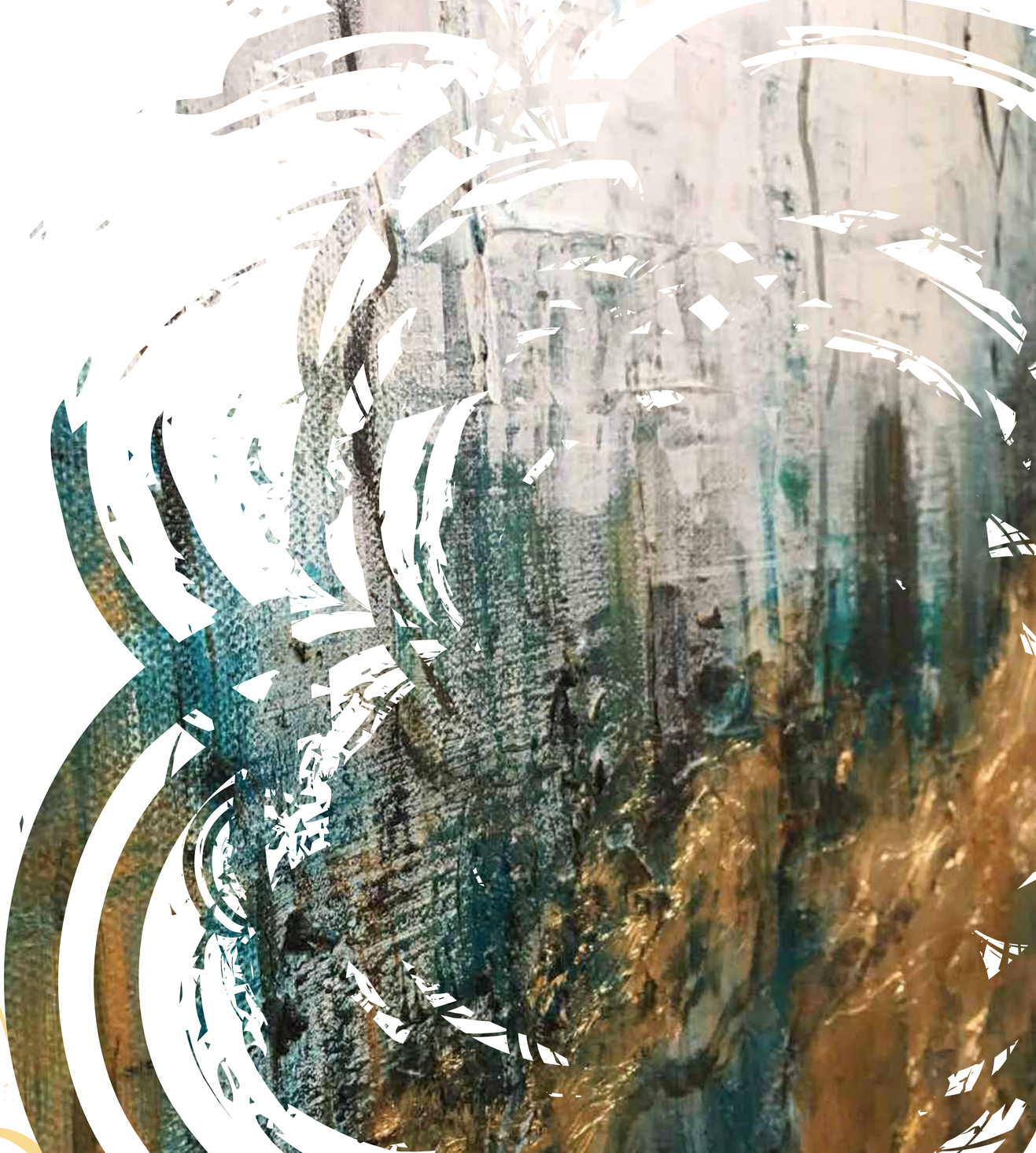
STORY 2 Remember

STORYTELLING AND ALTERNATIVE COMMUNICATION METHODS IN DEMENTIA CARE: TOOLKIT FOR FAMILY MEMBERS

Intellectual Output Three: Toolkit for family members to improve communication with people with dementia through storytelling and alternative communication methods

Toolkit prepared by the Romanian Alzheimer Society in coordination with the ERASMUS+ partners



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INTRODUCTION

Background to the toolkit
Purpose of the toolkit
Topics covered by the toolkit

BACKGROUND TO THE TOOLKIT

The toolkit has been created as part of a wider project, funded by ERASMUS+2018 (Agreement number 018-1-RO01-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 Association 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 March 2021.

