

Making Moments Matter

A manual for volunteers supporting and communicating with people living with dementia



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Welcome

Welcome to our “Making Moments Matter” project. This manual is carefully crafted to guide volunteers in facilitating interactive singing activities within care homes for people living with dementia. We recognise the transformative influence that volunteers can have in care homes, especially through their engagement and connections with residents.

Our vision is to encourage all care homes to involve volunteers, assisting staff in providing meaningful activities for residents, particularly those living with dementia. To connect with people living with dementia we have to use all the skills and expertise that we can. One of the most powerful tools we can use is music and song. We firmly believe that music and singing should be integral components of dementia care. After all, the universal experience of listening to and enjoying music has proven to yield positive benefits for people living with dementia.

We invite all care homes to embrace the power of volunteering. This manual outlines how volunteers can support and lead singing activities within a care home environment. Your involvement is part of the transformation we strive to bring to the world of dementia care.

About St John of God Dementia Care at St Joseph's



We are the largest home in Ireland solely dedicated to dementia care. Sixty people call St Joseph's their home and we also provide a Day Care Club and respite service.

We hold the Butterfly Approach accreditation from Meaningful Care Matters, where people living with dementia are free to be themselves. In 2020 we won the Charity Impact Award in Ireland and in 2021 we received the Investing in Volunteers Award, the national quality mark

of excellence in volunteer management in Ireland and the United Kingdom. We have over 100 volunteers who enhance the quality of the care that we offer to residents, Day Care Club members and their families. Our volunteer team help us to make that all happen.

For more information visit:
www.saintjosephsshankill.ie

About Hope! Respostas Sociais



HOPE is an organisation that focuses on global health and social inclusion, specifically within the realms of aging and dementia.

Over the past 9 years, we have conceived, executed, and overseen a range of local and regional projects aimed at community intervention for individuals living with dementia and their caregivers. These initiatives encompass social inclusion, enhancement of quality of life, advocacy for fundamental rights, and the empowerment of caregivers and professionals providing care.

As a non-profit and social solidarity entity, we were established to address emerging societal challenges comprehensively and inclusively. Our efforts extend to older people, those dealing with mental health issues, people living with dementia, and those facing the threat of social exclusion.

For more details, please visit our website at: www.hope.pt.

Making Moments Matter

Project Origin and Goals

St Joseph's and Hope! Respostas Sociais created this project, Making Moments Matter, to demonstrate the power of volunteering within nursing home/care settings.

The project has three key outputs:

- Develop a Volunteer Programme Charter to support people living with dementia
- Develop a Training Manual for volunteers supporting and communicating with people living with dementia using music as the medium for connection
- Develop and pilot a Volunteer Training Session to support volunteers making “moments matter” in care homes.

You'll find the Volunteer Programme Charter on pages 4 -6 of this manual. This manual was created to assist and support training sessions and also act as a repository of information for each volunteer on how best to support a person living with dementia to be themselves, and how best to communicate with someone living with dementia, both verbally and through non-verbal channels.

The manual contains information on dementia, communication tips, introduction to the volunteer-led activity and resources to support volunteers to roll out this activity in nursing/care homes.

We hope that you find this resource very useful and practical. Singing is one example of a volunteer-led activity, however there are many other activities that can be supported by volunteers.



The Volunteer Charter

The Volunteer Charter

Our Volunteer Programme Charter is based on the Investing in Volunteers best practice framework. It has six pillars of agreement:

- 1/ Vision for Volunteering
- 2/ Planning for Volunteers
- 3/ Volunteer Inclusion
- 4/ Recruiting & Welcoming Volunteers
- 5/ Supporting Volunteers
- 6/ Valuing & Developing Volunteers.

As an organisation, having each of these pillars in place, ensures that we recognise that volunteering is a two-way process that makes a difference in the lives of people living with dementia, their loved ones and our volunteers. Further information about the six areas is below:



1/ Vision for Volunteering

Volunteering is embedded within the overall vision, values, culture and aims of the organisation and its impact is recognised and communicated. Organisations understand why they involve volunteers. It is important to have a vision for volunteering so that everyone in the organisation, including volunteers, knows why volunteers are involved. Volunteer involvement is also reflected in management, financial and resource planning.



2/ Planning for Volunteers

People, policies and procedures have been put in place to ensure volunteering is well-managed. The right people, policies and procedures prepare us to welcome volunteers to the team and to support them as well. They also help us to ensure that systems are in place to protect volunteers and others and that records are maintained in line with data protection.



3/ Volunteer Inclusion

There is a positive approach to inclusion, equity and diversity and a proactive approach to making volunteering accessible. Doing this means that we create an environment where everyone feels safe and able to participate and where possible there is a wide range of accessible opportunities that can be adapted throughout the volunteer's journey.



4/ Recruiting & Welcoming Volunteers

It is easy for people to find out about opportunities, explore whether they are right for them, and get involved. The reason why we do this is to make the recruitment process straightforward so that volunteers can learn more about the opportunities available before committing to volunteer. We make sure to provide relevant training to support our volunteer team.



5/ Supporting Volunteers

Volunteers feel supported at all times, that they are a part of the organisation and that their contribution makes a difference. It is essential that volunteers feel part of the organisation so that they can discuss their role, give feedback and have good communication between them and the organisation and there are systems in place for volunteers to have a positive and managed exit.



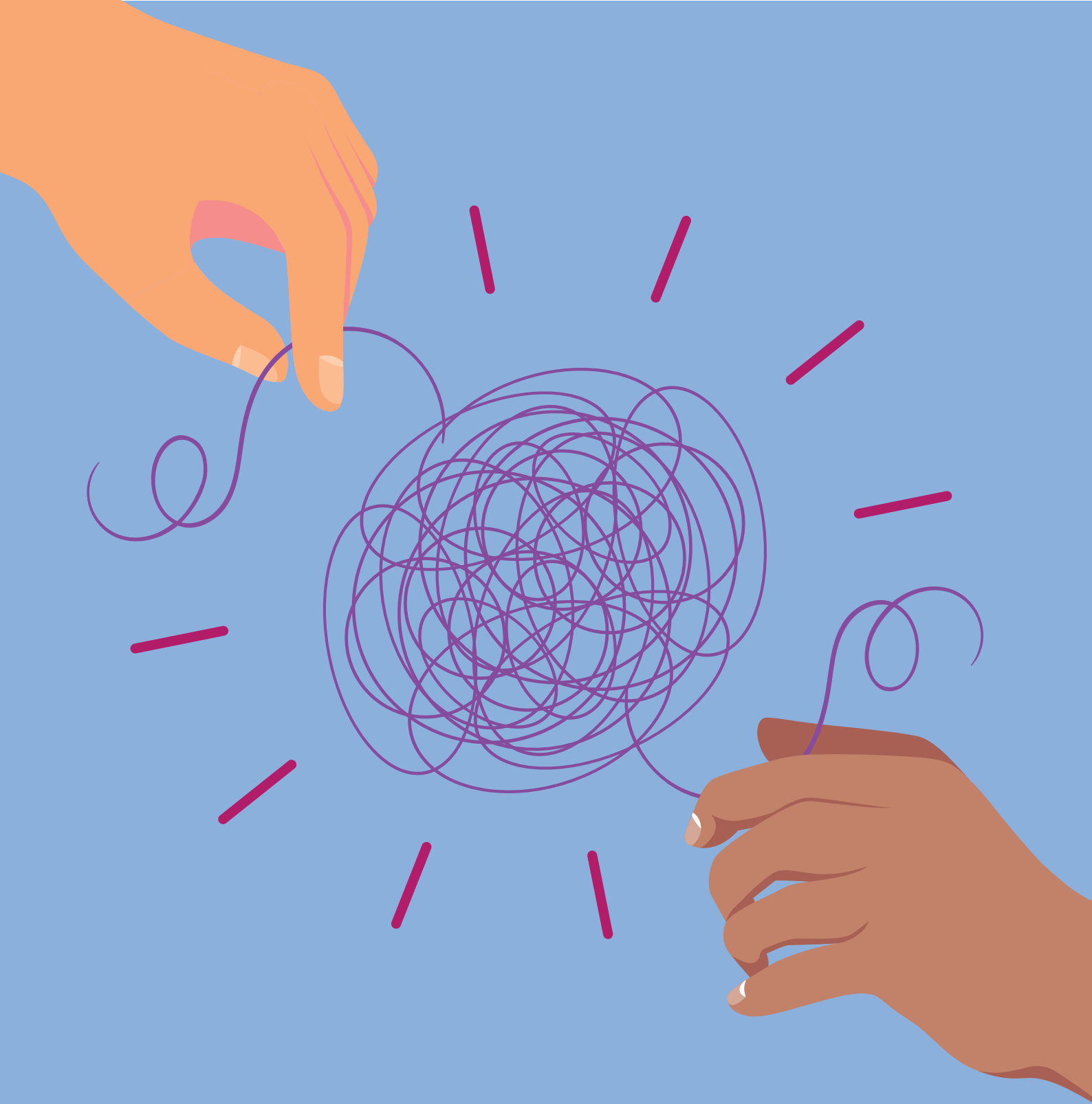
6/ Valuing & Developing Volunteers

Volunteers are valued and there are opportunities for volunteers to develop and grow through their experience. We value and develop our volunteer team, so they know that their contribution is meaningful and rewarding. They have the opportunity to learn from other volunteers and their future aspirations are supported.

