

1. Short introduction

My name is Martin Kresse, I am 68 years old and I care for my wife Regina who is two years younger. She was diagnosed with early onset dementia in 2014. A few years earlier, she has sensed that something is wrong and she received psychotherapy treatment as an outpatient because of depressive symptoms. Since November 2021, she lives in a care home for people with dementia because life at home with me and at the day centre was sometimes too exhausting and sometimes not stimulating enough for her.

2. How do you experience everyday life as a family caregiver?

I have experienced everyday life with my wife as enriching because she is very sensitive. She has slowed me down in a good way, she has encouraged me to use my intuition and to become creative, and she has helped me to focus on what really matters and on what is possible. Until last year, we went on nice holiday trips and I have learned: if I focus on what Regina means and not on what she says, and if I listen and respond to her feelings, we can experience a satisfying togetherness. My main task is to avoid stress for her. If that does not work, she responds with refusal and fits of rage. It was also difficult for me that she has very irregular sleep patterns. She is full of creativity and spontaneity – you could also say chaos – and my task was to understand her, to look after her, to respond to her but also to organise our life in a sensible way. I experienced that I had to fend for myself to organise help and assistance for Regina. Fortunately, I was in a rather good position because I had a good network from my activities in politics and my job. I wish for a pro-active community case management to support especially older caregivers. The new system in Germany for care levels and cost absorption has improved but we do not have enough staff in care homes and this will most likely not change in the near future.

The self-image of people with dementia and their family caregivers is changing: they want to live their life in a self-determined way in their community. Dementia is becoming less daunting and more part of normality. If we consider the demographic development, it becomes obvious that there are simply not enough people to work in care. This necessitates a change in the system: more support for people with and without disabilities in their communities and less specialised institutions, which is also in line with the UN disability rights convention. We need an inclusive social space without barriers. Professionals who work with the elderly need to spend less time with single case management and provide more community-based interventions to develop dementia-sensitive communities. Day centres, inclusive living opportunities, service points, outpatient services, counselling, self-help groups etc. all need to be available. City development needs to consider all this and make sure that there are enough spaces for young and old, disabled and non-disabled people to move and connect. Normal people need to be guided by professionals so that everyone can live together. The potential is there.

3. Why did you choose to participate in HOMESIDE?

Regina has always enjoyed creative activities. In the past, she has played in theatre groups. Later she has discovered her passion for painting and only recently, she started singing. I heard of the HOMESIDE project from my Alzheimer's society. I hoped that we would be randomised to the music intervention because I thought that Regina's new musical interest could be supported. I also always enjoyed music and especially singing. I think that the reading intervention would not have been very beneficial for Regina because her concentration and her speech has deteriorated a lot during the last year. Regina agreed happily to be enrolled in the HOMESIDE study.

4. Did you notice any positive or negative effects from the music intervention?

The mutual music activities have helped us a lot to improve our relationship. Because Regina's verbal expressions and her paintings became less and less representational, I had already learned to listen to the underlying meanings and her mood. The mutual music experiences have improved and enriched this stance. We have gained new forms of communication. We have not only used singing but also dancing and musical instruments. We have re-activated our African instruments, which has brought back the memories of our many stays in Africa. This is usually revitalizing but also sometimes sad because we are confronted with the development and all the things that are not possible any more. In the music therapy sessions, Regina sang intuitively and she often transported strong rhythmic patterns so that I chose to accompany her on the big drum. At the same time, it became apparent that her old skills in playing the recorder and guitar were not available any more. The experiences in music therapy strengthened our sensitivity to emotions, broadened our musical expressiveness and were enjoyable. For this deep emotional connection, I need a safe space and a clear time frame to protect me from emotional overload. Music therapy supported me and valued me as a family caregiver. It also helped me to understand better Regina and we are happy about the new level of connection through music when words fail or are not available any more. As the family caregiver, I was the focus of the music therapy intervention, which I found encouraging and inspiring. I sometimes translated ideas to Regina. So now we sing and hum, we move rhythmically and dance, especially in difficult situations like getting dressed to avoid stress, and it has improved very much our quality of life.

5. Do you still use the musical activities?

Unfortunately, the progression in early onset dementia is very quick and Regina is often in bed now. We still sing a lot. Dancing has turned into swaying, rocking and cuddling. Regina has recognised the music therapist better and better over the course of the video sessions and started to build a relationship with her. At the beginning, I doubted whether online video sessions could reach us. I knew music therapy from my professional life in psychiatry as a valuable psychodynamic therapy intervention that addresses the whole person. I have now learned that it is possible - despite the physical distance – to build relationships, to improve daily routines, to work biographically... In my opinion, three sessions are not enough to implement changes long-term. I really cannot understand why music therapy is not covered by health insurance in Germany, especially as effective medication is not available. Creative therapies have a positive impact on the quality of care, the quality of life and the relationship quality with the family caregiver. In Germany, physiotherapy or occupational therapy is covered by the health insurance but not music therapy. The health insurance and government should be interested in supporting family caregivers, as they are the biggest care service provider in Germany. So they should be interested to provide music therapy. Music therapy helps the person with dementia to build and keep emotional connections and it helps the caregivers to understand better their loved ones, which is needed to provide good care. Therefore, music therapy is a valuable contribution to the health system and should be recognised and receive financial appreciation.