The project has 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 members of people with dementia through the use of alternative communication methods and storytelling

3. Enriching people's with dementia well-being through the upskilling of health and social care professionals and informal care partners

4. Raising public dementia awareness 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 toolkit represents the third. The other IOs are:

- **IO1:** Creative arts and storytelling use for people with dementia and their family members in UK, Greece, Romania, Bulgaria and Ireland (The booklet is freely available **here**);
- **IO2:** Creative drama and storytelling program aimed at health and social care professionals to improve the well-being of people with Dementia (The handbook is freely available **here**);
- **IO4:** Policy document advocating the use of creative initiatives in dementia care and supporting the development of dementia-friendly communities.

INTRODUCTION

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PURPOSE OF THE TOOLKIT

If you are reading/using this toolkit, most probably you are a family member of someone with dementia and you have noticed emerging communication difficulties in your interactions with the loved one. We would also like to think that what brought you here is your preoccupation with how you can ensure a rich life for your loved one for as long as possible, and that you are searching for ways to maintain meaningful and satisfying communicative interactions with them.

This toolkit aims to enhance the communication skills of family members of people with dementia through the use of tools derived from storytelling approaches as well as alternative communication methods. The toolkit includes a brief presentation of the most frequent situations where communication problems may arise, it describes how storytelling and alternative communication methods can be used in these situations and it provides step by step instruction for activities that family members can do together with the person with dementia in order to train their communication skills.

TOPICS COVERED BY THE TOOLKIT

The toolkit consists of two parts.

PART 1 "Reflect and understand" gives an overview of the communication challenges that family members might encounter when caring for a person with dementia and introduces a few alternative communication methods and approaches to address these difficulties. It is designed for the family members to serve as a tool to facilitate self-reflection and increase understanding of current communication practices.

PART 2 "Activities for practice" consists of seven activities with detailed step by step instructions, which we named "adventures", aimed to be practiced by the family members together with the person with dementia. You do not need to read the first part in order to be able to engage in these activities. However, we think that it will assist your understanding of why the practical activities are important and how these might work for you.

INTRODUCTION

We hope this toolkit will support you in your search for new ways of re-connecting with your loved one, regardless of the stage of dementia journey you may be at. We encourage you to try out as many different communication methods as possible.

By trying out the activities you might discover they have a positive impact both for you and for the person with dementia, and that it will give you the opportunity to reconnect and to spend quality time together.



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PART 1
REFLECT AND UNDERSTAND

This part gives an overview of the communication challenges that family members might encounter when caring for a person with dementia and introduces a few alternative communication methods and approaches to support communication in these challenging situations. It is designed for the family members to facilitate self-reflection and increase understanding of current communication practices.



RE-LEARNING COMMUNICATION **TO SUPPORT PERSONHOOD**

The communication gap in dementia care
The communication challenge for the family members
To keep communication open, focus on the person

THE COMMUNICATION GAP IN DEMENTIA CARE

When caring for a person with dementia it is common to encounter communication difficulties, which may also vary throughout the course of dementia. These difficulties often occur as a result of deterioration of cognitive and sensory abilities, such as impaired hearing, understanding, memory, or ability to respond appropriately.

For the person with dementia, this might mean that they are unable to communicate their needs (e.g. pain) and as a result, they might become more distressed and experience a decline in their wellbeing. Consequently, the family members might struggle to understand what the person with dementia is attempting to communicate and feel stressed and frustrated.

Repeated failure to communicate with each other can leave family members feeling that they are losing familiar conversations with their loved one and they might conclude that there is “no point” in communicating, given the declines in cognitive skills.

However, despite these difficulties, embracing a person-centred approach by attempting to empathize and understand the person with dementia, may help preserve important relationships and allow both the care partner and person with dementia to feel valued and interpersonally connected.



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RE-LEARNING COMMUNICATION **TO SUPPORT PERSONHOOD**

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THE COMMUNICATION CHALLENGE FOR THE FAMILY MEMBERS

As dementia progresses, the communication difficulties also increase, and you might need new strategies and tools to address them. This implies that family members must constantly adapt their communication skills to match the changing needs of their loved ones.

