

# **While the Music Lasts**

on Music and Dementia

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Research Group Lifelong Learning in Music  
Prince Claus Conservatoire / Hanze Research 'Art and Society'  
Hanze University of Applied Sciences, Groningen  
Veemarktstraat 76  
9724 GA Groningen, The Netherlands  
[www.lifelonglearninginmusic.nl](http://www.lifelonglearninginmusic.nl)

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*With gratitude to Hanze University of Applied Sciences, Groningen*

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Rineke Smilde, Kate Page and Peter Alheit



Eburon Delft

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*For most of us, there is only the unattended  
Moment, the moment in and out of time,  
The distraction fit, lost in a shaft of sunlight,  
The wild thyme unseen, or the winter lightning  
Or the waterfall, or music heard so deeply  
That it is not heard at all, but you are the music  
While the music lasts.*

T.S. Eliot (from: *The Dry Salvages*, 1941)

# TABLE OF CONTENTS

<b>Preface</b>	iv
Chapter	
<b>1</b> <i>If music be the food of love, play on</i> <b>Introduction</b>	<b>1</b>
<b>2</b> <i>...music, and only music, can do the calling</i> <b>Conceptual Framework</b>	<b>7</b>
<b>2.1 Music and Dementia</b>	<b>8</b>
The person-centred approach	9
From person-centred to biographical approach	12
Music as a new way of communication	14
<b>2.2 Communication and Participation</b>	<b>17</b>
Musicians, staff and residents	17
Widening professional and local perceptions	21
<b>2.3 Learning and Leadership</b>	<b>21</b>
Learning in transition: biographical learning, transformative learning and situated learning	21
The creative music workshop and artistic leadership	25
Applied musical improvisation	27
<b>3</b> <i>first-hand observations</i> <b>Grounded Theory - Methodology</b>	<b>33</b>
<b>3.1 Introduction</b>	<b>34</b>
<b>3.2 The pragmatist background of grounded theory</b>	<b>35</b>
<b>3.3 Our own methodological approach</b>	<b>39</b>
<b>4</b> <i>What does the song hope for?</i> <b>Analysis</b>	<b>43</b>
<b>4.1 Identity</b>	<b>44</b>
Threatened identity	44
Recognition	60
Integrity	71
Responsibility	75
Learning benefits	77
Professional identity	85
Conceptual summary	88

Chapter	
<b>4.2 Communication</b>	91
Interpretation and interaction	94
Space and pace	100
Language: quality and form	120
The role of instruments	142
Use of 'language'	146
Modelling	150
Musical frameworks	152
Leadership in interpretation	166
<b>4.3 Participation</b>	172
Participation modes	172
Curation of space	173
Transitions: opening situation	180
Breakdown of participation	185
Risk taking	192
Membership	194
Shared leadership	202
<b>4.4 Development</b>	211
Ratification	213
Improved quality of the team	220
Sustainability	222
Transitional learning	228
Community of practice	232
Conceptual summary	237
<b>5</b>	
...you are the music <i>While the music lasts</i> <b>Conclusions and Discussion</b>	239
Reflections on chosen qualitative approach	240
Research findings	242
The space of social learning	245
The space of professional learning as a musician	247
The space of a basic curriculum of Higher Music Education	248
Final note	250

<b>Appendices</b>	251
<b>I The Practice of Music for Life</b>	252
I.1 The Music for Life project	252
I.2 Practice development	258
I.3 Management and partnerships	261
<b>II Project management: Linda Rose and Peter Renshaw</b>	264
II.1 Roles and responsibilities of a project manager	264
Conceptual framework for the management of Music for Life	265
What does management look like in practice? Three scenarios	276
II.2 Reflections on project management	281
Emergent issues	284
Epilogue	288
II.3 Transferring the project	289
<b>III Passionate about connecting – founder Linda Rose</b>	292
<b>IV Protagonists</b>	297
<b>V List of musical instruments</b>	298
<b>References</b>	302
<b>List of graphics and musical transcriptions</b>	308
<b>Index</b>	309
<b>About the authors</b>	319

## Preface

This book has been written for musicians who want to engage with audiences beyond the concert hall and other traditional venues. The study is equally worthwhile for conservatoires and music academies aiming to change the increasingly unrealistic goal of training young musicians solely for the stage.

