



CREATIVE DRAMA AND STORYTELLING IN DEMENTIA CARE: INFORMATION FOR PRACTITIONERS

Intellectual Output One: Creative arts and storytelling use for people with dementia and their care partners in UK, Greece, Romania, Bulgaria and Ireland

Report prepared by the Ageing and Dementia Research Centre (ADRC) at Bournemouth University, UK in coordination with the ERASMUS partners



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FOREWORD



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In the last decades dementia care has become a very dynamic field. This has not always been the case, as 20 years ago it was characterized by profound therapeutic nihilism. With an aging population in Europe, the prevalence of neurocognitive disorders is high, and it will dramatically increase in the future.

In the “old culture” of dementia care, people living with dementia were seen more as recipients of care and not as collaborators. Another presumption was that people affected by this condition were unable to reflect or to communicate their feelings and views on their situation. The myth that older people are not “psychologically minded” and that they cannot be changed was generally spread in the care system; however, gradually, these assumptions have started to be questioned.

Until recently, there has only been limited attention paid to the development of a social construction of dementia from an individual perspective. Psychotherapies have been offered to older adults less often than to younger people. An assumed lack of insight from people with dementia was probably the most common cause of lack of cooperation within care. And, despite visible improvements, tensions are still observed due to, on the one hand, the desire to protect the individual’s rights to freedom and, on the other hand, the possible paternalistic interventions of professionals.

Professionals are still striving to find cures or truly effective means of delaying the onset of dementia and so reduce the challenges this can place on individuals affected by the condition and society, including that of caregivers and the resultant loss of productivity, employment and massive economic burden.

Although the “old culture” dementia care still operates in some places, more optimistic and dynamic approaches are becoming the norm. Below we list some of the factors that help explain this optimism.

- Firstly, the omnipresence of the condition in its various manifestations (Dementia in Alzheimer’s Disease, Vascular Dementia, Lewy Body Dementia, Fronto Temporal Dementia, Dementia in Parkinson’s Disease etc.). Old age psychiatry has evolved rapidly over the past ten years and it is now recognized as a specialty in some European countries. Advances in basic neurosciences research have significantly improved our understanding of the physiology and pathophysiology of the brain; we have now a better knowledge of the workings of molecular biology, genetics, neuron networks thanks to incredible technological as well as computational neurosciences approaches, including

modeling and large-scale data analysis/integration methods. Biological markers for specific neurocognitive disorders have been discovered and, as a consequence, since 2011 the diagnostic criteria for dementia have changed, both for clinical practice as well as in basic research.

- Over the last 30 years there has been a considerable increase in knowledge about dementia in general population as well, the public perception having changed from the view that dementia is an inevitable progression of old age to an understanding dementia as an illness.
- An important degree of attention was given in the last 20 years to listening to people with dementia and their care partners; their voice has become much more effective. It has been recognized that both professionals as well as family members who care daily for people with dementia have a contribution to make and have insights that can open up the world of dementia to the inquirer.
- Alzheimer's Societies have been set up in most European countries as well as over the world. They are energetic and articulated organizations - and this is another proof of the increasing public interest. Many books have been written by people with dementia and their care partners, many movies with this subject are also representing a significant awareness.

A new culture of dementia care has been developed and became very influential, namely the significant awareness of the importance of care as cure. Listening to people with dementia and their care partners is nowadays essential in the care process. The difficulty of seeing "the person behind the illness" when supporting people with dementia was the greatest barrier when developing psychotherapies and patterns of communications with this population. The central concern in caring for someone with dementia has become the maintenance of that person as a person. It is not easy to achieve this. If personhood is to be maintained, it is essential that each individual is appreciated in his or her uniqueness. In comparison with previous practice, the new culture of dementia care has provided a humanistic, holistic model of the person with dementia, that of a living human being-in-the-world.

There is no doubt that people with dementia are able to express their views to a much greater degree and for a longer period of time than has generally been thought to be possible. However, the literature and clinical practice too suggest communication is the core problem and that people with severe dementia are capable of insight. The responsibility for easing the communication process has to belong to the practitioners. It is a skilled job and a great deal of patience is required; it will stretch our imagination too. We have to explore the world of metaphor and symbolism and also to be open to possibilities of non-verbal communication. Hearing the voice of people with dementia is both a challenge and a journey, and we ourselves will be crucial in this process.

This has radically changed the services in the last decade - emphasizing on the significance of the relationships to which people adjust to accommodate the dementia. The importance of social interactions between people with dementia, as well as with their care partners and creative engagement with others should be seen as important aspects of the quality of care.

We speak now in dementia care about creativity and dynamism. Storytelling therapy represents a narrative approach to psychotherapy with people with dementia and creative drama means "dramatic experiencing" in which persons with dementia become engaged. Both of them are among recent interventions used in the care of people with dementia.

The booklet entitled “Creative Drama and Storytelling in Dementia Care: Information for Practitioner”, is part of a larger project funded by ERASMUS+2018 (Agreement number 2018-1-R001-KA204-049556) that aims to develop and evaluate a training program and toolkit to support the use of creative drama and storytelling amongst dementia practitioners and informal care partners and a public policy document for creating dementia friendly communities and institutions.

We hope that the project will be successful; it is likely to believe that by providing opportunities for people with dementia to tell their stories or to discuss about imagined scenarios and to be listened to, the care partners could offer them an opportunity to make sense of the world which they live and the challenges that they may have encountered.

The key message is thus to try to listen to the underlying meaning of stories and to reflect back to the person with dementia the nature of their feelings in a form that the person can make sense of; and then, to listen to the emotional meaning of the stories that are told. It is also necessary to listen to the poetical and metaphorical aspects of the stories that people with dementia tell. The focus of care must be on the needs of the whole person and the family, as perceived by the individual, at that point of time in their lives. Instead of expecting the person with dementia to “function” in our world, through these therapies we will validate their experience of the world.

We hope this booklet will contribute to the promotion of social inclusion through creative drama and storytelling and that the project Story2remember will foster the inclusion of these therapies in the standardized system of care for people with dementia as well as support the development of national dementia strategies based on the principles of social inclusion.

THE INFORMATION BOOKLET

Purpose of the booklet

This booklet provides an overview of how creative drama and storytelling are being used within the dementia care field and the benefits they may have for the well-being of people living with dementia and their care partners. It draws on theoretical understandings of 'social inclusion' to illustrate how researchers and practitioners across the globe, including within the ERASMUS partner countries, are using these creative initiatives to promote this important facet for people affected by dementia. The booklet is aimed at dementia practitioners who are currently using drama and storytelling within their practice, or have an interest in doing so in the future.

Background to the booklet

The booklet has been created as part of a wider project, funded by ERASMUS+2018 (Agreement number 2018-1-R001-KA204-049556), that aims to develop and evaluate a training program and toolkit to support the use of creative drama and storytelling amongst dementia practitioners and informal care partners such as family members. The research team consists of European partners from Alzheimer Society and Habilitas in Romania, Gaiety School of Acting in Ireland, Bournemouth University's Ageing and Dementia Research Centre in the UK, Alzheimer Bulgaria and The Greek Association of Alzheimer Disease and Related Disorders (Alzheimer Hellas). The project began in October 2018 and will conclude in September 2020. Throughout the two years the research will address four main objectives:

1. Improving health and social care professionals' competence when working with people with dementia through the development of an educational program that uses creative drama and storytelling
2. Enhancing the communication skills of family care partners of people with dementia through the use of creative drama, role-play and storytelling
3. Enriching people with dementia's well-being through the upskilling of health and social care professionals and informal care partners
4. Raising public awareness of dementia and highlighting the benefits of creative initiatives for supporting the global policy agenda of building dementia-friendly communities.

To achieve these objectives, the project will deliver four intellectual outputs (IOs), of which this booklet represents the first. The other IOs are:

- IO2: Theatre and storytelling program aimed at health and social care professionals to improve the well-being of people with Alzheimer Disease
- IO3: Toolkit for family care partners on improving communication with people with dementia through role play and storytelling
- IO4: Policy document advocating the use of creative initiatives in dementia care and supporting the development of dementia-friendly communities.





How the booklet was created

The information presented in this booklet was gathered through a combination of methods. These included an extensive review of the published academic literature (in English), conducted between December 2018 and February 2019, as well as telephone interviews undertaken with dementia practitioners throughout the partner countries during February–March 2019. This latter method was important for ensuring creative drama and storytelling initiatives that had not been published in academic journals could still be included in the booklet. An overview of the literature review process can be seen in Appendix 1 and the interview schedules are outlined in Appendix 2.

Topics covered in the booklet

The booklet is divided into four chapters. The first provides an overview of dementia and the current global political focus on supporting people to live well with the condition; paying particular attention to the social inclusion agenda and developing dementia-friendly communities. This provides the theoretical and practical context for the second chapter, where, drawing from the literature review, the use of creative drama and storytelling within the dementia care field will be discussed. The information included in this chapter will focus on where these initiatives are currently being employed, how they are being used, as well as the benefits for people with dementia and the wider social inclusion agenda. The third chapter provides an overview, and examples of creative drama and storytelling initiatives within each of the partner countries, drawing from the interview data. The final chapter draws comparisons across the ERASMUS partner countries and summarises the information contained throughout the booklet. Based on these conclusions, it then outlines recommendations for policy and practice within this field.

Chapter 1:

DEMENTIA AND CURRENT POLICY

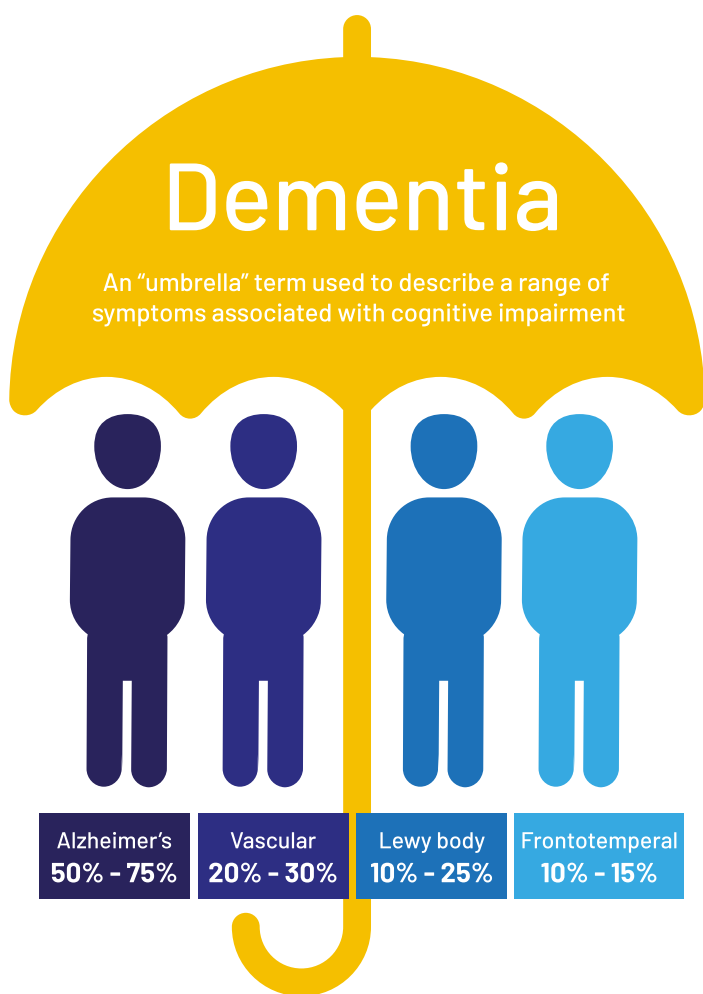
This chapter provides an overview of dementia, exploring what it is and how it can impact on an individual and their care partners. It then discusses current treatment for dementia and how Governments are seeking to enhance the well-being of people affected by the condition.



The umbrella of 'dementia'

Dementia is degenerative and can lead to deterioration (gradual or rapid) of a person's cognition and memory abilities, language skills and orientation and navigation capabilities, which in turn may prevent the individual from performing some activities of daily living (such as washing or cooking) as well potentially alter some of their behaviours. 'Dementia' is an umbrella term used to describe a group of symptoms that can occur in a person when their brain cells stop working as they used to. Within a biomedical model, this deterioration can be seen in stages. It is important to note that these stages can be hard to define and not everyone will go through them in the same way. These stages progress from:

- the early stage- where a person's symptoms are noticeable but they should be able to remain fairly independent
- to the middle stage- where a person may have more difficulties with memory and communication and require greater support with activities
- to the late stage- where a person is likely to experience severe memory loss, problems with communication and daily activities and greater changes in behavior and physical problems. They are likely to rely heavily on others for most of their care.