Examples of how we put these pillars of agreement into practice are detailed in the Volunteer Programme Charter on page 4.

For further information visit:

<https://investinginvolunteers.co.uk>

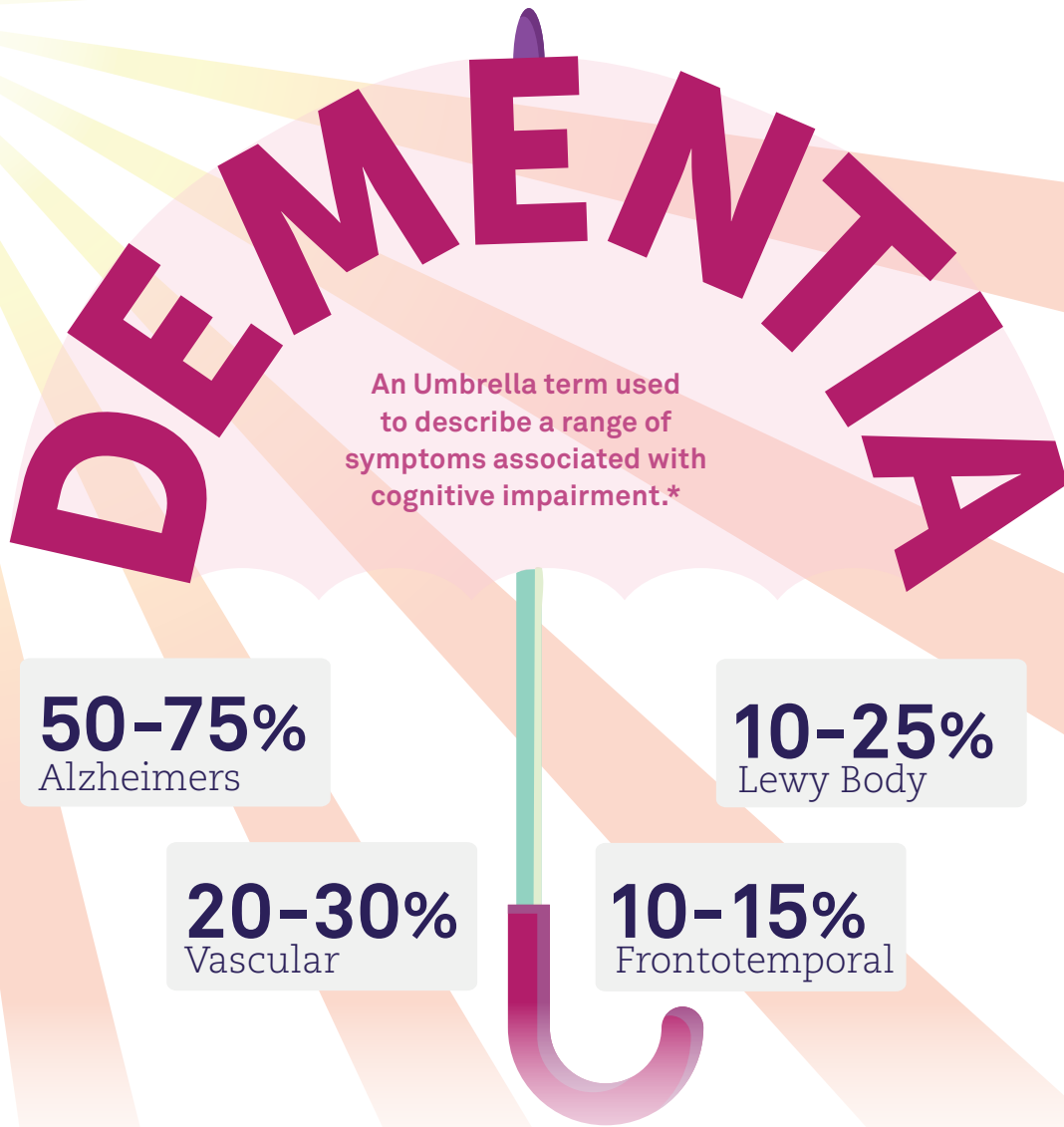


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About Dementia

Dementia is a complex condition that impacts not only the brain but the entirety of a person's being. Its effects extend beyond the person and touch the lives of their families.

Dementia is an umbrella term that encompasses a range of conditions characterised by a gradual decline in cognitive functioning. Symptoms of dementia encompass memory loss, diminished social skills, and altered emotional responses to

people, places, and events. While a person living with dementia might outwardly appear healthy, their brain's internal workings are not working properly.

Although the highest prevalence of dementia is in older people, it isn't part of the normal aging process. Anyone can get dementia, however it is more common after the age of 65. In some cases, people between 40 and 65 years of age may develop early or younger onset dementia.

*Source: World Health Organisation

Stages of dementia

Dementia unfolds through distinct stages, as outlined by Naomi Feil's theories. Not every individual experiences all of these stages, but they provide a framework to understand the journey of those affected:



1 / Early Experience

People living with the early experience of dementia, will be aware of the impairments that they are experiencing, they will appear to be orientated to the time of day but they may try to hide or deny that they have memory loss and other symptoms often associated with dementia. They will often be a little suspicious or defensive as they struggle with clinging to their independence.

At this stage the person may:

- Be aware of losses
- Appear to be orientated
- Be frightened of becoming “crazy”
- Be frightened of losing control and independence
- Sometimes be defensive in body posturing
- Be confabulating (making up stories) to fill in the gaps
- Be good at maintaining good social façade to hide short-term memory loss.



2 / Different Reality

This stage of dementia can be defined as when people are experiencing or living in a different reality to our own. For example, they may say they have to go to work or collect the children from school. When the truth is they have been retired for many years and the children are now adults with children of their own. Living with dementia they often draw upon feelings and experiences from events in their past to make sense of their feelings and experience of the world now.

At this stage the person may:

- Be visibly disorientated
- Have a loss of sense of chronological time
- Not be using learned social rules and therefore may be inappropriate in behavioural responses
- Appear to be more relaxed in their illness as they are less aware of their losses
- Be unable to “fill in the gaps” anymore.



3 / Repetitive Emotion

At this stage people express their feelings through repetitive sounds, words or actions to communicate their feelings. The emotion is in the behaviour.

At this stage the person may:

- Express their feelings through repeating words or sounds or motions, for example, humming or rummaging through things or walking or pacing back and forth
- Struggle to find words to communicate
- Be unaware of time
- Not be able to fill in the gaps that they would have been able to in the earlier stages.



4 / Late Experience

People who have intense later 'stage' dementia care needs. Verbal communication skills are often impaired. A person may appear to have 'shut out' the outside world.

At this stage the person:

- Often has their eyes closed
- Has little movement or vocalisation
- Is still responsive to positive stimulation, such as, nurturing voice, touch, smells and sounds.

Common symptoms of dementia

Dementia manifests in various ways, and each person's experience is unique. Seven common symptoms include:



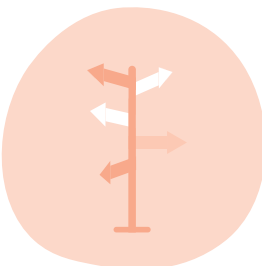
1 / Memory loss

We all have experienced those moments of walking into a room and forgetting why we were there, and why we came into the room. This is normal. When we have difficulty recalling the names of an everyday item (a key, a phone), that is also normal. However, the difference with the early stages of dementia is when a person can't remember the object in their hand or what to do with it. We may recall the information at a later stage in the day, but recall difficulty in that moment.



2 / Difficulty with dates and timeframes

People living with dementia can struggle with times, dates and numbers. We all know what year it is but for someone living with dementia they may believe they are living 40 or 50 years ago. They may talk about their parents or loved ones in the here and now, but in reality they have passed away. People may want to collect their child from school, not remembering that their child is now grown up with children of their own. This is called different/altered reality. It's important that we go to their reality and not bring them to ours.



3 / Finding the way

For many people living with dementia, they may find the route to the shops confusing, they may get lost, they can't retrace their steps and a route they have taken for many years is now forgotten. They may feel disorientated, confused and frightened. With this cognitive decline, the confusion of the situation is increased as the sequence of events breaks down.



4 / Changes in audio perception

Loud sounds can have a negative impact on a person living with dementia. Someone living with dementia may believe that the sounds from the TV or radio are real, happening in front of them or the voices are people in their home. Turning off background sounds, like the TV and radio will eliminate any distractions.



5 / Changes in visual perceptions

For someone living with dementia, they may interpret shadows differently. They may believe moving shadows are real and perceive them as an object or animal, which can be frightening. Natural light is best and the use of lamps will eliminate shadows that could be a source of fear.