When taking the changing music profession and its market opportunities seriously, higher music education institutions can become aware of creative opportunities for establishing professional music practices in areas in society that are remote from concert halls and big festivals, from public media and stardom, and instead look for settings which reach out to various kinds of audiences. This does not mean, of course, that the results presented here wish to diminish the wonderful gift of being an accomplished soloist or chamber musician, but they would like to show that the role of music can be exhaustive, where artistic connection can bring about strong communication between people. Music can make a difference and be deeply influential, especially in social fields of illness and suffering, weakness and depression.

'Music and dementia' is the challenging topic of this book. It is not about educational suggestions to care staff to sing well-known children's songs in care homes for residents with dementia, just to lift the mood. Through engaging in music as a participatory process, its goal is to make *the person behind the dementia* visible again. The project presented in this study not only shows that this idea can be realised for people with dementia and their caregivers, but it has also opened up learning processes for the musicians involved which nobody would have expected before, nurturing their professional lives and development. The project has changed their understanding of the place of music in people's lives; it has touched their personality and stimulated deep reflections about their identity. This positive effect should benefit young musicians in their music education.

However, musicians are not the only target group. The discoveries of the study are also helpful and inspiring for caregivers of people with dementia and for families of a loved one living with dementia.

The book explores the interaction between music and dementia through the stories of people who have been working closely together: three musicians, eight women living with dementia, five caregivers, a staff development practitioner, a project coordinator and three scientific observers. The result is a book in which all of them have participated in their own way. It consists of field observations, reflective journals, conversations, interviews and careful scientific analyses. If it can be read by many people at a profit, the project has worked. There will be, in the words of Clifford Geertz,<sup>1</sup> a 'thick description' of a new friendship between music and dementia, a story about a fascinating practice that will stimulate and bolster committed people.

<sup>1</sup> Geertz 1973.



The authors would like to thank first of all Linda Rose, founder of the project 'Music for Life' and in addition Wigmore Hall and Dementia UK as well as the organisation Jewish Care in London, in particular Padraic Garrett, for their trust and cooperation. We would also like to thank Peter Renshaw for his invaluable reflective contribution to this book.

First and for all however, we are deeply grateful to the protagonists of the story, who were willing to share their learning path and experiences. We will meet and get to know them in the next chapters where we will unfold our fascinating journey.

*Rineke Smilde, Groningen (The Netherlands)*

*Kate Page, Perth (Australia)*

*Peter Alheit, Berlin (Germany)*

1

*If music be the food of love, play on...*

# Introduction

*If music be the food of love, play on...*

William Shakespeare<sup>2</sup>

# 1 Introduction

During approximately the last fifteen years we have seen an increase in the creative work of musicians and other artists engaging with new audiences in the wider community beyond the concert hall and other traditional venues. This happened first and foremost in the United Kingdom, gradually spreading throughout Europe. A decade ago, Peter Renshaw already argued that, “It is imperative that musicians and the whole arts community begin to engage in both a local and global debate about who we are and what we can achieve together.”<sup>3</sup> He felt that a fundamental challenge to the arts was to ensure that performers, composers, teachers and artistic leaders “create live, shared experiences which have something to say and make sense to audiences in different contexts.”<sup>4</sup>

Active participation in cultural activities, as for instance in participatory music-making, can be seen at the heart of building up individual and collective identity. This goes for all audiences, be it a classroom with children or a group of people living with dementia. The aim of the research into ‘Music and Dementia’ as described in this book was to explore the practice of music workshops created for elderly people with dementia and their care staff as they take place within the project ‘Music for Life’ in the United Kingdom. Music for Life was founded by music educator Linda Rose<sup>5</sup> since 1993 and has been developed in association with the organisation Jewish Care<sup>6</sup> and a growing team of musicians. Since 2009 the project has been managed by the well known concert venue Wigmore Hall, London in partnership with Dementia UK.<sup>7</sup>

## The practice

The project comprises a series of interactive creative music workshops in care homes and day care centres for people with dementia. During a period of eight weeks three musicians work with a group of eight residents and five

<sup>2</sup> From *Twelfth Night*, 1601.