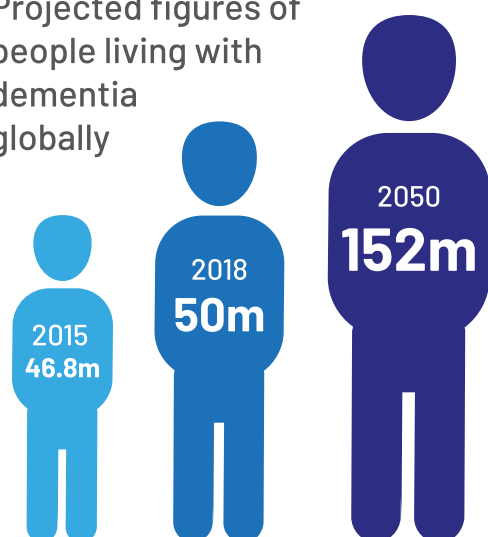


Alzheimer's disease is the most common cause of dementia accounting for around 2/3rds of all cases, and the one that the majority of people have heard about. However, there are many other types of dementia too including Vascular Dementia (20% of all cases), Lewy Bodies (15% of all cases) and Frontotemporal Dementia (less than 5% of all cases). It is possible for people to have more than one type at the same time (around 10% of all cases) and these are referred to as 'mixed dementia'. Although it is beyond the scope of this booklet to discuss the underlying neurological causes of these dementias, if you are interested there is a lot more information available through Alzheimer's Disease International or World Health Organisation.

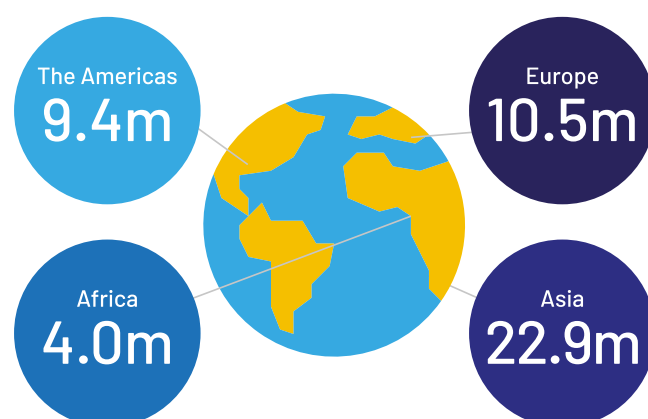
A global concern

Around the world there will be a person diagnosed with dementia approximately every three seconds. In 2018 it was estimated that globally 50 million people were living with dementia and this is predicted to triple to 152 million by 2050; that is a 204% increase. Much of this increase will be seen in developing countries as the population's life expectancy gradually increases, so that by 2050 around 68% of people living with dementia will be in low and middle income countries. Furthermore, the total worldwide health and social care costs of dementia in 2018 were around US\$1 trillion, more than the costs of cancer and heart disease combined, and these are likely to increase to US\$2 trillion by 2030. Around 20% of these costs were from direct medical treatment whereas direct social sector costs and informal care costs accounted for around 40%. These figures suggest that if global dementia care were a country, it would be the 18th largest economy in the world exceeding the market values of companies such as Apple (US \$742 billion) and Google (US \$368 billion). Therefore, there is no wonder that dementia is viewed as a global priority and countries are seeking ways to provide better support and care for people with dementia and their family members as well as reduce the associated financial impact.

Projected figures of people living with dementia globally



The estimated number of people living with dementia in different global regions

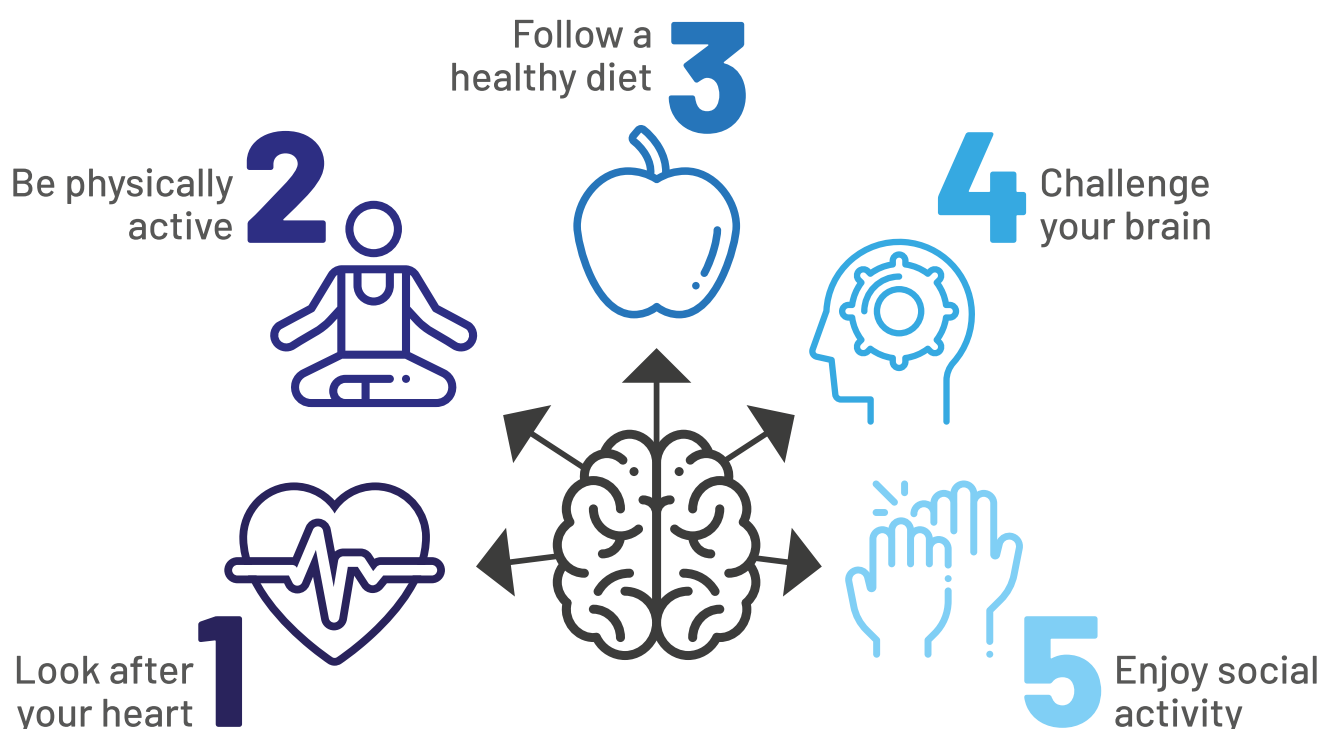


However, it is important to note that only between 20-50% of people living with dementia in high income countries will have been diagnosed and this will be less in low and middle income countries. As such, it is likely that approximately three quarters of people with dementia have not received a diagnosis, and therefore do not have access to treatment, care and organised support that getting a formal diagnosis can provide.

The risks of developing dementia

Dementia predominately affects the older population. Indeed, the figures demonstrate that the incidence of dementia increases with age, doubling with every 6.3 year increase in age, from 3.9 per 1000 person-years at age 60-64, to 104.8 per 1000 person-years at ages 90 and above. However, there is also a growing recognition of cases that start before the age of 65. For instance, in the UK around 43,000 people are living with younger onset dementia (below the age of 65 years old). Research has suggested that around a third of cases may be preventable from lifestyle changes. A person's risk of dementia may increase if they:

- Have hypertension, obesity or hearing loss in their midlife (45-65 years old)
- Smoke, are depressed, physically inactive, socially isolated or develop diabetes in later life (above 65 years old)



Other research has also pointed to a genetic cause for dementia suggesting that people with the Apolipoprotein E (ApoE) $\epsilon 4$ allele were at increased risk of developing dementia, although this allele only accounts for approximately 7% of dementia cases.

Impact of dementia on the people affected by the condition

When understanding the impact of dementia on a person, it is important to be mindful that the commonly held view is one of 'tragedy' and loss, as people are seen as losing the essence of their identity and consequently become a 'burden' on society. These understandings are perpetuated throughout mainstream media as well as in researchers' accounts. Whilst on one hand they can help to publicise the condition and so ensure that it receives funding to address the issues, these accounts can also serve to create a stigma and fear associated with the condition. For instance, people with dementia and their care partners report a loss of friends and social life post diagnosis as people avoid them or do not seek to interact with them or include them. Consequently, people with dementia may choose, or be forced to withdraw from social situations and activities that were important to them and this can result in social isolation and a loss of identity as well as poor physical and psychological well-being. Furthermore, this stigma can mean that care partners of people with dementia are often left on their own to provide all of the support that is required. This can lead them to experience high levels of stress and tension, and can result in burnout and poor physical and psychological health and well-being.

However, more recently it has been acknowledged that people with dementia can live well and for a long time, IF appropriate support is provided. This involves supporting both the person living with dementia and their care partners with the neurological/biological, psychological and societal challenges they may encounter throughout the trajectory of the condition. It is also important to be mindful that people with dementia are not a homogenous, androgynous group and so any support needs to be tailored accordingly to each person. For instance, older men with dementia have been shown to be reluctant to engage with traditional health and social care support services, and so a more refined understanding of how to engage them with these services is required.

Treatment for dementia

Unsurprisingly, over recent years the majority of research focus and money has been concerned with finding a cure for dementia through the development of medications. However, due to the complexities associated with the condition and its multiple causes, to date this avenue of research has been fairly unsuccessful, with a failure rate in clinical trials of 99.6%. At present there are two available drugs and whilst these can treat some of the symptoms (often only temporarily), they do not provide a cure. It is hoped that in the forthcoming years, with more financial investment, better collaborations between drug companies and researchers, and more advanced ways to detect a person's potential for developing dementia at an earlier age, then the success rates for drugs will increase; but this is still some way off. Consequently, it becomes even more important to focus on providing support and care for those currently living with dementia and their care partners.

The social inclusion agenda

Providing support for people with dementia not only means enabling them to overcome the associated biological/neurological difficulties but also address the psychological and social challenges they can face. To deal with these issues, research, practice and policy have sought to adopt a social inclusion agenda. This acknowledges people with dementia and their family members as individuals with rights, who should be treated the same as everyone else and be able to participate in society as much, or as little, as they choose. A social inclusion agenda highlights how social structures (e.g. lack of dementia services, poor diagnosis rates or limited signage in communities), 'discursive factors' (e.g. the way we talk to or about people living with dementia, as well as the stigmatization more generally of dementia), neurological difficulties (e.g. memory loss, communication and navigational problems) can exclude people with dementia, and it emphasises the need for people to:

- Maintain their rights as citizens to live safely, free from harm and discrimination
- Have a voice within their community and a status that respects them
- Participate in meaningful relationships where they are valued, respected and feel they can connect emotionally
- Have the opportunities to participate in economic, social and cultural activities within their communities and through this continue their life-long learning and personal growth
- Access health services where the staff are 'dementia-aware' and are trained to uphold their human rights and provide them with best practice care
- Engage in their own health decisions as well as collaborate in research that aims to enhance their well-being

As such, a social inclusion lens provides a much more holistic account of what it means to live well with dementia.

Promoting a 'dementia-friendly' and positive community

Many global dementia policies have drawn on this social inclusion agenda to emphasise the need for creating and sustaining 'dementia-friendly' communities. For instance, within the UK, the Alzheimer's Society has been a leading ambassador of this policy. They have defined a 'dementia-friendly' community as one where:

'...people with dementia are understood, respected and supported, and confident they can contribute to community life. In a dementia-friendly community, people will be aware of and understand dementia, and people with dementia will feel included and involved, and have choice and control over their day-to-day lives'.

This emphasises the need for communities to respect and support people with dementia. However, it is also important that they are 'dementia-positive' and view people with dementia and their family members as equal contributors within society; thereby ensuring they can uphold their rights for true social inclusion. It is likely that achieving these aims will require better societal awareness of dementia and the impact it may have for individuals and their family members.

Empowering people with dementia to have high aspirations, confidence and know they can contribute



Dementia currently presents one of the greatest global health challenges. With the promise of a cure still a distant realization, it is essential that Governments seek measures to ensure that all people affected by the condition are supported to live well. Drawing from a social inclusion agenda highlights the need to create and sustain 'dementia-friendly' communities where people with dementia maintain their rights as citizens, have a voice, participate in meaningful relationships and have agency. To achieve this, it is important the correct support is provided to people upon diagnosis and then continued throughout their journey with dementia, and that health professionals, care partners and the wider general public become more 'dementia-aware' and 'dementia-positive.'