We are surrounded by colours everywhere in our homes, the shops, and public spaces. We interpret colours in our everyday activities very differently to someone living with dementia. For example, blue lino on the floor can be viewed as water or the sea. A black welcome mat at the front door can be a hole in the ground. This can be very scary. A plasma screen on a wall mount could be interpreted as a black hole. All of these items could make someone living with dementia feel frightened, anxious and worried.



6 / Difficulty with activities of daily living

The sequence of completing everyday tasks can become increasingly difficult to complete. Each step of the task can be confusing, for example, when trying to make a cup of tea, the tea bag might go into the fridge instead of the cup. It is important that we accompany someone through these everyday tasks, rather than doing it for them, this will support their independence and self-worth. We can help by maybe starting the task for them, or prompting them, so that they can finish it or carry out some of the steps.



7 / Changes in social interactions with others

Dementia can also affect how we interact with others. A person living with dementia may no longer follow the sequence of a conversation or be able to hold a conversation with others. This can lead to the person withdrawing from social situations, hobbies or activities at a time when it is really important to maintain that connection with others.

Dementia can also affect the part of the brain responsible for recognising people. A person living with dementia may no longer be able to recognise long-term friends and family members. Think of how you felt when you met someone wearing a mask and you didn't recognise them. You probably experienced feelings of confusion, anxiety and worry trying to remember. These are all feelings experienced by someone living with dementia every day.

Gaining Deeper Understanding/ Bookcase and Traffic Light

There are currently estimated to be over 55 million people worldwide living with dementia. The number of people affected is set to rise to 139 million by 2050. A new case of dementia arises somewhere in the world every 3 seconds.

Dementia knows no social, economic, or ethnic boundaries. There are estimated to be over 9 million people living with dementia in Europe with this figure set to double by 2050. In Ireland alone, there are 64,000 people living with dementia, and in Portugal, estimates exceed 200,000. In light of these numbers, fostering a comprehensive understanding of the impact of dementia becomes paramount.

As we've come to understand, living with dementia is a multifaceted experience, encompassing diverse experiences and perspectives.

Here are some examples that offer a deeper understanding of living with dementia. Through these comparisons, we strive to build connections, cultivate empathy, and refine our ability to communicate and support people living with dementia on their individual journey.

Crossing the bridge

Each person's journey is as unique as they are. The experience of a person living with dementia is moving from one reality to another. Understanding and supporting people living with dementia involves empathetically acknowledging their reality and adapting our approach. In other words, crossing the Bridge of Life with the person. We can do this in two ways:

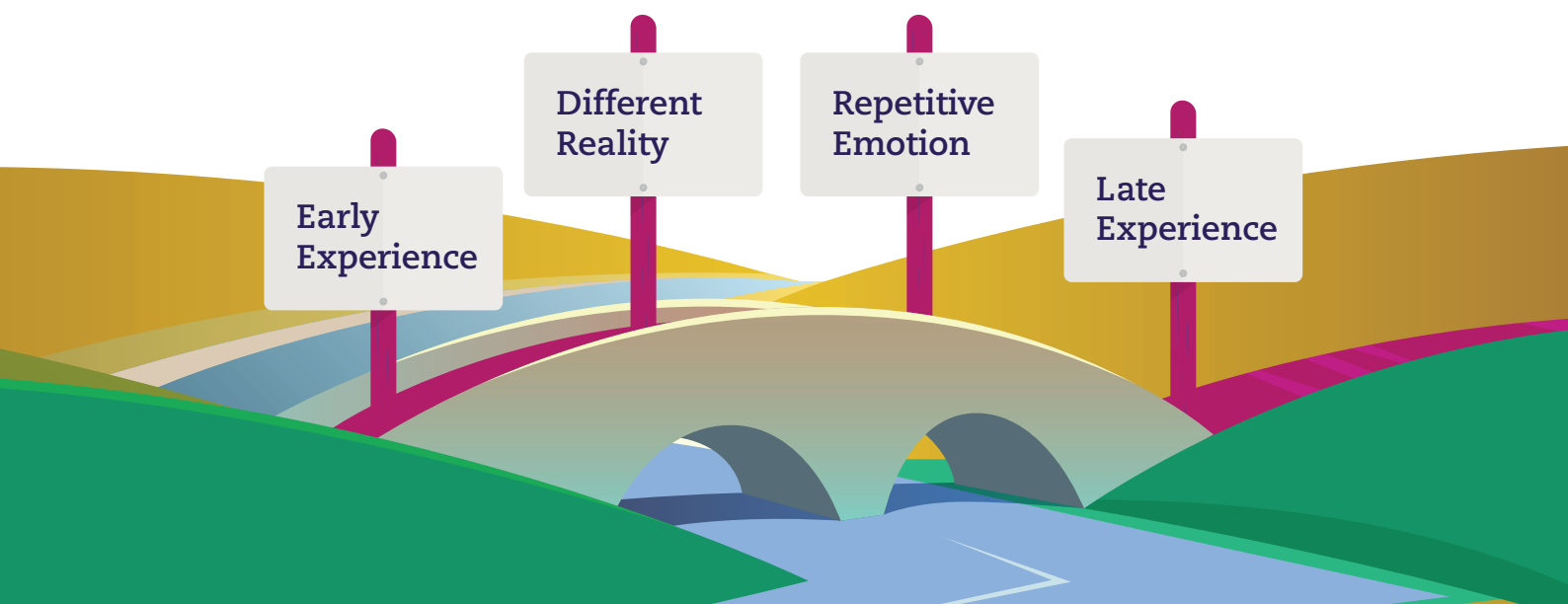
1 / Supporting a person living with dementia involves understanding where the person is in their experience of dementia and being able to adapt your approach to fit with that point 'on the bridge'.

Imagine the journey through dementia as a bridge, where each person stands at a unique point. To effectively support someone living with dementia, it's essential to recognise where they are on this bridge – whether they're in the early stages, experiencing a different reality, expressing repetitive emotions, or in the later stages. By understanding their position, you can tailor your approach, communication,

and interactions to match their current perspective and needs. This adaptive approach creates a smoother bridge of understanding between you and the person living with dementia.

2 / Connecting with a person living with dementia involves crossing the bridge with them. It also involves supporting families to cross this bridge with the person living with dementia and not trying to pull the person inappropriately back to our side of the bridge.

Connecting with a person living with dementia requires empathetically entering their reality – crossing the bridge they're on. By doing so, you establish a genuine and meaningful connection, even if their perspective differs from yours. Additionally, it's crucial to guide families and loved ones in joining this journey across the bridge, rather than insisting that the person conform to our understanding. Instead of trying to force them back to our reality, we support them on their path, recognising the value of their unique experiences and emotions. This approach fosters a more compassionate and supportive environment for everyone involved.





The Bookcase of Memories and Emotions

Imagine your memory as a bookcase, containing the volumes of your life experiences. On its upper shelves rest your recent memories – the events of the morning or yesterday. As you descend, the lower shelves cradle your earlier memories, harkening back to childhood days and school adventures.

For those living with dementia, the upper shelves of this bookcase become less stable, causing the books of memories to wobble and tumble frequently. In contrast, the lower shelves stand steadier, preserving long-term memories like precious tomes.

Now, envision an adjacent shelf, the “emotional shelf,” closely intertwined with the shelves of memories. This shelf houses the emotions and sensations that accompany specific life moments. Picture finding the memory of a beloved schoolteacher on the

memory shelf, and on the emotional shelf, the enduring feeling of inspiration ignited during those classroom interactions. This emotional shelf boasts remarkable stability and resilience. Even as the journey through dementia shakes the two shelves, the emotional shelf remains robust, safeguarding the emotions tied to each memory.