In the early stages of dementia, family members need to learn how to support conversations at home without challenging the person to remember specific words or events. They may benefit from learning how to redirect the topic of conversation and how to use cues to help the person access information while maintaining a sense of dignity and self-respect.

As individuals lose awareness of their cognitive and communication difficulties, family members may need to learn how to facilitate communication interactions that maintain social closeness without expecting equitable participation.

Finally, in the later stages of dementia, family members may benefit from direct instruction in the use of tone of voice, familiar objects, the environment, and touch to provide comfort and to maintain quality interactions.

Humming a lullaby and dimming the lights while assisting the person to undress and get ready for bed may provide cues to memories of familiar bedtime routines.



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TO KEEP COMMUNICATION OPEN, FOCUS ON THE PERSON

Personhood is the recognition, respect and trust each of us receive from the others. Because people with dementia experience cognitive decline it might be more difficult for them to retain personhood once the disease progresses and – in consequence – some of their needs might not be met.

In terms of psychological needs, these are common to all of us but people with dementia are usually more vulnerable and less likely to be able to take action to satisfy these needs. Such needs are:

• **Comfort:** the feeling of trust that comes from others.
You can help meet this need by showing warmth, by providing safety and security and by creating a relaxed atmosphere.

• **Attachment:** security and finding familiarity in unusual places.
You can help meet this need by recognizing and supporting the reality of the person and by showing sensitivity to their feelings and emotions.

• **Inclusion:** being involved in the lives of others.
You can help meet this need by providing a sense of acceptance, regardless of abilities and disabilities. Finding a way to use positive humour can also help the person with dementia to feel they belong and to have fun.

• **Occupation:** being involved in the processes of normal life. You can help meet this need by treating the person with dementia as a full and equal partner in what is happening; try to consult and work together with them as often as possible.

• **Identity:** what distinguishes a person from others and makes them unique.
You can meet this need by showing acceptance and respect for the person with dementia and by celebrating their achievements – no matter how small.



RE-LEARNING COMMUNICATION **TO SUPPORT PERSONHOOD**

The communication gap in dementia care
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To keep communication open, focus on the person

A few general strategies that might support you to provide person centred care, even in challenging situations:

1. Use what you know about the person.
The individual living with dementia is more than a diagnosis. Whenever interacting with them try to consider what you know about their values, beliefs, interests, abilities, likes and dislikes—both past and present.

2. Recognize and accept the person's reality.
Put yourself in the shoes of the person with dementia and try to understand their reality. Doing so recognizes behaviour as a form of communication, thereby promoting effective and empathetic communication that validates feelings and connects with the individual in their reality.

3. Think about how you can facilitate meaningful engagement.
Every experience can be seen as an opportunity for engagement. Try to account for their interests and preferences, allow for choice and success, and recognize that even when the dementia is most advanced, the person can experience joy, comfort, and meaning in life.

4. Aim to maintain authentic, caring relationships.
This type of relationship is about being present and concentrating on the interaction, rather than the task. It is about "doing with" rather than "doing for," as part of a supportive and mutually beneficial relationship.

Keep these strategies in mind when moving on to read about alternative communication methods or how to deal with particular challenging behaviours, as they provide a basis for questioning your own behaviours and will help you re-learn to communicate with your loved one. Whenever you find yourself in a difficult situation ask yourself if you can use one or more of these strategies and how you can apply them in your particular context.



COMMUNICATION STRATEGIES FOR
CHALLENGING BEHAVIOURS LINKED TO DEMENTIA

This chapter explores some of the more challenging behaviours a person with dementia might experience, including hallucinations, delusional ideas, repetitive behaviours, repetitive questions, sunset syndrome, refusal of medication, refusal to wash, and wandering. Communication strategies as well as general principles and practices are proposed that can support communication in these challenging situations.



COMMUNICATION STRATEGIES FOR CHALLENGING BEHAVIOURS LINKED TO DEMENTIA

Hallucinations
Delusional ideas
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HALLUCINATIONS

Hallucinations are sensations that appear to be real but are created within the mind. For example, the person may see the face of a former friend in a curtain or insects crawling on their hand. In other cases, a person may hear someone talking and may even engage in conversation with the imagined person. These false perceptions are caused by changes within the brain, usually in the later stages of dementia.

COMMUNICATION STRATEGIES TO SUPPORT HALLUCINATIONS

In the long term, try to understand how and when hallucinations appear. Are there particular moments, contexts or states the person with dementia is in that might be associated with the hallucinations? Is there something that can be changed? The specific strategies suggested below can support you in this process. Please choose the best fit for each new situation.