Chapter 2:

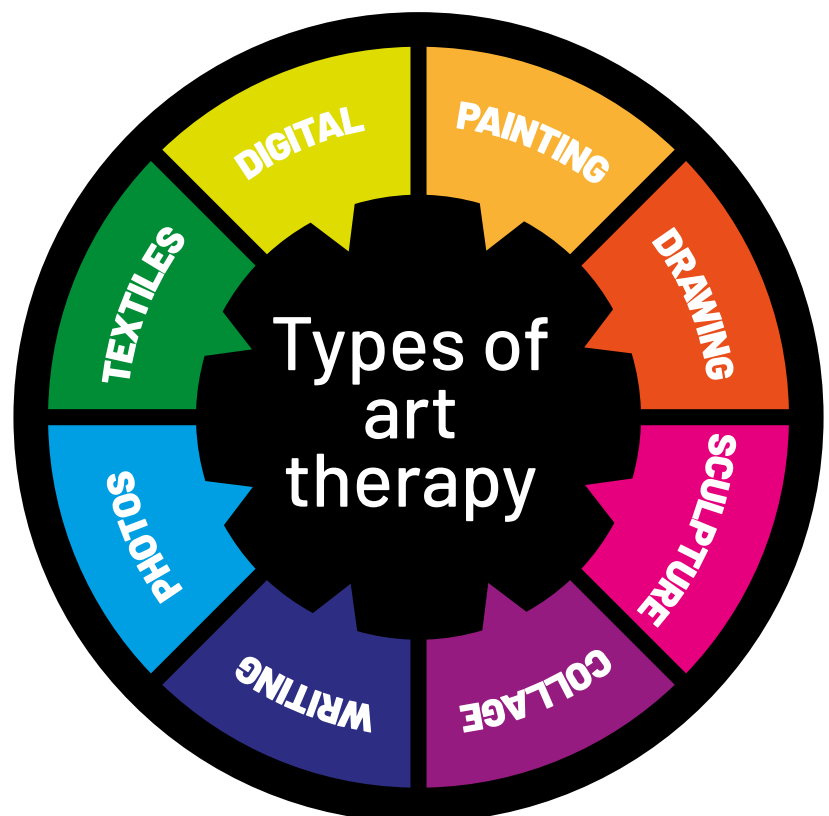
CREATIVE DRAMA AND STORYTELLING IN DEMENTIA CARE

The Arts in dementia care

Once it is acknowledged that 'support' is not just about finding a cure for dementia or managing the associated neurological symptoms, but also about enabling people to participate and feel included within society, then the true power of the creative arts can be realised. The use of creative mediums within the dementia care field is growing rapidly, and practitioners are beginning to see the benefits they can have for the well-being of both people living with dementia and their care partners.

A thorough overview of creative initiatives in dementia care has shown there are many, including music, dance, drama, visual art, literature, photography and sculpture. These have taken place across a variety of settings such as in a person's own home, care homes, hospitals, schools, theatres, cinemas, museums, libraries, art galleries and outdoors. The benefits of these initiatives are plentiful and some of them have been illustrated below.

- **Connection:** facilitate a connection to the self and others that enables people to socially interact and form meaningful relationships
- **Engagement:** promote lively and fun engagement and mental, physical and social stimulation
- **Expression:** enable people to process and share their emotions, sometimes without the need for language
- **Humanity:** provide a space where people feel relaxed or supported, thereby enhancing their mood
- **Involvement:** provide a space where people feel welcomed and included within a group of diverse participants
- **Possibility:** promote new experiences for people and the opportunities to engage with new skills and life-long learning
- **Selfhood:** enable people to reconnect with their sense of identity and engage independently with a range of activities that are tailored to their capabilities, interests, needs and choices
- **Transformation:** facilitate a transformation in people by transporting them to a different time, emotional space or into the moment, and so change the way they feel



Defining creative drama and story-telling

Creative drama is one such art form, and its use within the dementia care field is beginning to grow. A creative drama activity can be delivered by anyone and focusses mainly on the experiences of participants as they engage with the dramatic activities. It is important to note that creative drama is different from drama therapy, which is a psychological therapy delivered by a trained therapist in a one-to-one or group setting and often has a specific therapeutic aim to the activity. It also differs from 'theatre' where the emphasis is on the actors to communicate a message to the audience. However, this does not mean that creative drama initiatives cannot also involve an audience.

Whilst there is no definition for creative drama in the dementia care field, the Gaiety School of Acting in Ireland, suggests:

"Creative drama is the preferred term for dramatic experiences that are designed for the development of cognitive, affective, aesthetic, and moral thinking of participants. It is holistic in nature and uses a variety of methods that combine internal reflection and external representation. The common core of basic activities is always improvised. The process leads to an acceptance of self as well as an awareness of personal resources, and the internal and external influences on living. For this reason, creative drama has been used as a means of addressing the mental, physical, and emotional development of varying cultures. In practice, individuals and groups set out to resolve problems and seek solutions through the medium of exploration and expression."

Story-telling is a creative process that encourages people to use their imagination to tell stories about people or objects that are presented to them. Through these means it enables them to express their personalities, experiences and individual characteristics. It differs from reminiscence work, where the focus of the discussions are around a person's life history (both past and present), rather than any imagined scenarios. Unlike creative drama there is rarely a performance element to the work, as people tend to only create and discuss their stories as opposed to enacting them out.

The use of creative drama and story-telling in dementia care

An extensive review of the academic literature published between 2000 and 2019 highlighted 33 papers that had discussed the use of creative drama or story-telling within the dementia care field. Of these papers, 25 were discussing separate studies or uses of different creative mediums. The scarcity of the papers in this timeline demonstrates that developments of creative mediums are still within their infancy. The sections below provide an overview of the data collected from the literature review.

Settings

The majority of countries using these creative mediums were in Europe (UK and Scandinavian countries), the United States of America and Canada. Only one paper highlighted the use of storytelling within China. This could be due to the fact that only studies published in English were included within the review, however

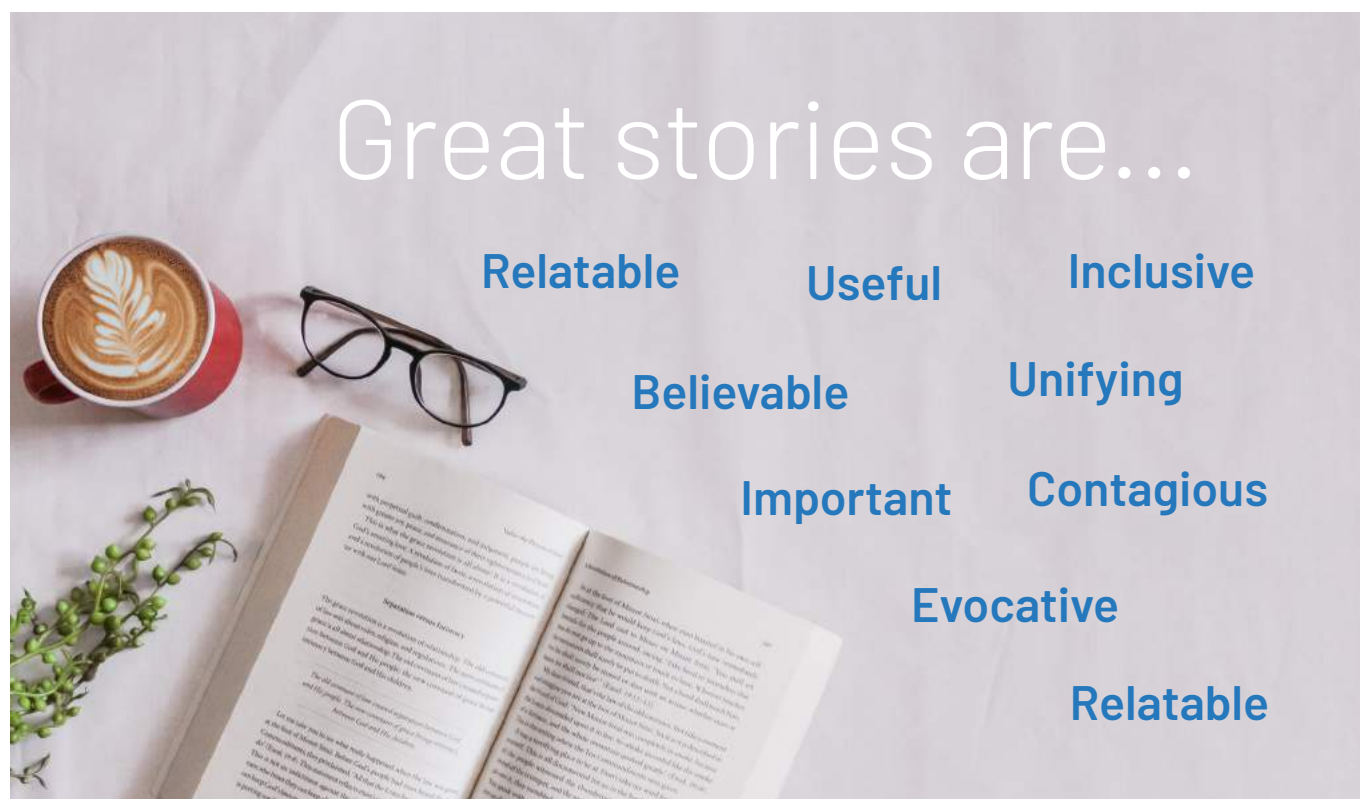
it might also reflect that at present Westernised countries that are most open to using these creative mediums. These creative initiatives were used within Day Centres and Community Centres as well as care homes.

How creative drama and storytelling are being used

The studies reported using the creative initiatives either directly with people with dementia and/or their care partners or as part of an educational tool to raise dementia awareness amongst informal and paid care partners, health professionals and the general public.

The main storytelling initiatives used within the dementia care field were TimeSlips and an approach that linked to Erikson's phases of development.

TimeSlips: this is a group storytelling initiative that was developed in the 1990s and is now used across the world. The aim is to elicit a performance of the self in the present, rather than traditional reminiscence activities that focus on supporting people with dementia to talk about their past lives. In a typical session, people with dementia are seated in chairs around a facilitator. Following this, facilitators encourage the participants to exercise their imaginations by presenting them with a photograph (one photograph per person in the group) and asking three types of open-ended questions ('who, what, where'), sensory questions and then questions related to the world outside of the image. The images chosen are often surprising in subject matter to appeal to the imagination (such as a man hugging a tiger) and/or appealing to senses other than visually (such as two girls brushing a sheep). Participants' responses are echoed by the facilitator and recorded on a flipchart. Facilitators do not correct storytellers but instead provide whatever is needed (eg. more time, prompts) to allow the person to respond to the image. Responses are woven into an inclusive narrative and periodically read back to help people with dementia to develop the story further or bring it to a close.



Storytelling and Erikson’s Developmental Phases: this is a group storytelling initiative where people with dementia gather in a circle around a facilitator who follows a pre-planned structure to the activity. This includes:

1. Ritual greeting and addressing by name (5 minutes)
2. Lighting the storytelling candle (5 minutes)
3. Telling the story (20-30 minutes)
4. Music-pause for reflection (5 minutes)
5. Open invitation to discuss the subject of the story and the themes covered (15 minutes)
6. Distribution of a gift associated with the story (5 minutes)
7. Blowing out of the storytelling candle to show the session has finished (5 minutes)
8. Meeting around a coffee table to continue the conversation (30 minutes)

People with dementia are free to interrupt the facilitator spontaneously during the storytelling activity structure. The stories selected are designed to incorporate one or more of Erikson’s eight development phases as well as contain descriptions of different general human themes that are associated with various phases of life. The eight phases of development as outlined by Erikson can be viewed in Table 1 and some of the general human themes addressed within the stories are outlined in Table 2.

Table 1: Erikson’s eight developmental phases

Phase	Positive component	Negative component	Developed strength	Stage of development
1	Trust	Mistrust	Hope	Childhood
2	Autonomy	Shame and doubt	Determination	Childhood
3	Initiative	Guilt	Purposefulness	Childhood
4	Activity	Inferiority	Competence	Adolescence
5	Identity	Confusion over identity	Loyalty	Adolescence
6	Intimacy	Isolation	Love	Adulthood
7	Generativity	Stagnation	Care	Adulthood
8	Integrity	Despair	Wisdom	Adulthood

Table 2: Example of general human themes and relation to Erikson

Stories	Human themes in stories	Erikson phases of development
1	Resignation, hope, meaning of the 'good mother' and homecoming	1
2	Being an outsider, longing to escape, physical functional impairments, being cheated and obtaining redress, and homecoming	2
3	Marriage, being faithful. Patience and courage, and homecoming	3,5,6
4	Shame, pride, tryout, humility and reconciliation, creating a home and homecoming	4
5	Making a promise on a deathbed, next generation, being tested, being brave, obtaining redress, a happy marriage and homecoming	7
6	Loyalty, being cheated, being brave, ability to act, integrity, wisdom and homecoming	8

The creative drama approaches within the dementia care field include those that have been used directly with people with dementia and/or their care partners or have used their accounts to provide dramatic stories that can act as an educational tool to raise dementia awareness amongst dementia practitioners and informal care partners.

When working directly with people with dementia and their care partners using creative drama approaches, studies included:

- 1. Veder method:** this was undertaken by two care partners who had received training from the Theater Veder. This is a group activity conducted in a living room that is built up according to a fixed sequence. This begins with welcoming the person with dementia into a group, activating long-term memory, taking a break, activating short-term memory and closing with individual contact to say goodbye. During this method special attention is given to validation, reminiscence and theatrical stimuli. Every drama activity has a central theme and the care partners play a role that refers to this theme. Costumes, props and recognisable characters are used to create a stage set, along with songs, poems as well as objects, smells and flavours that refer to the central theme of the drama activity.
- 2. Lifestory drama:** this was undertaken in a day centre and sought to act out life scenes of someone with dementia. These were obtained through lifestory work with the person beforehand. Key scenes of their life were re-created through props and people within the day centre (staff and those with dementia) played different roles within the drama. This was also set to sound effects and period music. The story was narrated by the person with dementia.