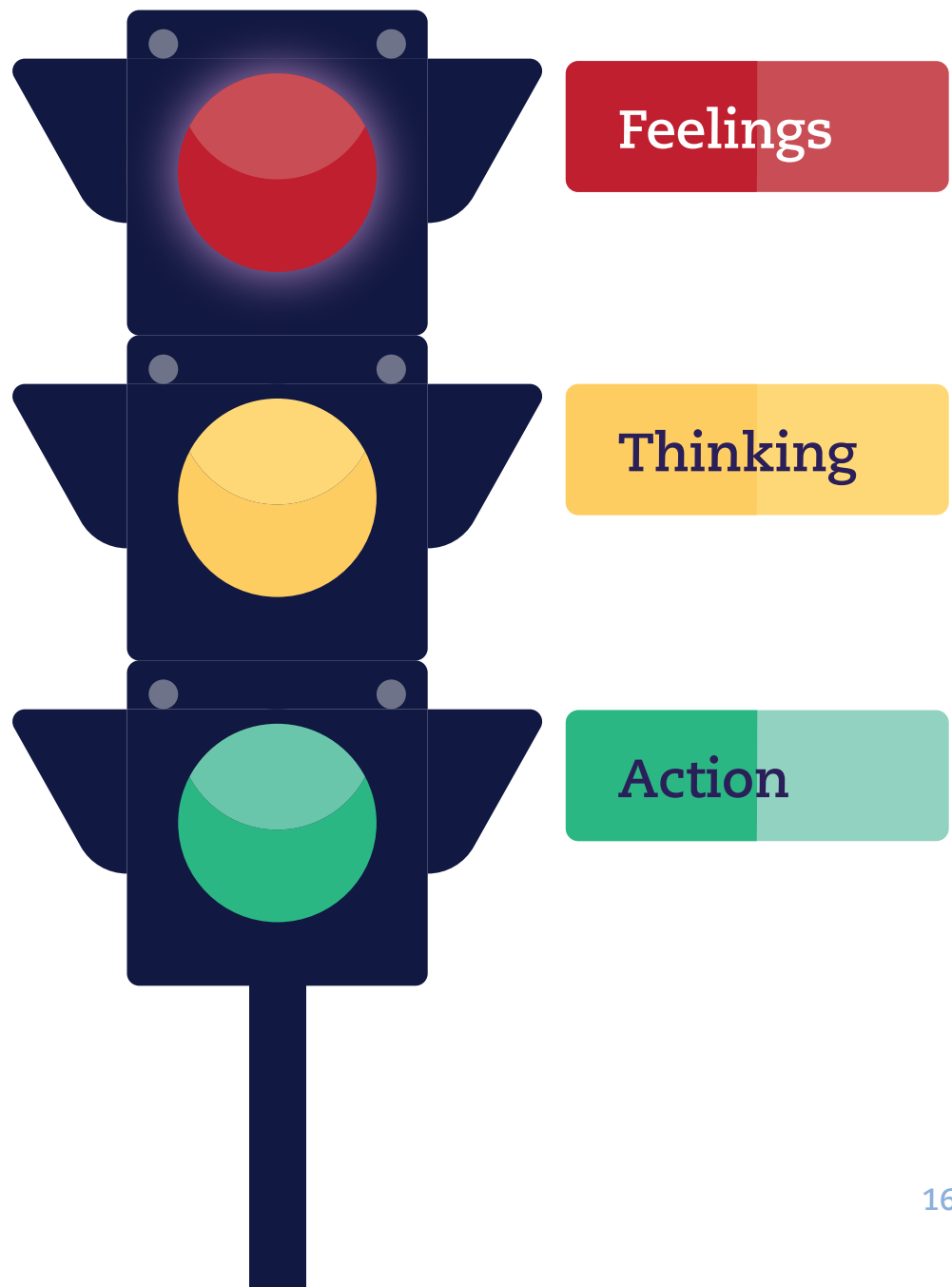
As the path of dementia unfolds, the shelf of memories, being less resistant, may sway and even drop a memory, like the cherished recollection of that schoolteacher. Yet, the emotional shelf, robust and resilient, will cradle the feeling of inspiration associated with that memory, preserving it over time.

In the realm of dementia, a person may lose the name or face of a person, and even the specifics of a past situation, yet the emotions and sensations felt at that moment endure. To navigate this delicate terrain, asking questions may sometimes unsettle a

person living with dementia, particularly as their condition advances. Instead, mirroring emerges as a profound tool for connection. Repeating their words with a genuine smile bridges gaps when you're unsure how to respond. Furthermore, sustaining interactions

and providing diverse, enjoyable experiences, all while honouring their identity, preferences, and life story, becomes a powerful way to affirm that a person is infinitely more than their dementia.

The Traffic Light Approach



In the world experienced by people living with dementia, emotions take centre stage, underscoring the significance of feelings above all else. This principle, encapsulated in the phrase “Feelings Matter Most,” offers insight into their unique perspective. To grasp this perspective, let’s draw a parallel with a familiar scenario – a set of traffic lights. Within this analogy, each light carries profound meaning.

Imagine the red light as a representation of emotions – the heart’s signals and sensations. The amber light symbolises thought processes, assessments, and judgments – essentially serving as a filter. Lastly, the green light embodies actions, signifying responses and behaviours.

Yet, the dynamics shift within the experience of people living with dementia. The connection between emotions and actions, typically mediated by the amber light, undergoes alterations. The amber light becomes “faulty” or may even cease to function. For those living with dementia, the path from feelings to actions transforms. The journey becomes a direct route – they FEEL and they ACT, without the usual interplay of the amber filter.

This distinct wiring can lead to moments of incongruence. A person living with dementia might exhibit responses that appear out of sync or disconnected from the situation. Consider a sudden door bang – the sound alone triggers an immediate surge of fear or anger. This emotional reaction propels instant action, bypassing the customary logical filter. The person may not recall leaving a window slightly open upstairs, a minor action that caused the draft responsible for the door’s sound.

This metaphor highlights the fusion of feelings and actions in the lives of those living with dementia. It underscores the idea that, even as their memory may falter, the immediate emotional landscape significantly shapes their reactions. By comprehending this phenomenon, we deepen our capacity to empathise and provide support, recognising that every response emerges from the intricate interplay between the traffic lights of emotions and actions.



Understanding Communication

Communication goes beyond mere words. It's a fusion of verbal cues, body language, and the tone of our voice. Surprisingly, only 7% of communication is conveyed through words, while body language constitutes 55%, and the tone of voice holds 38%.

For those living with dementia, communication can become a complex challenge. The specific communication difficulties experienced are shaped by the underlying cause of dementia and the areas of the brain it affects. Words might slip away, replaced by related terms, or fluent speech might lack coherence. Understanding spoken words may falter, leading to partial comprehension or complete misunderstanding. Even reading, writing, and adhering to social conversational norms can waver. In some cases, people living with dementia might have difficulty expressing themselves and how they feel.

Each individual's journey through dementia is unique, resulting in a diverse array of communication hurdles. It falls upon us to adapt our communication – both verbal and non-verbal – especially when engaging with those living with dementia. Our words, tone, volume, pauses, alongside our gestures, movements, and spatial awareness, hold the power to positively or negatively influence the communication experience.

Making Moments Matter

Embedded within the Butterfly Model of Care is the concept of making every moment count for those in our care. These moments, whether fleeting seconds or minute-long exchanges, can significantly impact a person living with dementia. Simple actions such as eye contact, a smile, shaking hands, a shared stroll in the garden, browsing a photo album, tuning into their favorite music, or harmonising in song can transform that moment and the rest of their day.

Connect – Don't Correct

In the pursuit of meaningful moments, authentic connections stand at the forefront. Misnaming might occur, yet the key is not to correct but to connect. Introduce yourself gently, so they're not burdened by memory lapses: "Hi Mum, It's Mary, your daughter." Recognise that their reality might differ from the norm, and our role is to immerse ourselves in their world. A reassuring smile and eye contact pave the path to ease and rapport. Flexibility is paramount – going with the flow and following their lead fosters genuine connection.

Feelings Matter Most

Reflect on the traffic light example once again. People living with dementia navigate a world driven by emotions. Remember, your emotional state matters too – a person living with dementia absorbs your feelings. Your joy and contentment can uplift their mood, while frustration or agitation can ripple through their experience. It's a symphony of emotions, a shared language, that binds us together.

Life Story and Memory Box

Within each of us resides a unique life story – a tapestry of preferences, connections, and pivotal moments. At St Joseph’s, we craft Memory Boxes, repositories of physical mementos representing individual life stories. These treasures help us forge personal

connections, soothing anxiety and distress. Knowing someone’s life story, sharing their Memory Box, bridges the gap, and nurtures a sense of calmness during challenging moments.

Communication Tips

Communication lies at the heart of our connections, especially when engaging with people living with dementia. To foster meaningful exchanges, here are some valuable tips:

Do	Don't
Use Respectful Tone Speak with a tone that conveys respect and dignity, honouring their individuality.	Use 'Baby Talk' Speak to them as adults, avoiding condescending 'baby talk.'
Give Clear Explanations Keep explanations concise, using flexible language that is easy to understand.	Use Complex Language Refrain from using complicated words, phrases, or long sentences that might lead to confusion.
Use Affirmative Messages Convey one message at a time, using positive language that invites cooperation.	Overwhelm with Choices Avoid asking for complex decisions or presenting multiple options, which can overwhelm.
Use Eye Contact Position yourself at their eye level, maintaining direct eye contact and addressing them by their preferred name.	Use Negative Eye Contact Steer clear of glaring or staring, instead foster a comfortable and respectful environment.
Introduce Yourself Begin conversations by identifying yourself, explaining your intentions, and ensuring their attention.	Act without explaining first Always explain your intentions before initiating a task, maintaining eye contact during explanations.
Talk about Engaging Topics Initiate conversations on subjects that interest them, enhancing their involvement.	Exclude the person This includes speaking as if they aren't present; instead ensure they feel included in conversations.
Use Visual Cues Accompany words with gestures and visual cues to enhance understanding.	Disregard Distraction Refrain from talking amidst distractions; aim for a focused and conducive environment.
Have Realistic Expectations Keep expectations realistic, respecting their abilities and limitations.	Have Unrealistic Expectations Prevent overwhelming reactions by not imposing unrealistic tasks or multitasking.