Offer reassurance.
Respond in a calm, supportive manner. You may want to respond with, “Don’t worry. I’m here. I’ll protect you. I’ll take care of you.” Acknowledge the feelings behind the hallucination and try to find out what the hallucination means to the individual. You might want to say, “It sounds as if you are worried” or “I know this is frightening for you.”

Use distractions.
Suggest a walk or move to another room. Frightening hallucinations often subside in well-lit areas where other people are present. Try to turn the person’s attention to music, conversation, or activities you enjoy together.



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Respond honestly.
If the person asks you about a hallucination or delusion, be honest. For example, if they ask, “Do you see him?” you may want to answer with, “I know you see something, but I can’t see it.” This way, you are not denying what the person sees or hears, but you avoid an argument.

Modify the environment.
Check for sounds that might be misinterpreted, such as noise from a television or an air conditioner. Look for lighting that casts shadows, reflections or distortions on the surfaces of floors, walls and furniture. Turn on the lights to reduce shadows. Cover mirrors with a cloth or remove them if the person thinks that they are looking at a stranger.



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DELUSIONAL IDEAS

Delusional ideas, sometimes referred to as paranoia, are common in middle- to late-stage Alzheimer's disease. They are defined as firmly held beliefs in things that are not real. The most common one is the false belief that some member of the family is trying to steal the person's with dementia belongings. Other examples include the feeling of being stalked or monitored by some governmental agencies. Confusion and memory loss may contribute heavily to the arguments behind these ideas, but the background of the person is also important (e.g. a war veteran may have delusional ideas based on his previous military experience).

COMMUNICATION STRATEGIES TO SUPPORT DELUSIONAL IDEAS

Try not to take the suspicions too personally.
Overreacting or trying to argue with the person can result in unpleasant situations that may end up making the person too upset or even more suspicious. Remember that these emotions could persist even if they forget what they accused you of.

Communicate empathically
Communication and empathy are key in dealing with the behaviour –try to stay relaxed and not get aggravated by what has been said to you. Calm behaviour, smiling, gentle touches (for the people without sensory issues) can all have a positive influence on the person with dementia and the overall communication.

Provide facts and offer your help
If the challenging behaviour is related to memory loss, re-direct the conversation or give some cues about what the person forgot. Talk to the person with dementia while matching their concern about the matter at hand; this will ease the communication and make them feel understood. For example, if they don't find their wallet, one can try and offer to "look for it" with the person.

Ask additional questions
Asking additional questions will make the person feel supported and empowered and will make them talk about their worries more. Moreover, they can lose track of the initial topic and forget the ideas that were bothering them in the first place. The conversation may even head into a nicer direction and leave both sides feeling at peace and content with each other.

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REPETITIVE BEHAVIOURS

Repetitive behaviours are behavioural symptoms that are common in dementia. They are often a way of expressing anxiety, stress or frustration as a result of not being understood. The person could also be frustrated with their environment, which might be confusing. Repetitive behaviours can also result from boredom.

Repetitive behaviours can include: searching, patting, rubbing, scratching, picking, placing non-food items in the mouth, bathing, opening and closing doors, brushing teeth, moving objects, verbal repetition (also see the section on repetitive questions).

Sometimes, too much stimuli in their environment, can overwhelm a person with dementia (e.g. TV, radio, or background noises) causing anxiety and confusion. Creating a quiet space or redirecting their attention to something enjoyable and productive can be very effective.

As a family member try to remember the person is not being difficult on purpose. They may need reassurance rather than information.

COMMUNICATION STRATEGIES TO SUPPORT REPETITIVE BEHAVIOURS.

Repetitive behaviours can cause irritation or be overwhelming for the family members to deal with. Below are some things you could try to help you deal with these behaviours.

Look for a reason behind the repetition.
Does the repetition occur around certain people or surroundings, or at a certain time of day? Is the person trying to communicate something?

Focus on the emotion, not the behaviour.
Rather than reacting to what the person is doing, think about how they are feeling.



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Turn the action or behaviour into an activity.
If the person is rubbing their hand across the table, provide a cloth and ask for help with dusting.

Stay calm and be kind to the person with dementia.
Reassure the person with a calm voice and gentle touch.

Engage the person in an activity.
The individual may simply be bored and need something to do. Provide structure and engage the person in a pleasant activity.