- 3. Participatory Theatre:** this was undertaken with care partners of people with dementia. They were encouraged to depict and act out real-life activities and challenges they faced within their roles. These were performed to a live audience, who are encouraged to stop the dramatic action, come to the stage, replace the 'actor' and lead the action in the direction that seems appropriate to them. Any audience member is able to interrupt the performance (on its second showing), to intervene and take dramatic action to change the outcome. This is a useful way to offer solutions to problems/ challenges that may be occurring within the drama. This is perceived as offering more insight than merely discussing potential solutions from the comfort of a chair.
- 4. Improvisational creative drama and comedy:** this included creating a 'mockumentary' of an imagined situation for example the visit of the Queen to a day centre. This work was undertaken by the Grange comedy project who ran four workshops with people with dementia where they were encouraged to improvise on four main topics. These were: receiving the news that the Queen is planning a visit to their day centre; making practical preparations for the Queen's visit such as receiving a security visit from the Palace and a programme of activities; preparing entertainment for the Queen's visit; and receiving the visit of the Queen to the day centre. The workshops did not work to an exact script but allowed the scenarios to develop based on the main theme. Drama techniques were used by the actors to work with the issues that the Grangers came up with themselves. All of the workshops were filmed and photographed and then played back to the participants to remind them of the work they were undertaking and why.
- 5. Drama as part of wider creative activities:** these studies used a range of workshops to engage people with dementia that included the use of drama activities. Examples included asking people with dementia to choose a mood in which to answer the telephone and act this out to the rest of the group, who then had to interpret the mood and discuss/imagine the circumstances of the meeting. The workshops also encouraged people with dementia to interpret through drama and movement, the meaning of words they had discussed throughout art classes such as 'swirling.'

When using creative drama approaches as part of an educational tool, studies sought to work alongside people with dementia and their care partners to develop vignettes that were then performed to audiences.

- 1. Vignettes:** these asked participants (people with dementia and care partners) to construct hypothetical situations of what it might be like to live with dementia or early onset dementia. During these sessions professional actors would improvise the suggestions and work with the participants to co-construct the scenarios from everyday life. In these studies, the people with dementia and their care partners acted as directors and audience members and were able to dictate what they wished to see. Participants did not have to draw from their own experiences. Furthermore, participants could create their own images of different scenarios and perform them to a group of people, who could interpret them. These images were brought to life with movement and sound. Expressions of Personhood in Alzheimer's was a popular ethnographic drama based on five vignettes that illustrate self and identity in dementia care through the use of bodily movements and behaviours (also referred to as 'embodiment').



Outcomes for people with dementia, care partners and others

Collaborating directly with people with dementia and their care partners:

When using creative drama directly with people with dementia either on their own or with their care partners, the studies often reported numerous benefits. These included:

1. Developing positive social environments that promoted laughter, fun and hope and enabled people with dementia to live 'in the moment' and to forget the serious challenges they may be faced with
2. Reducing the sense of apathy and social isolation that people may feel
3. Enhancing people's life-long learning by supporting them to engage in new art forms
4. Providing people a new set of tools through which to express their feelings, desires and aspirations and so enable 'meaningful' social interaction and communication
5. Providing a means to communicate the challenges they may experience when living with dementia
6. Contributing to the memory recall of certain key ideas such as word repetition, movement and rhyme
7. Being situated as 'students' within the process rather than 'patients' who are provided a sense of autonomy and control over the creative drama process
8. Facilitating a sense of achievement as people with dementia and their care partners can contribute to research that will offer benefits for others in a similar position

Similarly, researchers using storytelling techniques with this population also reported positive benefits for those taking part in the initiatives. These suggested that people with dementia experienced:

1. A sense of engagement and were more alert
2. A greater willingness to participate in interactions with other people with dementia as well as care staff
3. A reduction in depression and negative emotions as well as an increase in positive emotions
4. A better ability to recall previous life events and discuss them
5. The opportunity to 'play' again and feel a sense of pleasure
6. A chance to communicate both their social and basic needs

Where staff and care partners participated in these initiatives alongside the person with dementia, they reported more positive views of the person with dementia and a greater understanding of their life. This insight ensured that they could provide better support for the person by tailoring other activities to their interests and previous life experiences; thereby ensuring they were meaningful and provided a sense of purpose.

This suggests that creative drama and storytelling initiatives can be used directly with people with dementia and their care partners, in a variety of settings, and can enhance important aspects of their social inclusion and well-being.

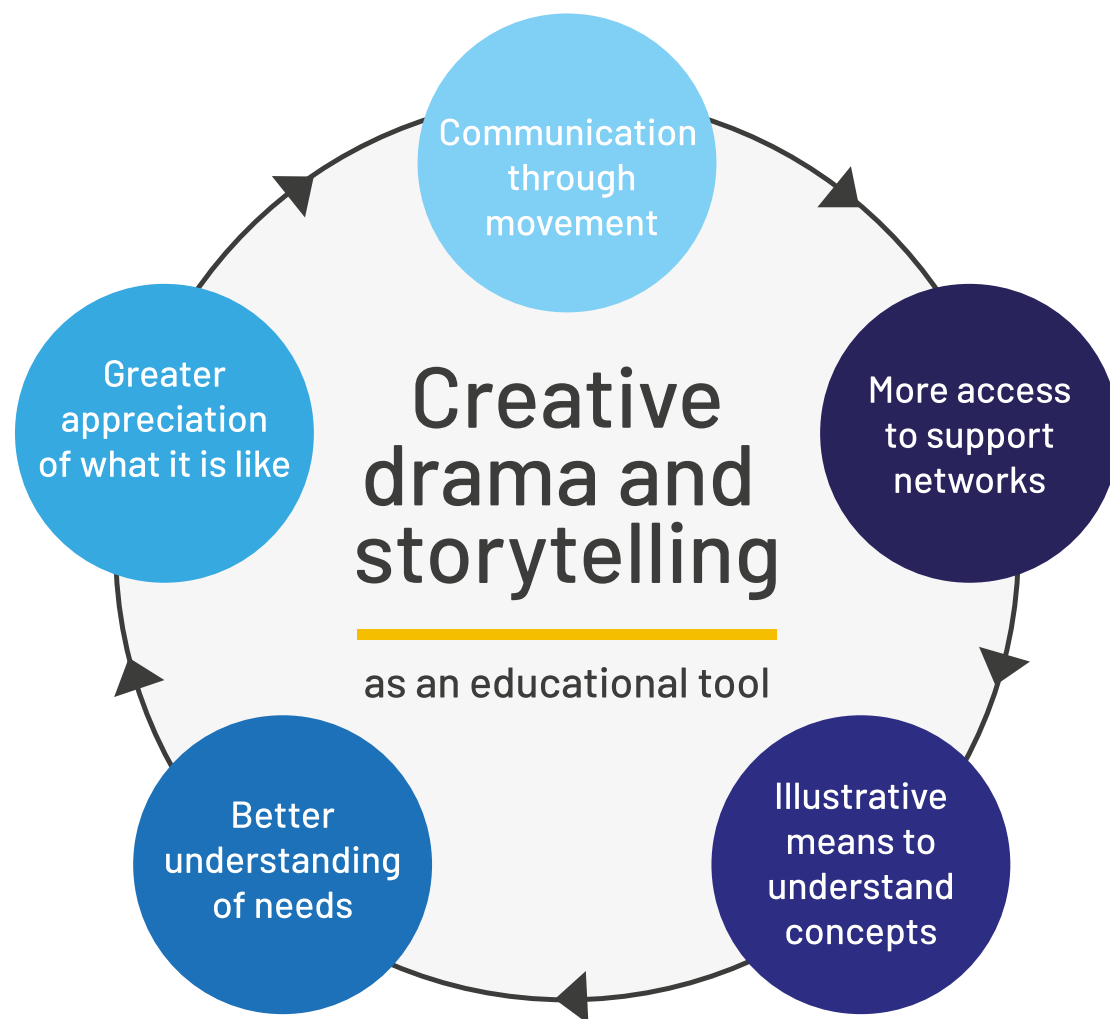
Creative drama and storytelling as an educational tool

Predominantly, creative drama initiatives were used as an educational tool and were delivered to paid healthcare professionals and dementia practitioners, care home staff, social work and nursing students, relatives of people with dementia, informal care partners and the general public. Findings from the studies suggest that this method was viewed positively by those watching and provided them:

1. Greater appreciation of what it is like to live with dementia and to support someone affected by the condition at both home and in care facilities (such as hospitals and care homes)
2. Better understanding for the need to focus on the PERSON rather than their condition, when providing support to live with dementia
3. Greater understanding of how people can communicate their sense of 'self' and identity through their actions and bodily movements
4. More enhanced understanding of the support networks that can be accessed when living with dementia
5. A more simplistic, illustrative means whereby they could grasp complex theoretical concepts such as 'embodiment'¹, which in turn would enable them to deliver better care and support to people with dementia.

In two studies storytelling was used as an educational tool to enhance the dementia awareness of medical students within the USA. In both instances, the students learned how to use the TimeSlips storytelling

¹The expression of 'self' even at the late stages of dementia through bodily movements and behaviours



method and either delivered, or watched others deliver it, within care homes for people with dementia. Through these means, the students reported a more positive attitude towards people with dementia and suggested it:

1. Reduced their feelings of fear and discomfort when interacting with this population
2. Provided them with feelings of comfort and an enhanced sense of relationship with people with dementia
3. Challenged their views on the ability for people with dementia to be creative and provided them with a better understanding of how they can improve the lives of this population
4. Encouraged them to focus more on the humanistic aspect of care rather than drawing from a solely medical approach that was traditionally taught within their lessons.

These findings suggest that creative drama and storytelling initiatives may be a useful tool for raising dementia awareness amongst a wide group of health and social care professionals, students and the general public. This is essential for the wider social inclusion agenda and supporting the well-being of people living with dementia and their care partners.



Facilitators and barriers for using creative initiatives within dementia care

Two papers reported on the implementation of a creative drama initiative, namely The Veder contact method, within a nursing home environment. Although the papers report specifically on this approach, many of the lessons are likely to be applicable to other creative drama and storytelling initiatives. Key facilitators and barriers highlighted within the papers included:

- 1. Management:** Management buy-in to the initiatives is key throughout the preparation, delivery and on-going processes within care homes. The manager should be open to the creative initiatives and supportive of staff wishing to use them. The manager is also responsible for promoting a positive team culture that is required when introducing these new methods.
- 2. Trainer:** The trainers require the necessary skills to support staff to use the initiatives effectively. This requires educating them on the methods through simple to use and easy to grasp training materials as well as supporting staff to reflect, correct and encourage each other when delivering the initiatives. It is also important for trainers to provide constructive feedback and to encourage other work colleagues to do likewise. This facilitates on-going learning and enables staff to hone their creative skills.

- 3. Organisation processes/resources:** These include having the time and money as well as the number of staff to carry out the activities. Creative initiatives can be difficult to introduce if the organisation is also implementing different activities simultaneously and if staff are not provided with enough time/resources to introduce the work. In some organisations, their priorities can be focussed more on providing physical care to people with dementia rather than supporting their wider sense of social inclusion through other activities. To overcome these issues organisations require funding, the right spaces to carry out the activities and time to do so as well as low staff turnover rates. They also need a detailed implementation plan for the design, delivery and evaluation of the creative activities. Continual evaluation of the activities will ensure that they remain appealing and suitable to the participants.
- 4. Staff/participant attitudes and interpersonal skills:** It is imperative that staff understand the need to provide more than physical care for people with dementia, understand 'support' through a wider social inclusion approach and realise the benefits these creative initiatives may have for people living with dementia. Both people with dementia and their care partners must be open to the initiatives and willing to participate. To overcome this, it is important that trainers and care staff encourage people to participate and reassure them throughout. They are also likely to need a good understanding of the personal interests and backgrounds of the participants so that the approach can be tailored accordingly. This will require excellent interpersonal skills as well as a good knowledge of, and rapport with the participants.
- 5. Laws and policies:** National laws and policies may be wary of promoting creative initiatives due to the potential hazards for the safety of people with dementia. It is important that the benefits of these initiatives are promoted more widely and care for people with dementia is viewed within a wider social inclusion agenda rather than one focussed solely on health and safety.

Using creative arts and storytelling initiatives and techniques have been found to have positive benefits on the well-being of people with dementia and their care partners. Understanding the facilitators and barriers are important when initiating such initiatives to ensure they are supported and embraced by all who take part; enabling their true potential to be realised. Interestingly very few of these studies seek to outline the experiences of people with dementia when participating in the creative drama and storytelling initiatives. It is important that these experiential accounts are elicited and used in a way that can inform the development of similar future initiatives.

Chapter 3:

CREATIVE DRAMA AND STORYTELLING WITHIN THE ERASMUS PARTNER COUNTRIES

This chapter provides an overview of dementia policy within each of the ERASMUS partner countries (UK, Ireland, Romania, Bulgaria and Greece) and highlights, where applicable, how creative drama and storytelling are used by national organisations to enhance the social inclusion of people with dementia and their care partners. There are five sections to the chapter that draw on the data elicited from interviews with dementia practitioners in each of the ERASMUS countries. Examples of their work have also been provided throughout the chapter.