Do	Don't
<p>Use Non-Verbal Signals Pay attention to their non-verbal cues, striving to interpret their emotions and needs.</p>	<p>Forget Body Language Don't disregard your own non-verbal cues; they communicate just as much.</p>
<p>Use Paraphrasing Use paraphrasing to ensure understanding, employing a calm and reassuring tone.</p>	<p>Ignore 'Rambling' Avoid dismissing seemingly disjointed speech, as there might be key words with vital messages.</p>
<p>Use Repetition Repeat key words they use in otherwise unclear sentences to connect and clarify.</p>	<p>Ignore "Incoherent" Speech Avoid disregarding seemingly incoherent speech; there might be key words indicating an important message.</p>
<p>Speak Slowly and Clearly Speak slowly and enunciate individual words clearly, considering potential hearing impairments.</p>	<p>Shout or Rush the Person Refrain from shouting or speaking too fast, as it can create discomfort or confusion.</p>
<p>Talk about Familiar Topics Encourage conversations about familiar subjects, facilitating engagement.</p>	<p>Interrupt Unless beneficial, avoid interrupting their flow; it aids communication.</p>
<p>Respect Personal Space Respect personal space and use appropriate touch to convey comfort and connection.</p>	<p>Invade Personal Space if they're anxious or agitated, and avoid intimidation.</p>
<p>Understand Concepts/Meaning Seek the underlying concept or feeling behind their words, for example, 'mum' may mean 'I need comfort'</p>	<p>Neglect Key Words Acknowledge and respond to key words that reflect their feelings or emotions.</p>
<p>Use Active Listening Be attentive and receptive while they speak, validating their feelings and expressions.</p>	<p>Hurry Give them the time they need; don't rush them into saying or doing something.</p>

How to make a moment matter



There are lots of simple activities that can be done in less than a minute. Feelings matter most so be a butterfly and change the moment!

- SMILE!
- Say hello – greet someone by name
- Give a hug or kiss
- Shake hands/salute
- ‘Give me five’ – clap hands
- Tell a joke
- Recite a poem or sing a song
- Give a compliment/notice appearance
- Talk about the weather
- Do a little dance
- Wink or wave or do a thumbs up sign
- Talk about accessories
- Wear something funny
- Give a hand massage
- Offer a flower to touch or smell
- Pick up an object to touch or smell
- Read from a book or magazine
- Offer a cushion or a rug – make someone comfortable
- Hold hands
- Offer a sweet, biscuit, treat
- Say cheers when having a drink
- Discuss daily news
- Share a bit of gossip or personal news from your own life
- Ask someone’s opinion or advice
- Walk/dance arm in arm
- Brush hair
- Act ‘daft’ – make a silly face, pretend to trip up
- Say ‘bless you’ when someone sneezes.



Understanding the Human Rights-Based Approach

In the context of dementia care, it is crucial to recognise that people living with dementia, along with their caregivers and family members, possess the same Human Rights as any other person.

However, these rights are often hindered by not only the impact of the disease itself but also by various cultural, social, and economic barriers. The initial steps toward upholding, promoting, and safeguarding these rights involve acknowledging and understanding them. This project places a special emphasis on promoting and respecting the rights of people living with dementia through the active engagement of volunteers.

This manual is designed to empower volunteers to engage with people living with dementia in care homes using a human rights-based approach. The principles of this approach, outlined below, serve as a tool for volunteers to continually evaluate and analyze the extent to which they uphold and advocate for the rights of people living with dementia.

The Person-Centred Approach

The Person-Centred Approach, pioneered by Tom Kitwood in the 1990s, is a cornerstone of dementia care. It positions individuals at the forefront of their care, irrespective of their age or cognitive abilities. Understanding their identity, life story, preferences, abilities, desires, and ambitions is pivotal. This approach emphasises focusing on their strengths rather than their limitations. Kitwood introduced the concept of 'Personhood,' which encapsulates the status bestowed upon a human being by others within a relational context, comprising acknowledgment, respect, and trust.

Dawn Brooker, a colleague of Kitwood, outlined four pivotal elements that define a robust culture of person-centred care. This approach revolves around valuing individuals, honouring their uniqueness, and preserving their dignity and rights throughout their journey.

V

VALUE

Value people living with dementia and the people who care for them; promote their rights and citizenship regardless of age or cognitive

I

INDIVIDUALITY

Treat people individually; appreciate that all people living with dementia have a unique history, personality, physical and mental health, social and economic resources and that these will influence their response to the neurological

P

PERSPECTIVE OF THE PERSON

Look at the world through perspective of the person living with dementia, recognising that each person's experience has its psychological validity, that the person with dementia acts according to their perspective and that empathising with this perspective has great therapeutic potential.

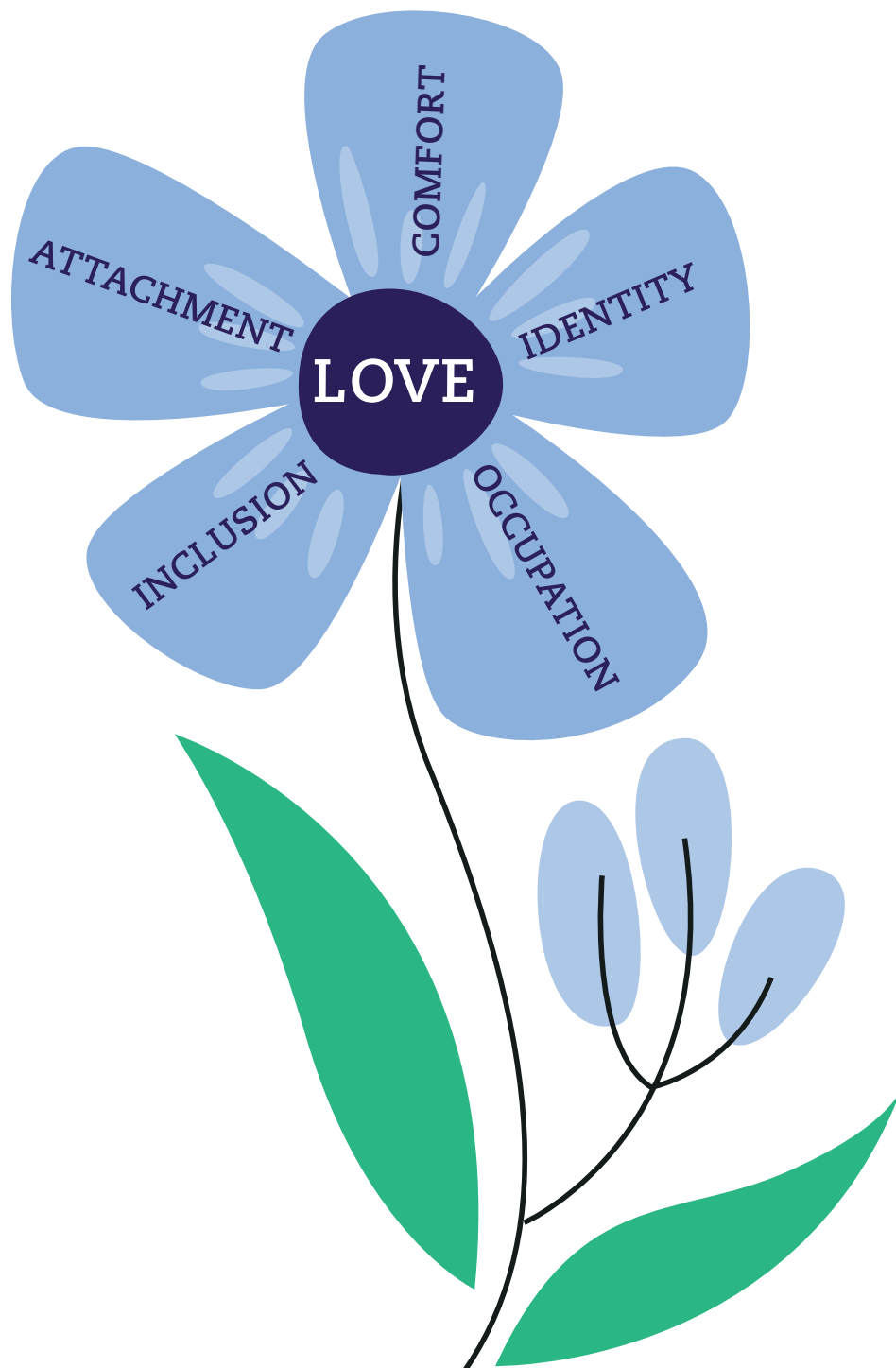
S

SOCIAL ENVIRONMENT

Recognise that all human life, including that of people living with dementia, is based on relationships and that people living with dementia need a rich and diverse social environment that can both compensate for their deficits and provide opportunities for personal growth.

Flower of Emotional Needs

Tom Kitwood identified a set of fundamental psychological and social human needs, which are essential for maintaining a strong sense of well-being. He formulated the concept of person-centred care, emphasising that these needs must be met to foster a holistic sense of fulfillment. Kitwood's model highlights six core psychological needs to consider when supporting people living with dementia.



Love

stands at the heart of this framework as a fundamental requirement. Recognising that people living with dementia experience the world through emotions, expressing your affection and appreciation becomes vital. Particularly during moments when you might be feeling down, showing how much they matter can have a significant impact.

Identity

is the embodiment of a person's Life Story. Understanding who they are and what makes them unique enhances their sense of identity.

Occupation

such as engaging in tasks like helping set up for a group activity, provides a sense of purpose, contributing to their overall well-being.