<sup>3</sup> Renshaw 2001.

<sup>4</sup> *Ibid.*

<sup>5</sup> See for more information Appendix III.

<sup>6</sup> Jewish Care is described in Appendix I.

<sup>7</sup> Wigmore Hall and Dementia UK are described in Appendix I.

members of the care staff, using musical improvisation as a catalyst to bring about communication in the widest sense at various levels. The objectives of the project are to strengthen the relationships between people with dementia and those with their caregivers. Musicians and care staff work as a team within the sessions.<sup>8</sup>

The musicians use a wide range of verbal and non-verbal ways in order to reach the individual residents and the residents and care staff as a *group*. Both the pleasure in music-making and the reflection of the care staff on the impact of the sessions are important. The insights and motivation which the care staff may gain can result in positive long-term effects on their work with the residents.<sup>9</sup> This is why, during a project, a professional development trajectory for the care staff takes place, led by a staff development practitioner of Jewish Care or Dementia UK. It is important: "Staff (...) come away from the project knowing each individual better. The knowledge is not based on facts about that person's life, even though it often sparks further interest into the person's history; it is based on having seen that person express their personality."<sup>10</sup>

One project takes eight successive weeks. Three musicians, one of which serves as the workshop leader, work together with the care staff development practitioner and care staff. During each weekly session, which lasts an hour, residents and members of the care staff are seated in a circle together with the musicians. In the middle of the circle a number of easy-to-play instruments are displayed in an attractive way. At the beginning of the session the musicians play a short piece that they composed especially for the group. This 'framing piece' serves as a framework for improvisation; "it marks the cornerstone of each workshop, providing a secure and predictable start and end to each session, but also with the opportunity to be shaped in response to the mood of individuals or to the group as a whole."<sup>11</sup> The opening piece is always followed by the 'welcome song', where the names of the participants within the circle are sung, serving as a recurring tool for recognition in the sessions. From there, through active sensitive and applied improvisation, an hour of shorter and longer music pieces follows, in which the residents and care staff are activated to participate, or sometimes even to make their own piece, together with one of the musicians.<sup>12</sup>

The musicians try to reach the residents by having their antennae on full alert. The smallest verbal and non-verbal signals of the residents can be picked up by the musicians, and the care staff gradually join in the process. Once musical communication is established, for example when one of the

<sup>8</sup> Smilde 2011.

<sup>9</sup> Rose and Schlingensiepen 2001.

<sup>10</sup> Rose and De Martino 2008: 23.

<sup>11</sup> Linda Rose in Renshaw 2010: 223.

<sup>12</sup> Smilde 2011.

residents holds a baton and the musicians respond to the person's movements, however minute, often a very special kind of interaction can be observed: "The workshop space becomes a place for all kinds of exploration, experiences ranging from the most joyful and celebratory to the gently amusing and teasing to the saddest sharing."<sup>13</sup>

In the workshops musicians need a '360 degrees radar' to keep everyone in the group safe enough to cope with unpredictability, risk, and trying something new. They need to be prepared to be out of their comfort zone whilst at the same time inspiring confidence in the group.<sup>14</sup> The musicians' sensitivity toward the people with dementia is of key importance. Often people with dementia have lost their language skills. The musicians do not perceive this as a problem; one of them interviewed in the preparatory phase of the research addressed this as "listening to something that is not tied to the words they use."

After each workshop there is a debriefing session between the musicians and members of the care staff, with the aim of providing an opportunity for reflection, discussion and learning. Members learn to articulate emerging issues, and the growing trust in the team enables staff, trainers and musicians to share dilemmas, pose questions, explore insights and express vulnerabilities, creating further opportunities for lasting change.<sup>15</sup>

Research shows that being engaged in musical communication can be beneficial for people living with dementia.<sup>16</sup> The Music for Life projects also show significant relevance for the interaction between the residents and the care staff, often deepened at a tacit and non-verbal level. The projects therefore are especially concerned with identity in its broadest sense, with finding, or rather 're-finding' the person behind the dementia.<sup>17</sup>

### **Focus of the research and the questions**

With the key question being what learning and development takes place in each project, the focus of the research in this book was to explore the practice specifically from the musicians' perspective in order to inform future musician development. The research also aimed at building a clearer understanding of the dementia care context in which the musicians work in this project in order to inform their wider needs for professional development. The underpinning research questions were therefore:

<sup>13</sup> Linda Rose in Renshaw 2010: 221.

