensible speech very challenging. Crucially, her ability to sing extended fragments of her favourite tunes, with melodic contour had been maintained as some of her other abilities had declined.

The micro-songs were systematically introduced during weekly music sessions at Lily's school, and were structured around songs of social greeting: 'Hello', 'Who's sitting next to me?', and the like; songs to promote movement and understanding; songs about feelings, children's songs, contemporary hits, and songs of relaxation such as 'Now it's time to rest', 'Music has finished' and 'Goodbye.' Lily learnt the micro-songs rapidly and retained them well, including over the breaks of several weeks brought about by school holidays. As well as facilitating social

greetings such as 'hello' and 'goodbye', choices such as 'yes please' and 'no thank you' were made, and Lily was particularly fond of expressing her feelings, and eliciting similar responses from all those in the group. She was almost invariably happy! It was evident

that, for Lily, it was important that all of those present, including staff, immersed themselves in musical activities, whose content and direction were often determined by Lily herself.

As a result of the research, The Amber Trust has set up a new free music service for visually impaired children and young people with neurodegenerative disease; 'With Music in Mind'. This aims to transform music provision for this group by providing parents, carers, teachers and therapists with freely available, specially designed resources. It offers families weekly music lessons or family sessions from specially trained music practitioners, with a particular focus on language and communication. This new music service is crucial for this small but extremely needy group, enabling them to sustain communication when words alone no longer function, to give them a medium through which to articulate their feelings when other channels of emotional expression are lost, enabling memories to be accessed and, above all, helping them to maintain a sense of well-being in an increasingly confusing and frightening inner world. **SEN**

For more on this research, go to <https://bit.ly/3qjlLO4>