Inclusion

holds significance, especially as memory wanes. Ensuring the participation of every person living with dementia is essential; they should never be excluded due to their condition.

Attachment

exemplified by participation in a singing group, offers a sense of belonging, which is a fundamental human need.

Comfort

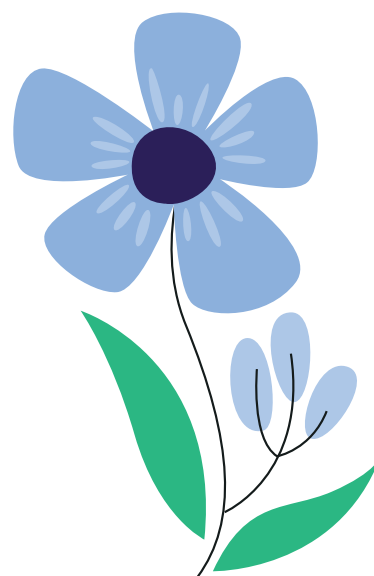
encompassing physical well-being (warmth, dryness, nourishment, and hydration), extends to emotional closeness and the ability to form bonds with others.

The Flower of Emotional Needs model serves as a reminder to address these facets comprehensively, creating an environment that nurtures the emotional and psychological well-being of individuals living with dementia.

Brooker (2015) offers insightful questions for self-reflection:

- Do my actions reflect my respect, appreciation, and recognition of this person?
- Am I treating this person as a distinct and unique human being?
- Am I genuinely attempting to view my actions from the person's perspective?
- How might my actions be interpreted by them?
- Do my actions contribute to this person's sense of social confidence and involvement, assuring them that they are not alone?

For further details, visit:
www.demright.org.



Charter of Rights

This Charter of Rights has been developed to empower people living with dementia, those who support them and the community as a whole, to ensure their fundamental Human Rights are respected, protected and promoted.

Human Rights focus on equality, dignity, respect, freedom and justice and are inherent to all human beings, regardless of any disability, illness or disease. Human Rights are absolute and universal (equal for all human beings), indivisible (equal in importance) and interdependent (they interact as part of a global framework of Rights).

Dementia can be defined as an umbrella term for a number of neurological conditions that contribute to the progressive decline of brain function, which can cause problems with memory, thinking, problem solving, language, behaviour and perception.

There are over 55 million people worldwide living with dementia today with a new case diagnosed every 3 seconds. It is one of the major causes of disability and dependency among older people worldwide.

People living with Dementia, their carers and families have the same rights as every other citizen. However, in addition to the impact of the disease, they often face cultural, social and economic barriers to fulfilling their rights.

Dementia Right Project believes that all policies, plans, legislation and programmes must be sensitive to the needs and preferences of people living with dementia, and values their Human Rights.

Principles to ensure real change

The PANEL principles provide a framework to put a human rights-based approach into practice and ensure real change for people living with dementia. PANEL stands for Participation, Accountability, Non-Discrimination and Equality, Empowerment and Legality. The PANEL approach is endorsed by the United Nations and includes all the cross-cutting principles identified by the WHO Global Dementia Action Plan.



Participation

People living with dementia, their carers and family members, like any citizen, have the right to participate in all decisions, including health and social care policies that may affect them or their wellbeing. People living with dementia and their carers have the right to accessible, accurate information, and be supported to enable them to participate in an informed decision-making process. They also have the right to full participation in all decisions regarding their care needs: assessment, planning, support, treatment and advanced-decision making.

Additionally, people living with dementia have the right to live their lives as independently as possible, with absolute respect for their will and preference, and to actively participate in their communities.



Accountability

As rights holders people living with dementia, their carers and family members have the right to exercise their Fundamental Rights in every part of their daily lives. As duty bearers, public and private bodies, voluntary organisations and individuals responsible for the care and treatment of people living with dementia, should be empowered to and held accountable for enabling people living with dementia to exercise their Human Rights.



Non-Discrimination and Equality

People living with dementia, their carers and family members have the right to be free from discrimination on any grounds, such as age, disability, gender, ethnicity, sexual orientation, religious beliefs, social, civil, family or any other status. All public health and social care policies and programmes must be developed and provided by professionals with dementia expertise, be person-centred, support equality and be accessible for all.



Empowerment

People living with dementia, their carers and organisations representing them must be empowered and supported to participate in dementia advocacy, policy, planning, legislation, service provision, monitoring and research.

People living with dementia and their carers have the right to access any social and legal services to enhance their autonomy, and ensure their full inclusion and participation in all aspects of their lives. They should be fully supported to ensure quality of life, maintain maximum independence; physical, psychological and social wellbeing, through access to work, education and meaningful daily activities.



Legality

People living with dementia have the right, to the same civil and legal Human Rights as any other citizen. Duty bearers, acting on behalf of someone who does not have the capacity to take a specific action or decision due to their cognitive impairment, must have regard for the principles and provisions of national legislation on capacity and disability, consistent with the Universal Declaration of Human Rights, the Convention on the Rights of Persons with Disabilities and any other international Human Rights instruments.

Where rights are not observed, people living with dementia and their carers have the right to seek remedy through effective complaint and appeal procedures and the right to be supported in that process.

For further details, visit:

www.demright.org.

The Activity



Understanding the activity

Background of the Activity: Fostering Musical Connections

Music and singing are the activities chosen for this manual, but it's important to note that there are many other activities volunteers can engage in to support people living with dementia. However, the choice of music and singing is also due to the fact that singing holds a unique power that deeply resonates with the human experience.

Music is a universal human experience; it's intertwined with our lives, enabling a direct connection with our emotions. This explains not only its impact on us but also how our brains react to this stimulus.

Today, we know that when we listen to music, various parts of our brain are activated, with three key areas standing out:

1/ Hippocampus

The area responsible for storing our memories. When we hear music that's significant to us, it can act as a trigger to evoke past memories associated with the emotions it stirs, potentially transporting us to specific moments in our lives.

2/ Frontotemporal Lobe

the area of the brain where we process and interpret auditory stimuli, produce and comprehend language, and plan and execute voluntary movements.

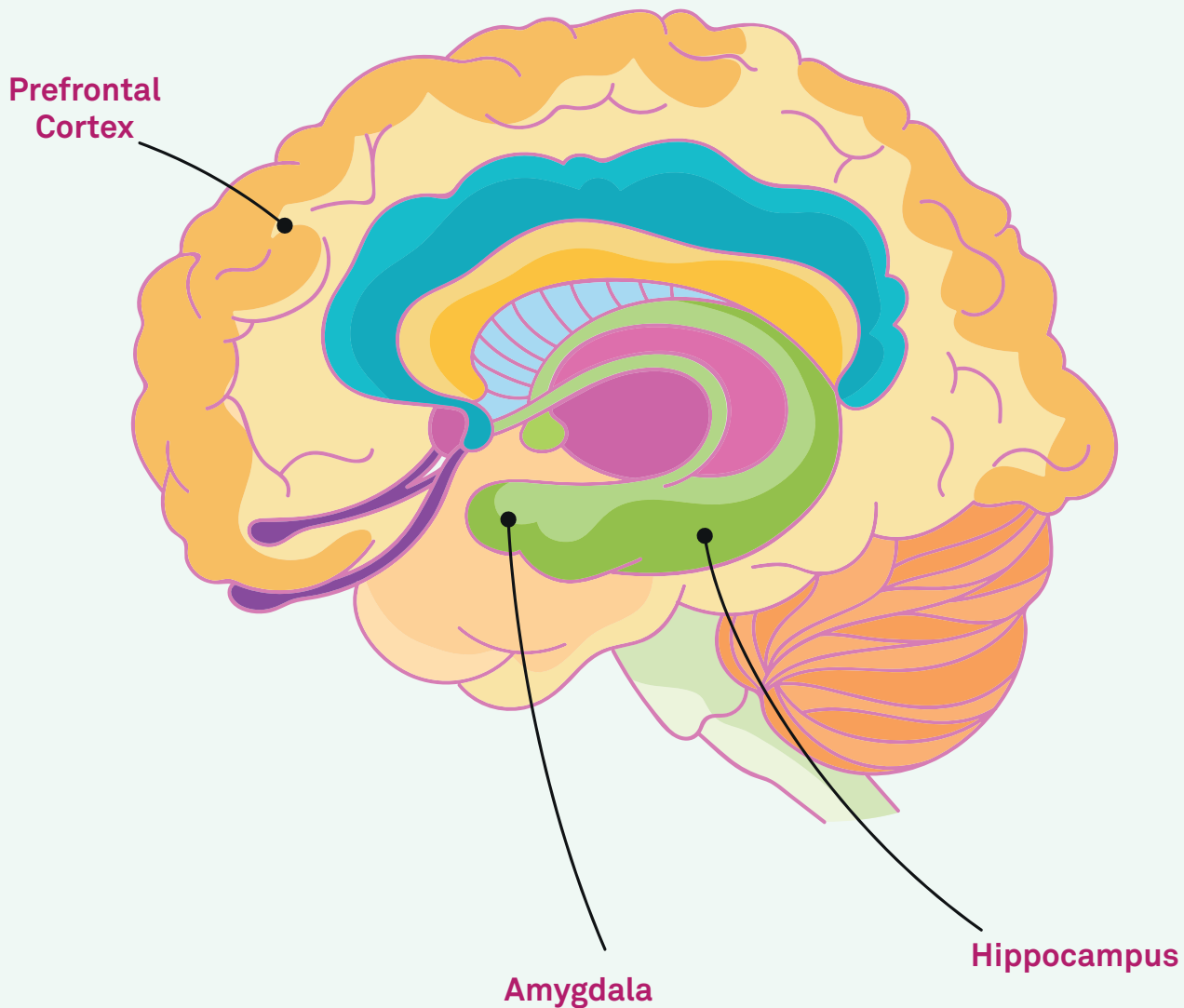
3/ Amygdala

Responsible for processing our emotions. Listening to a particular piece of music can activate our amygdala, generating emotional responses of joy, happiness, enthusiasm, or conversely, sadness or distress, significantly impacting our mood and day.