Overview of policy and creative practice in the UK

Within the UK, around 850,000 people, approximately 1.3% of the population, are living with dementia, as well as the cost to individuals well-being, this also comes at a cost to the UK Government of somewhere in the region of £26 billion a year in care and lost productivity. To address these issues, a series of national strategies were released in England, Scotland, Northern Ireland and Wales between 2009-2011, and have been reviewed and updated in the prevailing years. These reports have been concerned with 'Living well with dementia' and have outlined a range of ways this can be achieved, including:

- promoting nonpharmacological approaches for enhancing well-being,
- ensuring better knowledge of dementia and removing the associated stigma,
- enabling early diagnosis and improving the diagnostic process and support for people with dementia and their care partners,
- reducing the use of antipsychotic medications,
- creating dementia-friendly communities, and
- improving post-diagnostic dementia services so they meet the changing care needs of people with dementia and their care partners, promoting individuals agency in decision making as well as improving human rights and inclusion for people living with dementia.

In 2017, an All Party Parliamentary Group published the report 'Creative Health: The Arts for Health and Well-being' that drew on research evidence to outline the importance of the arts in promoting positive well-being for all generations including older people and those living with dementia. This work is supported by a range of organisations within the UK that campaign for social prescribing for people with dementia and their care partners. This involves directing people, at the point of diagnosis, to creative, nonpharmacological initiatives they can access that will support their sense of purpose and well-being. As such, it is clear that within the UK there is a growing understanding of the importance of supporting social inclusion in people with dementia and an openness to using creative initiatives to achieve this aim.

Four organisations were interviewed that provide creative arts activities for people with dementia and their care partners. These included Screen Memories in Scotland (<https://www.birkscinema.co.uk/community-hub/health-wellbeing-activities/screen-memories/>) who set up cinema 'chat' groups for people with dementia where they view pictures of films and discuss their meaning to them, as well as Small Things Creative Projects (<https://smallthings.org.uk/>), Musical Steps (<https://www.musicalsteps.co.uk/>) and Wyldwood Arts (<https://www.wyldwoodarts.co.uk/>) all based in England.

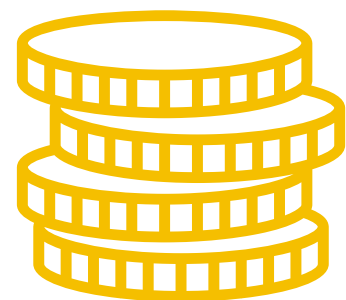
850K

People living with dementia in the UK



£26b

Approximate government spend per year



Small Things Creative Projects

This organisation takes a creative improvisational approach that is inclusive and engaging for people with dementia. They have developed the Storybox project, where they worked with thirty-six different groups of people with dementia, care homes and people that support people with dementia, over a three-year period. The amount of sessions depends on the group, the available funding and individual needs. They take a participant-led approach and run sessions on one-to-one or group basis over the duration of an hour. Each session has a different theme that draws people together in the activities. Different art forms are employed in every session, including music, craft, creative writing, performance and role play. The use of these different forms of art allows people to dip in and out the session depending on their abilities and personal preferences. Even though it can be challenging bringing this activity into a different care setting, the benefits of the project have been evident with participants reporting increased levels of mood as well as positive changes in their communication skills and behaviour. The interviewees also felt they had become more engaged, calmer and started socialising more. Their participation in this activity has also benefited the care partners as they feel better able to re-connect with the person with dementia.

“Just to do something positive and have a shared experience with someone that moves away from a kind of care giver and carer relationship”

Musical Steps

Musical Steps run intergenerational sessions with children and residents with dementia living in a care home. The sessions last approximately 40 minutes and they include rhyming and mirroring activities, singing and using musical instruments. Although they felt the early sessions of the initiative were not particularly successful, as residents did not engage and only observed the activity from afar, they have continued to learn from the experience. As the sessions developed they reported feeling more confident including the residents in the activities and this has enhanced their sense of engagement and subsequent enjoyment of the activities. The interviewee reported that by the end of the initiative the residents demonstrated a greater sense of joy and some even left their walking aids behind during the physical activities.

“You know, they got a sense of joy out of it and that’s the most important thing really”

Wyldwood Arts

Wyldwood Arts is an interdisciplinary arts organisation that focuses on an intergenerational approach to bring people’s voices to life and improve their well-being. The organisation is working in urban and rural communities, collaborating with artists, educational organisations and care facilities with older adults. A few of the projects included a storytelling approach to help people connect, and those stories have been created into productions. One example project included pupils from a school visiting older residents from



a nursing home. The pupils would attend for an hour once a week and share ideas and work creatively to develop narratives and poems with the older residents. These could be expressed through a medium of visual art or through drama and storytelling. The projects have allowed people to make new friends and express themselves in a non-judgemental way. The art has provided a safe space for sharing something that might be upsetting and then being able to move on from it.

“Coming this week has made me feel lighter about the past. I’ve been able to share my story and feel understood and not judged. That’s really powerful”

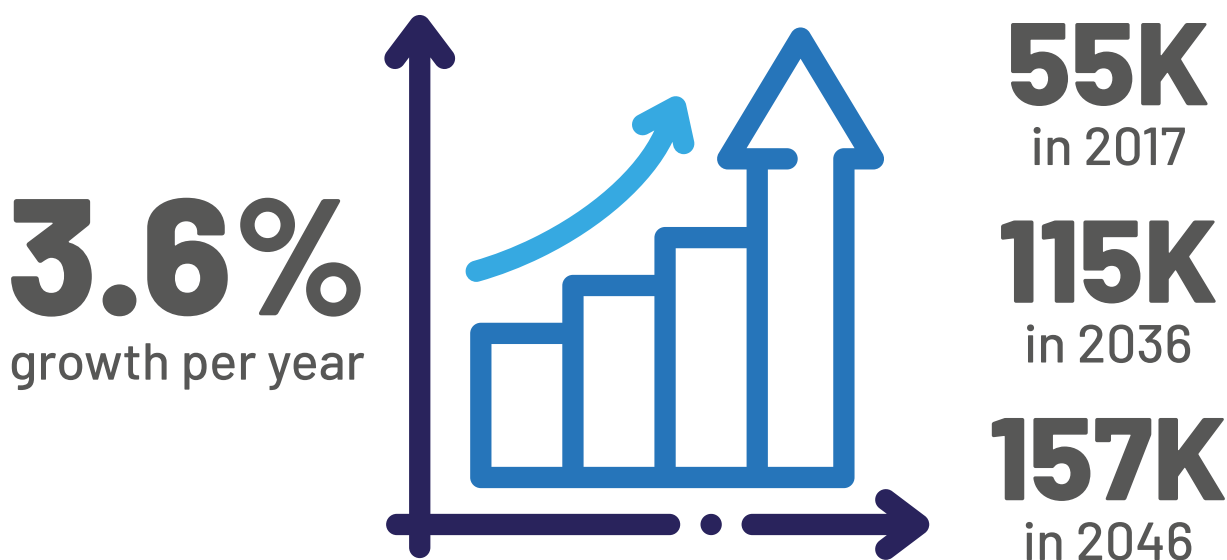
These findings suggest that throughout the UK there are a range of creative drama and storytelling activities, run by local charities and community groups rather than health professionals that aim to enhance the well-being of people with dementia and their care partners. Providing these activities within the community setting rather than a medical one is important for the sense of social inclusion experienced by people with dementia. During the interviews, the practitioners reported an array of barriers that they needed to overcome to ensure they were inclusive for all those involved.

One of the main challenges for running these creative activities was the limited amounts of funding that the participants could draw upon. This meant that even though some of the projects were very successful and the practitioners wanted to take them further, they were unable to and so had to stop them. This was detrimental for the well-being of people with dementia and their care partners who had come to enjoy the activities and rely on them for providing a sense of social inclusion. Additionally, the interviewees reported that engaging people with dementia and the staff from nursing and care homes had also been difficult. This was especially challenging when these creative projects were being brought into new facilities that had not previously engaged in creative arts. The care and nursing home staff would be apprehensive about participating and would often not appreciate the benefits that they could provide for those participating. Also, their workload commitments would make it difficult for them to attend and facilitate the sessions, meaning they rarely had the opportunity to witness the sessions and so challenge some of their assumptions. Other difficulties with facilitation included individual differences of participants, such as having people with verbal communication difficulties and hearing loss in a group of people who didn’t have those difficulties. Interviewees also reported the difficulties of planning ahead for the sessions as they were unaware of who would attend and what their energy levels and physical capabilities would be like. However, once these challenges were overcome, both people with dementia and their care partners were able to demonstrate positive benefits to their mood, engagement and overall well-being.

Overview of policy and creative practice in Ireland

In 2017, it was estimated that around 55,000 people, approximately 1.1% of the population, were living with dementia in Ireland. The rate of dementia is expected to grow at 3.6% per year for the next 30 years, meaning that by 2036 the number of people living with dementia in Ireland will be 115,426, and by 2046 this will have trebled to 157,883. In 2014, Ireland launched their National Dementia Strategy with the aim of improving dementia care so that people with the condition can live well for as long as possible and access services and support that are appropriate for their needs. It sought to promote a greater focus on timely diagnosis of dementia and on the value of early intervention, along with the long-term objective of making people in Ireland generally more aware and understanding of the needs of people with dementia, and of the contribution that those with dementia continue to make to our society. These aims align well with a social inclusion agenda. Specifically, the Strategy identifies six priority areas for action:

- Better awareness and understanding of dementia and a willingness to include them in societies as fully as possible for as long as possible
- Timely diagnosis and intervention as well as better end-of-life care
- Integrated services, supports and care for people with dementia and their care partners
- Better training and education for all those supporting people with dementia
- Focus on research and information systems concerned with dementia and the inclusion of dementia in future health policies
- Leadership focus on dementia care and better allocation of resources to provide the best possible outcome for those with dementia and their family members



To achieve this vision and implement the strategy over 2014-2017, the Department of Health and the Health Service Executive agreed a joint initiative with The Atlantic Philanthropies with initial funding of €27.5m. This highlights the substantial resources that have been allocated to addressing the challenge of dementia. In 2017, the National Strategy was reviewed and further outlined the need for primary prevention to be embedded in the Strategy as well as the requirement to provide a post-diagnostic system that emphasised knowledge, information, peer support, cognitive interventions and continuity of care and integration that would lead to higher levels of self-determination, choice and control on the part of people with dementia. It also argued for a personalisation agenda to be adopted that ensured the wishes and preferences of people with dementia were prioritised over the providers of care. To achieve this vision it highlighted the need for additional resources to be directed at dementia support and care as well as better education of dementia amongst health professionals, services providers, informal care partners and the general public. This again emphasises the need for a rights-based approach that draws from a wider social inclusion agenda.

Within Ireland, three organisations employing creative drama and storytelling techniques provided their insights into using the initiatives with people with dementia. The Alzheimer's Society, Ireland discussed applying storytelling techniques to provide training to people with dementia that would enable them to feel more confident when attending public engagement events. Through these means they hoped people would be able to deliver an 'authentic' account of their experiences and so raise dementia awareness amongst society. As the interviewee explained: "I believe that real stories have a greater impact on societies".

The other two organisations interviewed discussed the creative initiatives they delivered directly to people with dementia and their care partners. They highlighted the benefits it provided their participants including an increase in positive mood and activity levels, a sense of purpose, as well as the opportunity to engage with their creative skills and develop a feeling of community with others' present. Further details of their work have been provided in the two case studies presented below.

Age & Opportunity <https://ageandopportunity.ie>

Age and Opportunity is a national organization that aims to inspire everyone to reach their full potential as they age. They work with people over 50 years old, including those living with dementia, and facilitate them to engage in cultural, sporting, physical and artistic activities, such as dance and writing. This provides opportunities to learn and be involved as active citizens. They work with public and private partners to deliver innovative programs such as the Bealtaine arts festival and Go for Life- a national sports program for older people. They have also commissioned a theatre play tour, which is a storytelling piece. Their two-hour workshops with people with dementia are designed to enhance creative skills, support their interests and offer new experiences. In addition to this, they provide support to day care centres and offer artists' residencies in care homes. Evaluation feedback they have collected report that their workshops have improved people's creative skills, participation and mood.

"They increase their involvement, they become more active and happier"



Chester Beatty Library <https://chesterbeatty.ie>

The Chester Beatty Library is situated in Dublin and offers people the opportunity to view world class exhibitions. At present, they are part of the “Azur” project that aims to provide ‘dementia-friendly’ access to arts collections. This activity incorporates the elements of storytelling and creative arts. During the tour, groups of people with dementia and their care partners gather around an object and, led by facilitator, they reflect on the artistic values of that object (colours, theme, cultural connotations). The conversations enable participants to explore other elements of their lives such as how the colours might remind them of their holiday trips, or childhood memories and events. The activities focus on placing people with dementia ‘in-the-moment’ and storytelling is a big part of this. Over the course of an hour, the guide facilitates the conversation and enables everyone to reflect and openly express themselves, through creating a safe environment for sharing and a sense of belonging and emotional connection. Feedback they have collected suggests the activities and the storytelling process facilitates people’s sense of (re)connection with life and the other people around them.