<sup>14</sup> Ibid: 224.

<sup>15</sup> Rose and De Martino 2008: 21.

<sup>16</sup> See e.g. Sacks 2008.

<sup>17</sup> Kitwood 1997: 10ff.

- | What happens in the music workshops?
- | What is learnt and what does this mean for the development of those involved?

These questions led to sub-questions addressing issues of what needs to be in place in terms of organisation, partnerships and shared understanding in order to gain quality in the project and also the question what needs to be taken into account when transferring the practice, e.g. to another country.

During a preparation phase preceding the in-depth research of one particular eight-week project, the practice of Music for Life was investigated, starting by researching existing material and holding interviews with founder Linda Rose and Padraic Garrett, staff development practitioner at Jewish Care; the observation of separate workshops and interviews with various musicians engaged in the project throughout the years.

In the autumn of 2010 a particular Music for Life project was researched, which took place in a brand new residential home in London, managed by Jewish Care, which we have called the Emanuel Zeffert House. Three musicians were part of it, they included Matthew, the workshopleader and oboist, and the supporting musicians Anneliese (harpist) and Fiona (cellist). Also the care staff development practitioner Brian was involved in the research. Field notes were made consisting of observations of each workshop; narrative interviews took place, consisting of thematic interviews with the three musicians as a group and expert interviews with the workshopleader and care staff development practitioner following each weekly session. In addition, throughout the project reflective journals were kept by the three musicians and the care staff development practitioner.

Informed consent<sup>18</sup> was sought from all participants involved, including the families of the residents with dementia who took part in the music workshops. In order to secure the privacy of the participants, their names are shaded in this book.<sup>19</sup>

### **The contents of this book**

Chapter 2 comprises a conceptual framework which aims at providing important background information related to the researched practice. It consists of three parts that address the three areas of 'music and dementia', 'communication and participation', and 'learning and leadership'. Relevant information on dementia informs what needs to be known in order to connect responsibly to the context of engaging artistically with people with dementia and their carers in the institutional environment of a residential home. The person-centred approach underpinning this practice, together with key

<sup>18</sup> See also Garrett 2009.

<sup>19</sup> See Appendix IV for an overview of the protagonists.

learning processes and styles are described, as well as the role of (applied) musical improvisation as a tool for various forms of communication.

The third chapter focuses on the methodology of the research, describing 'grounded theory', in which the theory generated through coding of data and reflection can inform the development of practice. Grounded theory is explained both historically and as a method, and finally we address the way we worked in this particular study. The most substantial part of the study, chapter 4, consists of an analysis and 'thick' description of the data, which by means of the coding results in identifying the four main themes of Identity, Communication, Participation and Development. Conclusions and a discussion close the study.

The book contains five appendices, meant to support the reader in thinking about putting the project into practice. The first appendix deals with detailed information about the project Music for Life in the UK. In the second appendix project founder and developer Linda Rose gives a comprehensive overview of what is entailed in the project management of musicians engaging with people with dementia and their carers in residential homes. It includes a pragmatic and reflective framework for the management of the project, a wide-ranging analysis of the roles and responsibilities of a project manager, observations on monitoring and evaluation, and a description of three realistic scenarios illustrating what management might look like in practice. In the same appendix, reflections on project management are given by learning consultant Peter Renshaw, based on interviews with several practitioners involved with the Music for Life project.

The third appendix consists of a biography of Linda Rose and her work in the context of this study. The fourth appendix gives an overview of the protagonists and finally a list of instruments, constituting the fifth appendix, informs the reader about the musical instruments that are used in the practice.