Several studies have shown that the language we use to communicate with others, as well as our speech production and comprehension abilities, are stored in the left hemisphere of the brain. However, our rhythmic ability is stored in the right hemisphere. So, when we add singing to music, we bridge the gap between language and rhythm, making communication easier.

This bridge is crucial when engaging with people living with dementia who may have language difficulties. In some situations, singing can be the best way to stimulate their communication. When a person living with dementia has impaired speech production or comprehension skills, it's natural to resort to the skills they retain rhythmic ones. The person has rhythm and understands rhythm, so they may sing better than they speak, making singing an important means of expression.

On the other hand, rhythm has the power to trigger motor responses in us and thus facilitate our movements spontaneously, such as tapping our feet, snapping our fingers, swaying our body, head, and even dancing. Therefore, when a person living with dementia's gait is affected, they may still be able to dance better than they walk. In this way, music and rhythm can be essential unblockers of movement and motor action.



It's also clear that a song that is meaningful to us can evoke strong and varied emotions, depending on the memories it activates.

Creating a playlist can be a fundamental tool for communicating with a person living with dementia, and its impact is greater when the person chooses the songs themselves. In a recent study conducted in a preoperative environment, participants were divided into three distinct groups. One group received a calming medication to manage their pre-surgery anxiety, a second group was exposed to a playlist of songs selected by the doctor, and the third had access to a playlist of songs they had previously had the opportunity to create. The results showed that people who listened to a playlist composed of songs of their own choice exhibited lower levels of

anxiety before surgery compared to those who received the calming medication or listened to the doctor-selected playlist.

Thus, it's possible to understand that a playlist has a greater effect on people living with dementia the more meaningful the songs are to each person and the more emotions and memories they can evoke.

Harmonising memories and emotions

The magic of music lies in its ability to transcend time, allowing people living with dementia to bridge the gap between their past and present. Through music and singing, dormant memories, feelings, and emotions are stirred, often providing an avenue for expression that words alone might struggle to capture. Volunteers leading the singing activity facilitate a transformative experience for residents by creating an environment that encourages participation in various forms – whether through singing, humming, tapping, or simply listening. This collaborative musical journey fosters a shared sense of connection.

The first note...

While there are community-based dementia choirs, not all residents in care homes have the opportunity to participate. This realisation sparked an inspiring conversation at St Joseph's, driven by Marie, a dedicated volunteer who recognised the transformative potential of music for individuals living with dementia. Her suggestion to establish an impromptu choir for a weekly sing-along became a catalyst for a heartwarming initiative.

Orchestrating the idea – Marie's vision

The concept was simple yet profound: to create a musical experience that transcends individual differences and embraces the collective power of music. The plan unfolded as follows:

- **Curating a song list:**

Volunteers collaboratively compiled a repertoire of songs carefully selected to resonate with residents. In addition to well-known sing-along tunes, staff drew from individual preferences documented in life stories and memory boxes.

- **Mastering the melodies:**

Volunteers dedicated time to learn the lyrics of each song, ensuring their confidence in leading the musical journey unaccompanied.

- **Gathering in communal spaces:**

For 20 to 30 minutes, volunteers congregated in the communal areas of the care home, known as lodges. Armed with percussion instruments, they invited residents to join in as they felt comfortable. This environment welcomed staff and visitors to get involved in the collective musical experience, nurturing spontaneity and triggering cherished conversations and memories.

Standing ovation. Bravo!

The impact of the impromptu choir initiative has been nothing short of remarkable. Marie and Michele now visit three lodges each week, initiating the session with a selection of beloved staple songs. The beauty of this endeavour lies in its adaptability – residents are encouraged to join in, take centre stage with their party piece, or simply revel in the melodies. The once-reluctant have transformed into enthusiastic participants, even choosing to sing songs not on the song list. Visitors are drawn into the heartwarming atmosphere, enhancing their visits. Staff engagement adds to the positive energy, further uplifting the environment.

In this musical endeavour, every voice is valued. The power of music transcends musical skill, creating an inclusive space where the harmony of togetherness resonates far beyond the melodies sung.

The Activity: Engaging through the melodies

Duration:
60 - 90
minutes

Participating in singing or music activities can be a transformative experience for people living with dementia, fostering connections and enhancing overall well-being. The power of music lies in its ability to unlock memories and emotions, allowing individuals to express themselves even when words fail. For instance, the strains of a familiar melody can trigger recollections of cherished moments, like a favourite song from their past.

Below, we outline an activity that volunteers can lead in a residential care home, harnessing the therapeutic potential of music. Key considerations:

Leadership

It's recommended to have at least two volunteers lead the session, ideally with support from staff.

Location

Conduct the session in a living room or communal area, ensuring a comfortable and inclusive environment.

Group Size

Smaller groups of up to 10 residents are ideal, allowing for meaningful engagement.

Layout

Arrange seating in a circular formation, enabling everyone to see and interact with each other.

Inclusivity

This activity suits all residents, adapting to their unique preferences and experiences with music. That's why it's important to find out what each person's favourite song/songs are. Music is a universal experience but it's personal too. Music and lyrics can mean different things for different people.

Before the activity

1/ Song selection

Choose a repertoire of songs that resonate with the age group you're engaging with. Get the lyrics in case you or the residents might want to follow the words through the song.

2/ Personal stories

Consider residents' life stories; songs in their mother tongue or those connected to their background which might evoke deeper responses.

3/ Instrumentation

Prepare percussion instruments, even simple items like rice-filled bottles, to enhance engagement.



Activity 1: Singing together

1/ Introduction:

Familiarise yourself with each resident's name and, if available, their life story to establish a connection. Identify any favourite songs they might have.

2/ Communal song

Start by suggesting a well-known song, poem, or verse that most participants are likely to recognise.

3/ Instruments

Offer percussion instruments to residents who express interest in using them.

4/ Melodic journey

Lead the singing, making eye contact and connecting with each person. Encourage them to join in and create a harmonious atmosphere.

5/ Flexibility

Follow the song list while also welcoming residents to introduce songs that hold personal significance. Embrace the spontaneity.

6/ Connection and reminiscence

Allow time for chat and reminiscing between songs. Create a supportive environment where everyone feels comfortable sharing.

7/ Encouragement

Ensure each person feels encouraged to participate, recognising that some days may yield more engagement than others. Embrace the natural ebb and flow.

8/ Gratitude

Conclude the session by thanking participants for their involvement and listening.

9/ Future Preparation

Take note of any new songs introduced during the session, preparing the lyrics for the next gathering.



Activity 2: Sensory storytelling through music

1/ Introduction and connection

As in the previous activity, get to know participants individually, particularly their preferred songs.

2/ Sensory journey

Propose experiencing a sensory-rich narrative related to the current time of year and its traditions.

3/ Stimuli integration

While narrating the story, introduce sensory stimuli corresponding to the narrative elements. For instance, during a description of a cosy winter evening by the fireplace, distribute soft blankets, turn on a heater for warmth, provide a piece of finished wood to simulate a crackling fire, and generate the sound of wood cracking.

4/ Melodic interlude

Midway through the story, encourage participants to sing a traditional or familiar song that aligns with the narrative's theme.

5/ Fluid expression

Remain open to participants suggesting different songs if inspired to do so.

6/ Shared reflection

Allow time for participants to share their memories, traditions, and experiences evoked by the sensory journey.

7/ Encouragement

Ensure each person feels encouraged to participate, recognising that some days may yield more engagement than others. Embrace the natural ebb and flow.

8/ Enhanced engagement

If suitable, propose conducting the activity blindfolded, intensifying sensory perceptions.

9/ Gratitude

Conclude the session by thanking participants for their involvement and listening.

Post Activity

1/ Reflection

Volunteers should discuss the activity's impact and participants' responses, considering adjustments for future sessions.

2/ Innovation

Compile a list of new texts, poems, songs, and materials to craft fresh sensory stories.

3/ Tidy up and prepare for the next session

Collect and disinfect all materials used during the activity, ensuring a clean and safe environment.

Through the harmonious notes of music and the richness of sensory experiences, volunteers can create memorable moments that enhance the lives of people living with dementia.