“It’s not about long-term impact but more about being in the moment. Creating safe space for self-expression and increasing their confidence to speak up and fully participate”

Whilst all of the interviewees advocated the use of creative approaches to promote the voices and human rights of people with dementia as well as their sense of social inclusion, they also discussed challenges for advancing this work within Ireland. These focussed predominantly around the lack of funding and resources available. As such, they felt there was a need to raise societal awareness of the benefits of these approaches within the dementia care field and so encourage policy makers and practitioners to invest more time and resources. This would ensure they could continue to develop their work and provide long-term benefits for people with dementia, their care partners and wider society.

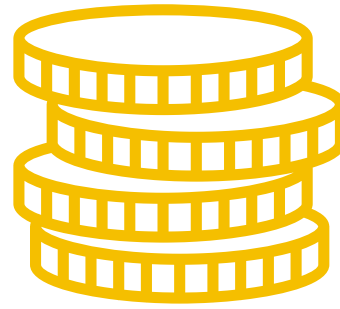
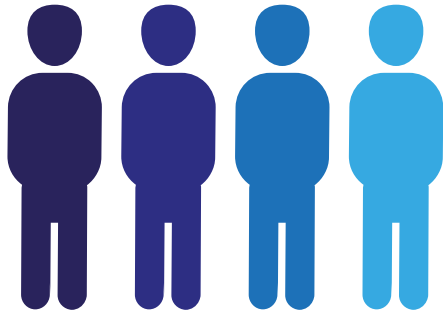
Overview of policy and creative practice in Romania

Romania, similar to other European countries, has an ageing population. Although at present the number of people over 65 represents 16.5% of the total population this is predicted to increase to 34.8% by 2060. Given the links between ageing and dementia, it is likely that Romania, similar to other Eastern European countries, will witness increase incidence rates of dementia over the prevailing years. Although a limited amount of data exists within Romania, it was estimated that in 2014 there were 158,000 people living with a dementia, however this is likely to overlook many undiagnosed cases. More accurate figures suggest that in January 2018 there were an estimated 245,000 people, approximately 1.2% of the population, living in Romania with a cognitive disorder. It was estimated that in 2013, this equated to a cost of between RON 18.24 billion and RON 14.52 billion, with just over half of these costs associated with providing formal care. However, it is noted that this does not take into account the care costs for care partners supporting people living with dementia.

Currently Romania does not have a national strategy for dementia, and there are limited plans for policy makers to introduce one. As such, many of Romania’s national policies focus on supporting older people

245K

People living with dementia in Romania (2018)



RON 18b

Approximate government spend per year

with their health and social care requirements, rather than addressing the needs of people with dementia. Although professionals can draw on the Law on mental health and the protection of persons suffering from mental disorders or the Law for Social Care of older people, to provide care for people with dementia and their care partners based on their level of disability, this is not specific enough to address the complex needs of this population; with the law often recognizing people with dementia as a potential psychiatric emergency. Particularly useful policies that professionals can draw on are the National Health Strategy 2014–2020 and the Action Plan 2014–2020. These aim to improve mental health more generally within the population, through:

- developing evidence-based mental health policies through collecting quality data for implementation and monitoring purposes
- improving access to, and the quality of diagnostic, preventive, and treatment services, as well as educating professionals on providing good support for people with mental health conditions and adapting existing infrastructure and services to beneficiaries' needs
- extending the range of services provided to people with mental health concerns by working with the non-governmental sector in the implementation of good practices and improving the level of education and understanding on the issue of mental health within the general population

Although these strategies address issues that are related to mental health they do not specifically address the problem of dementia in all its complexity. Consequently, further policy development is essential so that people with dementia and their family members can receive the appropriate support and formal services to live independently for as long as possible.

Furthermore, the support that is provided to people with dementia and their family members is restricted to a number of home care services that deliver care for a specific number of days a year or institutionalised care that is limited to a small number of state run centers such as day centers. These offer access to psychological services and physiotherapy as well as cognitive stimulation therapy such as arts therapy; although this is limited in state services. Unfortunately, however these centers tend to be situated within urban areas and unable to provide support for people who may have advanced dementia. The private sector

in Romania also provides care for people with dementia and their care partners however those delivering the services have limited learning resources and base their activities on their experiences rather than specific psychological theories or methods. In relation to the arts, in recent years courses have been developed in this field such as the creation of a qualification for the use of arts as a psychological, physical and social stimulation tool. However little else has been established within this field.

Five participants were interviewed in Romania who used some form of storytelling (although this was often reminiscence work) and creative drama within their work. One interviewee was a social worker for the Elderly Care Foundation in Romania. A core component of the organisation's work was within Day Centres where they provided cultural and artistic activities to those attending. Within these creative activities the use of storytelling was incorporated as a means of life-story work where participants used photographs as a prompt to discuss their life experiences as well as their feelings and values. Another interviewee was the Vice-President for an association concerned with neurodegenerative disorders. A key component of their work was to provide events and public forums where people could discuss or portray their experiences of living with cognitive difficulties and in particular Multiple Sclerosis. The final three interviewees were trained psychologists and used therapeutic activities within their clinical practice to support people in overcoming some of the psychological challenges of dementia and ameliorating cognitive difficulties. In these instances storytelling was predominantly used as a means of reminiscence to enable people with dementia to discuss aspects of their life and engage with any group work. A case study from one psychologist working with care homes and days centres is presented below.

Activities of a Clinical Psychologist

The psychologist works with elderly people, living with mild to moderate cognitive impairments in care homes and day centres throughout Romania. They deliver weekly workshops and during the course of 1.5 hours they seek to enhance social interactions and communication in people with dementia through the use of theatre, acting, writing and reminiscence activities. With the aid of health care professionals, people engaging in these sessions organise shadow theatre based on well-known fairy tales, build their own dolls and act out the stories. Feedback from the work suggests that participants demonstrate improvement in their communication, relationships and sense of self-esteem. The psychologist felt there were a number of challenges they faced when seeking to engage people with dementia in these creative activities. These were concerned with the fear and shame participants felt when trying to express their emotions; their lack of trust in the practitioner and the difficulties they had communicating.

The interviewees all discussed major challenges they faced when implementing these creative initiatives in Romania including a lack of financial and political support as well as reluctance from people with dementia to engage with the services. This latter barrier was attributed to a stigmatization of dementia and a feeling of shame from those diagnosed with the condition. They also reported a lack of trust in young practitioners delivering the services, who were perceived as too inexperienced to be able to provide any meaningful help and support. Overtime, as people with dementia engaged with the activities then these barriers could be overcome, and interviewees noted the positive benefits those attending could then achieve. This included improved communication and relationships with care staff, increased trust in the people supporting them as well as a heightened sense of self-esteem.

The interviewees also highlighted a range of attributes that practitioners working within this area would

need to be successful when delivering creative initiatives. These were: an understanding of dementia and the challenges that people living with the condition may encounter; the ability to communicate appropriately with people with dementia and their care partners and so develop trust and rapport; and a detailed understanding of the creative drama and/or storytelling technique so it can be used appropriately and to the best effect.

Overview of policy and creative practice in Bulgaria

A report produced in 2012, suggested that within Bulgaria there are around 100,000 people, approximately 1.4% of the population, with some form of dementia with around half living with Alzheimer's disease. At present there are no other reports that provide more recent figures on the number of people living with dementia in Bulgaria, although the National Centre for Public Health and Analyses include the hospitalized cases of people with dementia, and predict the number is around 2,457 for the year 2017. Given the ageing population in Bulgaria, this is likely to result in a rapid rise in the number of people affected by Alzheimer's and other forms of dementia over the forthcoming years. Despite this, the Bulgarian government has not developed mechanisms for early diagnosis, adequate treatment and provision of care for people with dementia. This is likely to have a detrimental impact on the well-being of those living with dementia as well as their family members.



This lack of dementia-awareness and engagement with the dementia agenda was reflected in the limited numbers of practitioners that could be found using creative methods to engage people with dementia and/or their care partners. Within Bulgaria three participants were interviewed including a social worker, a psychiatrist and Assistant Professor in the National Centre of Public Health and Analyses in Sofia and an informal care partner of someone with dementia. All three interviewees discussed the limited number of services available for people with dementia and highlighted that none of these provided creative drama or storytelling activities. Partly this was attributed to a lack of awareness within Bulgaria of the benefits of creative initiatives for the well-being of people with dementia and their care partners. As such it was felt that Government needed to introduce policies that would raise awareness of this important aspect of dementia care. The informal care partner discussed the difficulties he faced with finding nonpharmacological support around the community for him and his wife. Consequently, it was left up to him

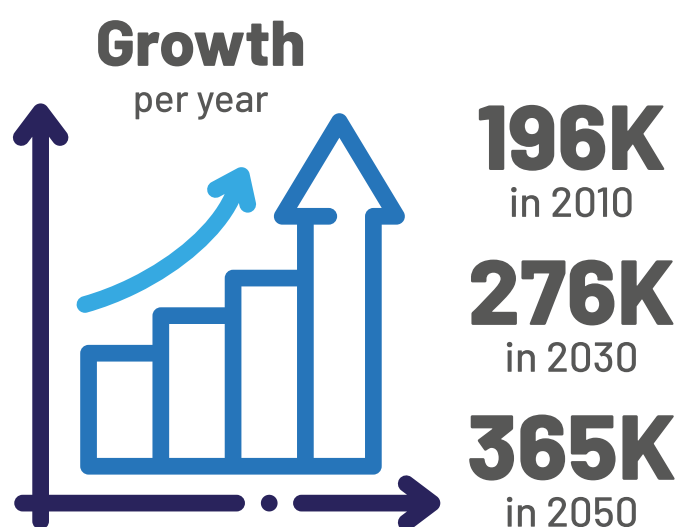
to provide the activities as well as educate himself on potential nonpharmacological interventions such as Cognitive Stimulation Therapy (CST). He highlighted the need for more services generally to be provided for people with dementia (not just creative activities) as well as more understanding and awareness of dementia amongst the wider society. As he exclaimed during interview:

“Unfortunately we are alone! My son helps us during the summer only. We couldn’t find any centers or specialist trained help for Frontotemporal Dementia and non-pharmacological therapies. Such centers do not exist in Bulgaria and I’m not aware of trained specialists as well!”

Overview of policy and creative practice in Greece

Although there is no adequate epidemiological data on dementia in Greece, the Alzheimer’s Disease International have calculated that in 2010 around 196,000 people, approximately 1.8% of the population, were living with the condition. This is predicted to reach 276,000 in 2030 and 365,000 in 2050. In December 2014, the Greek Parliament established the National Observatory for Dementia and Alzheimer’s disease, to ensure the implementation of the plan, which was approved by the whole spectrum of political parties within the Greek Parliament. So far, the implementation of the Dementia Action Plan includes the following: a) A national dementia registry is underway by the Greek National Health Service Organization b) A rating system to measure the impact of dementia on families is being developed, taking into account the severity of the disease, socioeconomic status, access to health and social care services. This will be used by the State to establish financial benefits for persons with dementia and their families accordingly c) Six Memory Clinics have been organised, in Psychiatric or Neurological Departments of General Hospitals in Greek cities d) Seven Dementia Day Care Centres in big cities and nine Day Care Centres in collaboration with Municipalities in smaller cities have been opened throughout the country e) Five hospices are under construction in various locations throughout Greece. The above actions are funded by the National Strategic Reference Framework 2014-2020.

Five participants were interviewed in Greece about their experiences of creative initiatives. These consisted of four psychologists who worked within day centres across Greece, including two as part of Alzheimer Hellas (Thessaloniki, Macedonia), one in Athens (Mainland Greece) and another in Volos (Thessaly). The fifth interviewee was an actor and theatre Director for the company Seven Eleven Theatre from Athens who implemented the Thallo program. The participants provided a detailed overview of their practice and how they incorporated creative drama and storytelling to enhance the lives of people with dementia and their care partners. Case studies illustrating this work are outlined below.



Alzheimer Hellas in Thessaloniki www.alzheimer-hellas.gr

Psychologists at Alzheimer Hellas work with people with dementia and their care partners, providing psychoeducational group therapy, support and cognitive enhancement at two Day Care Centers. Discussion and psychological therapies are the primary tools, but drama techniques together with experiential learning are used to supplement these one-hour support sessions. Whilst psychological therapies have helped the care partners to deal with the stress and emotion, the use of drama has provided them with further opportunities to express their feelings without needing words. Indirectly, this approach has also benefited the people with dementia, as the care partners reported feeling calmer and so better able to provide support to their loved ones. However, the practitioner discussed time constraints within their work as each session is only scheduled to run for one hour. This can make it difficult to work effectively within this timeframe, as a lot of emotions tend to surface that people then require further support to deal with. It is likely that these will only be addressed with more extensive and longer psychological therapies.

“Drama gives them a stimulus, a way to express themselves without using words”

Seven Eleven Theatre Company in Athens sevenelevan.me

Seven Eleven Theatre Company are the first organisation in Greece to produce a theatrical play that is based on the experiences of people with dementia. Over the last six years, the company has worked as external activity providers for nursing homes in and around Athens. They have implemented the Thallo program tailored to the care partners in domiciliary care, although the majority of their end-users are people with dementia. They adopt a holistic approach to dementia care, where they integrate aspects of drama and use free association thinking to facilitate the complex needs that people with dementia might face. They also work alongside care partners to provide theatrical exercises, aimed at enhancing their self-confidence in a fun way that ‘lightens their load.’ These interventions have resulted in improvements in mood, stress reduction and self-expression in people with dementia. The main challenge the organization faces is the varied group members who have a range of interests, education levels and socioeconomic status. This can sometimes lead to conflicts within the groups that require careful management. Consequently, many of the activities need to be adjusted to the interests and capabilities of the multiple individuals.