What started in Ireland...

We started our singalong group in early 2023. We meet at reception on a Thursday afternoon, get our song books and percussion instruments and we visit three of the six lodges in St Joseph's to spend time with the residents.

We had never really volunteered together so it was uncharted territory! What we've discovered is that there is no right or wrong way to do a sing along. And while we have a song book that's grown over the months and continues to grow, it's not a script. We go with the flow and we've learned to read the room in each lodge that we visit and on each individual day as well. We've also learned to pick up on the mood of each living room. Sometimes we sing along in the background and other times we're a bit livelier. If someone's having a sleepy day, we're not going to insist they wake up and join in! Sometimes family members are there as well and that adds another dynamic. It can be great because they also join in and their visit might hit some even higher notes.

"Because we know each resident much better, we can encourage them to sing for us".

Now we know the residents in each of the lodges and their favourite songs or poems. It's really great when a resident starts singing a song that's not in the song book. Then it will probably be added for the following week and we know we'll have some homework to do to familiarise ourselves with the new song. We have a bit of banter between ourselves as well as with the residents, staff and visitors. In the beginning we sat close to each other but now we spread out across each room so that we can include everyone. We're reaching out to everyone and hope that by sitting beside someone they might feel more confident to join in or to sing a solo. Because we know each resident much better, we can encourage them to sing for us and hopefully when they do, they feel that mutual sense of sharing a song and a moment together.

At the end of our visit, we have a chat about how the session went and jot down new songs to add to the songbook or new ideas to try out the next time.

It's a great way to make a moment matter for people living with dementia. We hope that you'll give it a go in a nursing home near you.

Marie, Michele and Jenny

...continued in Portugal

When I was born, it was a moment of great joy: after having 5 boys, the long-awaited girl had arrived. However, a concern appeared on my mother's face - "I won't see her grow up!"

And I grew up thinking that my mother was always older than my friends' moms. Older, but more loving, more patient, stronger, and harder working than my friends' moms.

My mother is illiterate, but she carries a unique wisdom within her: "Once is always enough"; "Don't make people talk badly about me or about you wherever I go". I grew up hearing these sayings countless times; they were lessons that books will never teach me. Yes, because my mother fought and fought for me to go to school and, more than that, to graduate. And always with her accounts in order, owing nothing to anyone.

"I strive to meet this new challenge in my life: taking care of the one who always took care of me".

She has always been an excellent advisor and confidante. Nothing escaped her; she could read me with just a glance.

Life went on, she saw me grow, get married, and become a mother of three children. She was always by my side, being my right arm, and maybe the left too. We were accomplices in this life, and I also saw her grow old... 75, 80, 85 years passed, and one day she began to not read me in her eyes anymore, started forgetting things, confusing events, conversations lost their meaning, and in our relationship, we were always managing misunderstandings.

The diagnosis of dementia came quickly, and with it came moments of despair, incapacity, remorse, impotence, and anguish as I feel that I am losing my mother, my confidante, and advisor... and it hurts, it hurts a lot.

Suddenly, my relationship with my mother shifted to focus on her comfort, on day-to-day care, on an endless schedule of appointments, pharmacy visits. In addition to all the roles in my life (daughter, mother, wife, professional, catechist, ...), I am also a caregiver. I am also a manager of expectations and emotions because my husband and

children do not always recognize that my mother's behaviors stem from the disease, and every day I strive to meet this new challenge in my life: taking care of the one who always took care of me.

It was in the midst of this whirlwind of emotions when the relationship with my mother was practically based on providing care that we both lived a revitalizing experience. My mother and I, with some effort due to her physical condition, joined the 'Singing by heart' project, and both of us were reborn.

On those sessions, my mother was happy; she sang, smiled, laughed. She regained the light and sparkle in her eyes. For me, that experience through music awakened emotions that were oppressed by the burden of care, and I let myself be carried away by the lightness of the moment.

The most incredible thing is that these magical moments were provided with simple songs and simple instruments. In fact, a simple music box sparked excitement and delight among the group. Everyone sang, clapped, and smiled again.

The intensity of those moments and emotions extended to the family circle. There is a sharing of what was experienced there and the testimony of what was done, not to be forgotten.

These meetings led to the revival of good memories for my mother and the discovery of a fun side that I thought no longer existed. Until today, I remember how worthwhile it was to rush to prepare my mother for the sessions, and every difficult step she had to take... because from those days on, we let the power of music enter our home every day, and every day, there are moments when we are happier!

Aida

Song list for Ireland

Below is a list of songs that our volunteer team in St Joseph's has created. Feel free to use this list in your care home and add to it as well! They are in no particular order. Enjoy!

- **Que sera, sera**
Jay Livingston
- **Do-Re-Mi**
Rodgers and Hammerstein
- **Singing in the rain**
Nacio Herb Brown and Arthur Freed
- **Show me the way to go home**
Jimmy Campbell and Reg Connelly
- **Daisy, Daisy**
Harry Dacre
- **Molly Malone**
James Yorkston
- **It's a long way to Tipperary /
Pack up your troubles**
Harry Williams
- **When the saints go marching in**
James M Black
- **He's got the whole world in his hands**
Alan W Livingston
- **My bonnie lies over the ocean**
Unknown
- **How much is that doggie in the Window?**
Bob Merrill
- **You are my sunshine**
Jimmie Davis and Charles Mitchell
- **Are you right there Michael?**
Percy French
- **Phil the fluter's ball**
Percy French
- **Oh, Danny boy**
Frederick Weatherley
- **Put your sweet lips**
Jim Reeves
- **Yesterday**
John Lennon and Paul McCartney
- **There is an isle**
Anna Maria Lynch
- **You are my heart's delight**
Franz Lehar
- **Beautiful Munster**
Unknown
- **Country Road**
John Denver
- **Come back Paddy Reilly**
Percy French
- **Some enchanted evening**
Rodgers and Hammerstein
- **She'll be coming round the mountain
when she comes**
Joseph K Phillips
- **I'm a Rambler**
Unknown
- **Sweet Sixteen**
James Thornton
- **Stille Nacht**
Joseph Mohr
- **A bunch of Thyme**
Unknown
- **That's Amore**
Harry Warden
- **Beautiful Munster**
Unknown

- **The boys of Fairhill**
Jimmy Crowley
- **She moved through the Fair**
Herbert Hughes
- **Grace**
Sean and Frank O'Meara
- **I wandered lonely as a cloud**
William Wordsworth
- **The old bog road**
Teresa Brayton
- **Ag Criost An Siol**
Sean O' Riada
- **Walk Tall**
Don Wayne
- **Two Little Boys**
Theodore F. Morse
and Edward Madden
- **Good Night Irene**
Huddie Leadbetter
- **The Black Hills of Dakota**
Sammy Fain and Paul Francis Webster
- **I Dreamt I Dwelt in Marble Halls**
Alfred Bunn
- **The Black Velvet Band**
Luke Kelly and The Dubliners
- **Dublin Saunter**
Leo Maguire
- **Once Nearly was Mine**
Rodgers and Hammerstein
- **When Irish Eyes Are Smiling**
Chauncey Olcott and George Graff Jr
- **King of the Road**
Roger Miller
- **The Green Green Grass of Home**
Claude "Curly" Putman Jr

Check out our **Making Moments Matter (Ireland edition) playlist**

Song list for Portugal

Below is a list of songs that our volunteer team in Hope! Respostas Sociais has created. Feel free to use this list in your care home and add to it as well! They are in no particular order. Enjoy!

- **Aldeia da Roupa Branca**
Unknown
- **Desfolhada Portuguesa**
José Carlos Ary dos Santos
- **Zumba na Caneca**
Tonicha
- **Uma Casa Portuguesa**
Reinaldo Ferreira e Vasco Sequeira
- **Nem às paredes confesso**
Unknown
- **Laurindinha**
Unknown
- **Teus olhos castanhos**
Alves Coelho e Francisco José
- **Meu Alentejo**
Bento Caeiro
- **Apita o Comboio**
José Malhoa
- **Rosa arredondaa saia**
Unknown
- **Regadinho**
Unknown
- **Minha Machadinha**
Cancioneiro Popular Português
- **Malhão, malhão**
Unknown
- **Rosinha do Meio**
Unknown
- **Oliveirinha da Serra**
Unknown
- **Ó rama, ó que linda rama**
Popular text adapted by Vitorino
- **Eu ouvi um passarinho**
Unknown
- **Grândola Vila Morena**
Zeca Afonso
- **Tiro, liro, liro**
Unknown
- **Ferreiro**
Unknown
- **Alecrim Dourado**
Unknown
- **Indo eu, indo eu a caminho de Viseu**
Unknown
- **Tia Anica de Loulé**
Unknown
- **O mar enrola na areia**
Unknown
- **Cheira a Lisboa**
César Oliveira
- **Milho Verde**
Zeca Afonso
- **Todos me querem**
Tonicha
- **Treze de Maio**
Unknown

Check out our **Making Moments Matter (Portugal edition) playlist**

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st John
of God 

Dementia Care

www.saintjosephsshankill.ie



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Respostas
Sociais

www.hope.pt