<http://thallo.care>

“The action helps a lot the people with dementia to express the best elements of themselves”

“People I see in the nursing homes are eagerly expecting this action, even if they are bedridden, they look forward to participating in our program”

Alzheimer Athens in Athens alzheimerathens.gr

A psychologist working in a day centre with people with dementia and their care partners has implemented two-hour workshops specialising in positive emotion and consisting of theatrical play and theatre classes. Over the course of the workshops, paper and pencil activities are introduced to the theatrical play to liven up the sessions and to encourage dramatization, improvisation and sketch. Participants have enjoyed these sessions so much that they turned them into a theatre performance that was displayed in a summer celebration party at the Day Care Centre. Initially, theatrical play workshops were run solely for people with dementia, however they have now expanded and been adapted to incorporate care partners as well. Participants have reported many positive impacts from these sessions, including enhanced creativity and imagination as well as cognitive and emotional reinforcement. People who engaged with this activity overtime displayed signs of interest and joy, even if initially they were reluctant to participate due to shyness.

“There are times where I have seen very serious people -that I believed they might not be carried away from theatrical play- to be the best participants”

Alzheimer Hellas www.alzheimer-hellas.gr

A psychologist working in a day care center with care partners of people with dementia discussed integrating elements of drama therapy, “theatre of the oppressed²” and psychodrama into their group and family therapy sessions. Some of those elements involved reverse role play, simulation and empty chair techniques. The implementation of these different techniques is adjusted for each individual case. Through the use of drama therapy and reverse role play, people are encouraged to practice empathetic understanding, so they can better their comprehension of the nature and progress of dementia. The techniques of “theater of the oppressed” and psychodrama also help care partners to express and relieve themselves of any negative emotions. The practitioner reported the initiatives were well received by the care partners and enabled them to reduce their levels of anxiety and depression as well as lessen the psychological difficulties they may experience whilst providing care. Whilst these sessions have demonstrated positive outcomes, the practitioner mentioned some challenging situations, when oppressed feelings and emotions arise unconsciously and unexpectedly. However, the practitioners are meeting those challenges with a positive attitude, “as this is the nature and the beauty of this job; challenges appear and we have to address these.”

“The exercises and the techniques of the theater of the oppressed and psychodrama help caregivers to forgive and free themselves from emotions of anger for the patient, which is a barrier in caregiving and overloads them a lot”

²This provides audiences with a performance of some of the challenges people with dementia and their care partners may face and then asks them to discuss how they might overcome them in real-life.

Alzheimer Volos <http://www.alzheimervolos.gr>

The organisation works directly with people with dementia and relative disorders, as well as their care partners. They incorporate role play in to therapy sessions with people with dementia and their care partners as well as fairy tale telling into educational lectures designed to raise awareness about dementia within the wider community. Role play aims to provide a safe environment where people are supported to learn or retrieve the skills that tend to decline with the progression of the condition. For example, one program includes working on emotional awareness, where people with dementia were tasked with recognizing or naming different emotions and then reproducing them in role play. In these scenarios, care partners are also encouraged to highlight the difficulties they may experience and act them out. It is hoped that this will enable them to learn new skills that they can use within their daily lives. At first people with dementia and their care partners can find it difficult to express themselves through the role play, overtime they become more open and flexible to the activity. The care partners have reported a sense of relief following these role play sessions, whereas the people with dementia have demonstrated better communication skills, improved mood and increased participation.

“The caregivers find it impossible to have the right to express some things or to succeed in the theatrical play. For instance, they may be ashamed of exposing what they live, through fear of criticism, fear of doing something wrong, but in the short term the safety of the group helps them to overcome it”

When discussing the challenges and barriers to their work, the interviewees highlighted difficulties associated with an initial lack of skills and knowledge about drama/theatre techniques. However, they overcame these by consulting and learning from specialists who were well trained in the practices. Similarly, another group encountered difficulties when they attempted to implement a drama model created in Britain due to the cultural differences between the countries. However, this was successfully adjusted after extensive research, trial and error. Further challenges to engaging people with dementia and their care partners in the creative initiatives included: differences in their interests and capabilities, meaning that the activities had to be tailored towards each individual; the stigma of dementia that prevented people from accessing the services due to feelings of shame and fear; and feelings from care partners that they would be perceived as unable to cope and so harshly judged if they accessed additional dementia services.

Through engaging with these initiatives, people with dementia and their care partners have reported a heightened sense of mood and a better ability to express themselves verbally and through their actions, as well as a reduction in anxiety, depression and stress. Care partners have also reported an improvement in their knowledge of dementia and its progression, which has resulted in increased levels of empathy when supporting people with dementia, as well as feelings of relief, as they are able to offload any negative emotions and feelings they may be experiencing in that moment.



Chapter 4:

SUMMARY AND RECOMMENDATIONS FOR CREATIVE DRAMA AND STORYTELLING IN DEMENTIA CARE

This final chapter summarises the use of creative drama and storytelling within dementia care, drawing comparisons from the literature review and the interviews conducted across the ERASMUS partner countries. The benefits of these creative approaches are situated within the wider social inclusion agenda that aims to develop and promote 'dementia-friendly' communities. Finally, the chapter outlines the barriers for introducing these creative approaches within the dementia care arena and provides recommendations for practitioners and policy makers wishing to advance this field.



Countries adopting creative drama and storytelling dementia care practices

The published literature suggested that within the dementia care field, creative drama and storytelling approaches were being used, predominantly, in the UK and Scandinavian countries, the USA and Canada. These countries have well developed and established policies that focus on promoting the wider social inclusion of people with dementia and their care partners, as well as addressing the neurological difficulties associated with the condition. As such, this may be reflected in their willingness to promote and fund these more creative approaches as a means to enhance the well-being of these populations. However, from the interview data it was also evident that pockets of this work were also being undertaken within some of the ERASMUS partner countries. Although, predominantly, these creative approaches were adopted by trained psychologists in clinical settings as part of their wider therapeutic work, there were also instances within countries such as Ireland and Greece where organisations/personnel from outside of the medical sector were embracing them. To successfully achieve 'dementia-friendly' communities it is important that all sectors, and not just medical professionals, are engaged with the dementia care agenda and are informed on how creative approaches such as drama and storytelling can support the social inclusion of people with dementia and their care partners.



Promoting social inclusion through creative drama and storytelling

The social inclusion agenda and policies such as ‘dementia-friendly’ communities seek to ensure people with dementia are *‘understood, respected and supported and confident they can contribute to community life’* as well as educate community members so they are *‘aware of and understand dementia’* and so feel confident including those living with the condition and enabling them to have *‘choice and control over their day-to-day lives.’* The findings from the literature review and the interviews suggested that creative drama and storytelling approaches had important benefits for the social inclusion agenda when used directly with people with dementia and their care partners or as an educational tool.

When engaging directly with these creative approaches, the findings highlighted that people with dementia and their care partners were provided with opportunities to participate in activities that were new to them and so promoted their life-long learning and sense of personal growth. These activities were delivered in relaxed social environments that encouraged laughter and fun and so reduced feelings of hopelessness and apathy that can be commonplace when living with dementia. They provided people with the tools to express their sense of ‘self’ both verbally and through their bodily movements. This ‘meaningful’ communication helped their care partners and others present within the activities to have a better understanding of them and the challenges they may encounter, and so feel more confident interacting and supporting them; thereby enhancing their relationship and the sense of emotional connection. Participating in the activities also provided people with dementia with positive psychological benefits such as an enhanced sense of alertness, a better ability to recall key ideas and life events and a sense of achievement as well as a reduction in depressive symptoms and negative emotions. These are important for their overall well-being and sense of self-esteem. Finally, many of the activities situated the person with dementia as ‘students’ who were able to inform and control the development of the creative process rather than ‘patients’ who passively received the activity. This provided a platform where their voices and opinions were respected and acted upon. Ensuring people with dementia are able to collaborate in activities as an equal partner is integral for their social inclusion and human rights.

The creative approaches were also able to contribute to the social inclusion agenda when being used as an educational tool. For instance, people with dementia and their care partners were often consulted in the design of vignettes and theatrical performances that would be delivered to an audience; thereby situating people with dementia as the experts and respecting their voices and experiences within these practices. The performances were delivered to a wide range of personnel responsible for delivering dementia care as well as the general public and were viewed as useful for providing a greater understanding of what it might be like to live with dementia or support someone affected by the condition as well as the support networks that can be accessed. Furthermore, the theatrical performances were perceived as a more simplistic medium to communicate complex messages and academic theories than could be achieved through lectures and written text. This ensured that audiences left the performances with a better understanding of how they can deliver care and support to people with dementia by recognising and valuing their sense of 'self' and focussing on the person rather than their condition. Enhancing the 'dementia-awareness' of all care practitioners, informal care partners and the wider general public is crucial to the wider social inclusion agenda, and these findings suggest creative drama and storytelling may be an engaging medium through which to achieve this. Additionally, when training medical practitioners to use these creative mediums (and in particular storytelling) with people with dementia, the findings suggested it: reduced their fear and discomfort of interacting with this population; challenged their views on the abilities of people with dementia; and enabled them to focus more on the humanistic aspects of dementia care rather than draw solely from the biomedical approach that was traditionally delivered within their training. Again, this is important for enhancing dementia-awareness, challenging the stigma associated with the condition and providing the best possible support for those affected by dementia throughout communities.

Challenges for incorporating creative drama and storytelling in dementia care

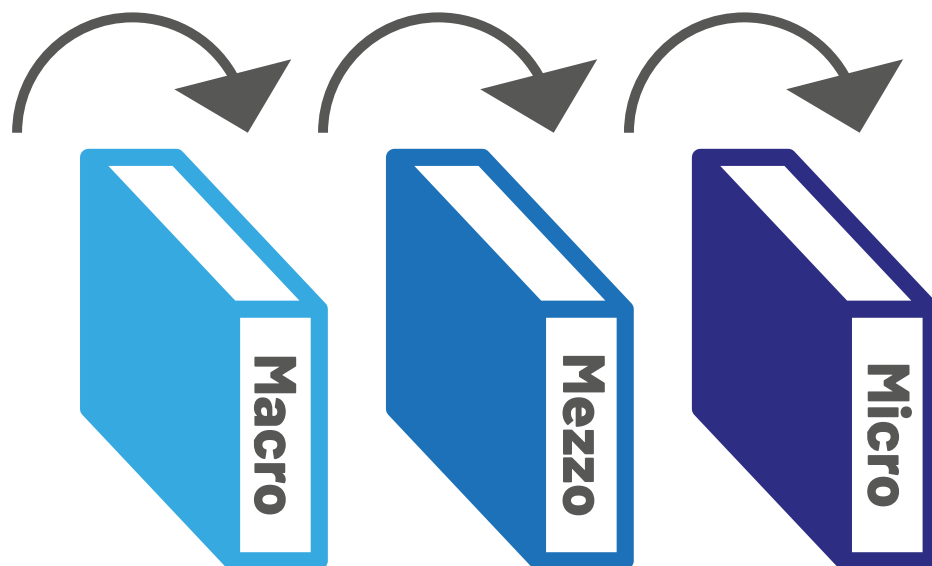
It is clear that creative drama and storytelling approaches offer great potential for enhancing the social inclusion agenda within the dementia care arena. However, if this potential is to be realised there are a number of barriers that need to be overcome. Findings from the literature review and the interviews suggest these barriers operate at a wider societal level (macro level barriers), within organisations (mezzo level barriers) as well as in interactions between people with dementia, their care partners and professionals (micro level barriers).

Macro level: when introducing creative drama and storytelling approaches within dementia care barriers may be encountered in countries that focus predominantly on the biomedical aspects of dementia or lack a dementia strategy. As such, many of their policies (if applicable) and resources are targeted at finding a cure for dementia and/or supporting people to address the neurological challenges they face. This emphasis places less of a focus on the human rights and social inclusion of people with dementia and their care partners and so fewer resources are directed at approaches and interventions that seek to enhance these facets. This is particularly evident in countries where their national laws and regulations are concerned primarily with ensuring people with dementia are protected and safe. Furthermore, in countries where these creative approaches do exist, the learning may not translate so readily across to other countries where these initiatives are not as prevalent due to differing cultural attitudes, values and practices. This lack of transferable context may result in practitioners residing in these latter countries opting out of using them within their practice.

Mezzo level: further barriers can include a lack of time, money and staff to deliver the activities as well as having an appropriate space in which to undertake them. These issues can be further exacerbated in care homes and day centres where managers are solely focussed on providing physical care for people with dementia and so closed-minded to initiatives that can promote and enhance their sense of social inclusion. As such they are reluctant to encourage their staff to use them as part of their practice. Furthermore, a lack of dementia awareness throughout some communities may mean that often these creative initiatives are seen as the responsibility of health professionals to deliver within clinical settings rather than something that can be taken up by practitioners and volunteers from different educational and artistic backgrounds. This is likely to prevent the exchange of knowledge and practice between different professionals and so inhibit the development and expansion of these creative approaches amongst wider communities. This lack of dementia-awareness can result in a stigma of the condition that may prevent people living with dementia from accessing these creative services for fear of 'outing' themselves as having dementia.

Micro: these barriers can be associated with a lack of training for professionals and volunteers in using creative drama and storytelling with people with dementia. This lack of training may mean that staff are fearful of using these approaches within their practice, are not aware of the benefits that they may provide for the social inclusion of people with dementia or do not know how to effectively deliver and communicate them to this population. Care partners may not wish to use them for fear of being judged as unable to cope. Furthermore, people with dementia may be reluctant to engage with these creative initiatives as they do not see the benefits of them or feel that younger, potentially more inexperienced care staff are able to deliver them effectively. This highlights the agency that people with dementia and their care partners retain when choosing whether to engage with these creative initiatives.

Barriers for
enhancing the
social
inclusion
agenda within
the dementia
care arena





Recommendations for incorporating creative drama and storytelling in dementia care

Given the multitude of barriers operating at different levels, it is clear that any solutions introduced must be targeted at all of these levels. Failure to do so at one level is likely to inhibit the overall advancement of creative drama and storytelling approaches within dementia care. Based on the findings from the literature review and the interviews, a list of recommendations are presented below for policy makers and practitioners wishing to promote these creative initiatives.

Recommendations for policy:

- 1. Develop a national dementia strategy based on the principles of social inclusion:** Dementia is a global challenge and so it is important that all countries outline a political strategy for addressing this. Although this strategy should promote the use of pharmacological research to attempt to find a cure for the condition, it must also seek to enhance the human rights and wider social inclusion of people with dementia through policies such as 'dementia-friendly' and 'dementia-positive' communities.
- 2. Promote creative initiatives to support the social inclusion agenda:** Once a strategy based on the principles of social inclusion has been established, national policies should seek to promote the use of creative initiatives such as drama and storytelling within dementia care. This can be achieved through providing funding for research and practice within this field, as well as developing political documents to publicise the benefits of these approaches for the social inclusion and well-being of people with dementia and their care partners.
- 3. Seek to challenge the stigma associated with dementia:** A key component of national dementia strategies must be to target resources at reducing the stigma associated with dementia. This will encourage people living with the condition and their care partners to access services such as creative initiatives that will enhance their sense of social inclusion and well-being.

Recommendations for practice:

- 1. Exchange knowledge between sectors and organisations:** It is important that all organisations are open to using creative drama and storytelling initiatives to promote the social inclusion agenda. These approaches should not be exclusive to trained psychologists in clinical settings but should be endorsed amongst the wider community such as arts practitioners. This will require organisations/personnel to share their knowledge and learn from one another.
- 2. Develop and publicise dementia-awareness training:** If these approaches are to be used by organisations/personnel outside of the dementia care arena then it is important they can access dementia-awareness training. This will ensure they feel confident working with this population and can develop the appropriate interpersonal skills to engage them within any creative activities. Furthermore, this training is likely to reduce the stigma associated with dementia and so enhance the wider social inclusion agenda.
- 3. Promote best practice guidelines for using creative drama and storytelling:** Linked to the previous recommendation, it is also important training is established that outlines how practitioners and volunteers can successfully use creative drama and storytelling with people with dementia and their care partners. This training can be delivered either face-to-face or via online platforms, but it must be sensitive to cultural differences and provide best practice examples of how these mediums are currently being used to enhance the social inclusion of this population.
- 4. Ensure effective planning, implementation and delivery of creative initiatives through engaging directly with people with dementia:** It is crucial that practitioners develop a plan to successfully implement and deliver creative drama and storytelling initiatives. People with dementia should be involved and act as contributors from inception through to evaluation, thereby enabling the core initiative to be focused on their experiences. This will require: understanding how and where to recruit participants and volunteers; selecting appropriate environments that are safe and welcoming; designing activities that are engaging and tailored to the interests of the participants; and continually evaluating the activities so they remain appealing to those attending. This planning process is particularly important within care homes and Day Centres where numerous activities may be on offer for people with dementia and their care partners and so support staff will likely have conflicting demands.
- 5. Publicise the benefits of creative drama and storytelling for people with dementia:** These initiatives have been shown to enhance the well-being of people with dementia and their care partners either through direct engagement or indirectly through challenging the stigma associated with the condition and educating audiences on ways to provide better support for people who are affected. Consequently, it is important that the benefits and outcomes of these creative initiatives continue to be publicised through multiple mediums that will engage directly with people living with dementia, as well as academic audiences and all professionals and care partners working with people with dementia. This is likely to encourage their wider use amongst communities as well as ease some of the apprehension people with dementia and their care partners may have about participating.



Conclusion

The findings from this report highlight the importance of creative drama and storytelling initiatives for the wider social inclusion of people with dementia and their care partners. Engaging directly with these activities provides people with a sense of purpose and the tools to express their identity either verbally or through their bodily movements as well as an opportunity for 'meaningful' social connection and life-long learning. Furthermore, it was shown that these creative initiatives could be used as an educational medium to raise dementia-awareness amongst professionals, care partners and the wider public and so challenge the stigma associated with the condition. This is crucial for the social inclusion agenda and ensuring people with dementia and their care partners can access appropriate support and care, and uphold their human rights to live free from harm and discrimination. However, to ensure the uptake of these creative initiatives within the dementia care field it is important that they are promoted by governments as part of a wider social inclusion agenda and that organisations are provided with the financial resources and appropriate training to implement them. It is hoped that this report can serve as a campaign tool to achieve this, through raising political awareness of creative drama and storytelling for people with dementia and promoting their wide use throughout socially inclusive, 'dementia-friendly' communities.

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Appendix 1:

SYSTEMISED LITERATURE REVIEW METHOD

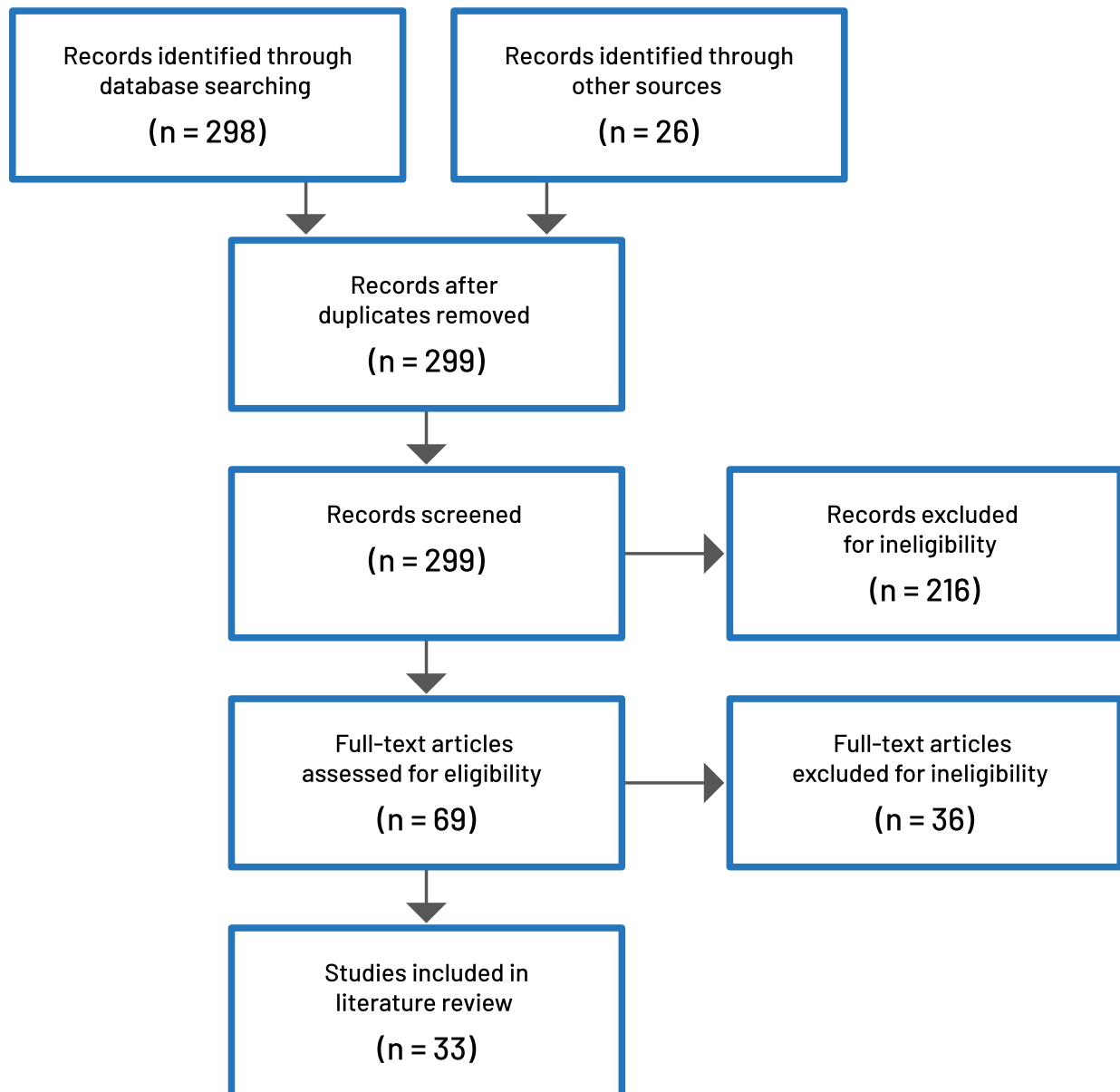
A systemised review was conducted on the use of creative drama in dementia care. The following search terms, including Boolean operators (eg, AND, OR) and truncation symbols (denoted by *) were used for this review: (dementia) OR (Alzheimer*) AND (drama) OR (creative drama) OR (theatre) OR (story-telling) OR (improvis*) OR (poetry) OR (image work) OR (embodiment) OR (creative performance).

The following electronic databases were accessed for this review, selected due to their content being relevant to the subject area: PsychInfo, Web of Science, Medline, ScienceDirect, CINAHL (all via EBSCO), Cochrane and Google Scholar. When using Google Scholar, the relevant papers were selected from the first ten pages. The selected papers were also entered into Google Scholar and papers that used those citations were assessed for inclusion criteria. The literature search was conducted between December 19, 2018 and February 9, 2019.

During screening, records were included or excluded based on the following criteria: Date: from 2000 to recent, Language: English, Participants: human with dementia and informal/formal carers, Journals: academic, peer reviewed, full text, Purpose of the intervention: care, education, awareness and support, NOT diagnosis or therapy, Type of Intervention: had to have a drama element to it.

The search protocol described above originally resulted in 298 journals being returned through the database searches and 26 additional searches through other sources or hand searching. Duplicate articles were removed, resulting in 299 journals. Subsequently, articles were removed based on the inclusion and exclusion criteria looking at the titles and the abstracts. This resulted in 69 articles being obtained as full-text documents. After all of these articles were read, a further 36 were removed due to not meeting the inclusion and exclusion criteria; mainly because the interventions did not have any creative element to them. In total, 33 articles were included in the final review. Figure 1 represents the flow diagram of the search procedure.

Flow chart documenting the systemised review



Appendix 2:

SYSTEMISED LITERATURE REVIEW METHOD

Thank you for agreeing to take part in the interview today. I expect that the discussion will last around 20-30 minutes? Will that be ok? I have a few questions that aim to understand who you are, the work that you undertake and the impact that you believe it has for people with dementia or their care partners.

So just to begin then...

1. Background information

- Could you tell me a bit about yourself please?
- Who are you?
- What is your job title/role?
- What is your professional background? What did you train as?
- How long have you been working for your organisation?

Now could you provide me with a bit of information on your work...

2. Your work

- Could you please tell me a bit about what you do in your organisation?
 - How did it begin?
 - Who do you work with/how many people are in your organisation?
 - Who are your clients? (**this should include people with dementia or those supporting people with dementia**- no need to continue the interview if they do not meet these criteria)
- What are the aims of the work you do?
- How do you incorporate creative drama and storytelling into your work?
- How long do sessions typically last? And how often do people come along to them (once a week/every other week?)
- Do you have any theories that guide your work? If yes, could you explain what these are please?
- What do you believe the skills needed are in this line of work? (what skills do you demonstrate?)

3. Impact of your work

- What impact do you think the sessions have for the participants?
 - What are the benefits?
 - What are the challenges they have to overcome?
 - How do you measure these?
- Do you encounter any personal challenges in your work?
 - If yes, what are these?
 - How do you address these?
- Can you provide a case study/case studies for some of the work you are doing that we can include in our work? Either highlighting positive benefits or challenges that needed to be overcome.

4. Future impact of your work

- How would you like to take your work forward?
- How do you think you can achieve this?
- What support might you require?
- What challenges might you encounter?
- How might you overcome these?

Thank you for giving up your time. Do you have any other questions that we have not covered in the interview?