Provide an occupation for their hands.
Repetitive movements may be reduced by giving the person something else to do with their hands, such as a soft ball to squeeze, clothes to fold or provide them with an activity blanket.

Know what the person enjoys.
Try having a list of things they enjoy for when they are feeling agitated, such as going for a walk, playing their favourite music, using noise cancelling headphones, singing their favourite song, or try a familiar task. Redirecting their attention to something enjoyable and productive can be very effective.



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REPETITIVE QUESTIONS

Repetitive questions refer to the situation when the person with dementia asks you the same question over and over again. Short-term memory loss, limited attention span, increased distractibility, boredom, feelings of insecurity or anxiety about their ability to cope and anxiety about future events could be the causes for repetitive questioning. Repetitive questioning may also be an attempt to express a specific concern or ask for help or attention.

COMMUNICATION STRATEGIES TO SUPPORT REPETITIVE QUESTIONS

The strategies recommended for repetitive behaviours also apply to this situation.
In addition, one way to deal with repetitive questions is by using reminder cards. When a question is repeated a few seconds after you have just answered it, a reminder card may help to keep the information in mind.

FOLLOW THESE EASY STEPS FOR SUCCESSFUL REMEMBERING:

- State the answer to the question or concern.
- Write the answer on an index card or notepad.
- Read the card aloud with the person and give it to them.
- When the question is repeated, DO NOT say the answer, INSTEAD say, *"Please read the card"* or *"Have a look at this card, it says what we are going to do today".*
- Do this each time the question is repeated.

EXAMPLE:

Where are we going?

We are going to church (write this on the card).

HELPFUL HINTS:

- Print a clear message; Use large print; Use a few, simple, positive words.
- Make the message personal; Use personal pronouns (I, my, we) in the message.
- Read the message aloud; If there are reading errors, change the message.

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SUNSET SYNDROME

Sunset syndrome, also named “Sundown syndrome” or “Sundowning” commonly occurs in the late afternoon, evening or at night.

It refers to a variety of behavioural and psychological symptoms including: confusion, disorientation, mood swings, abnormally demanding attitude, suspiciousness, visual and auditory hallucinations, delusional thinking, moaning and wandering, resistance to redirection, agitation, screaming and yelling, drowsiness, falling and ataxia (lack of voluntary coordination of muscle movements that can include gait abnormality, speech changes, and abnormalities in eye movements).

Some of these behaviours may not be specific to sundowning and can be the manifestation of dementia, delirium and other neurological disorders.

COMMUNICATION STRATEGIES TO SUPPORT THE SUNSET SYNDROME

Communication should be kept simple when sunset syndrome is present.

Simple instructions should be used for the person with dementia, without major shifts in daily routines and without increasing the person’s with dementia communication load/effort.

Using a **calm voice and friendly gestures and posture** is important. A gentle touch (e.g. on person’s with dementia shoulder) can calm the person with dementia and increase communication and cooperation.

Whenever possible, you can use tools such as **redirection, reassurance, and distraction**. Talking to the person with dementia with a soft, calm voice, giving a hand massage, or just holding their hand may reassure the person with dementia and diminish anxiety and mood swings.

Listening to their favourite music and/or sounds of nature might relax the person with dementia.

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REFUSAL OF MEDICATION

Refusing medication is very common in people with dementia and it may be caused by being suspicious about the contents and their effect as well as the intentions of the people giving the medication. Other reasons are the bad taste, the size of the pill, difficulty swallowing, or side effects experienced from the medication that the person with dementia may not be able to communicate about.

COMMUNICATION STRATEGIES TO SUPPORT THE REFUSAL OF MEDICATION

Find out the reason for refusal

Ask the person why they do not want to take the medication, how they are making them feel, why do they think they are bad for them, etc. Gaining a better understanding to why the person with dementia is refusing to take the medication is key in resolving this issue. Communication is the main way to explain the importance of taking the medication. Being forced to do something the person absolutely disagrees with can seriously damage your relationship with them.

Explain as long/often as needed

The person with dementia should never be scared or threatened into taking the medication. One should stay calm and reasonable while talking to their loved one. Taking it slowly is key to making the person feel relaxed and listened to. Explaining it all clearly, in different ways if needed can help the person with dementia feel like they are informed to make their own choices. Making the person feel like it was their decision and choice is very important, try not to rush this conversation.



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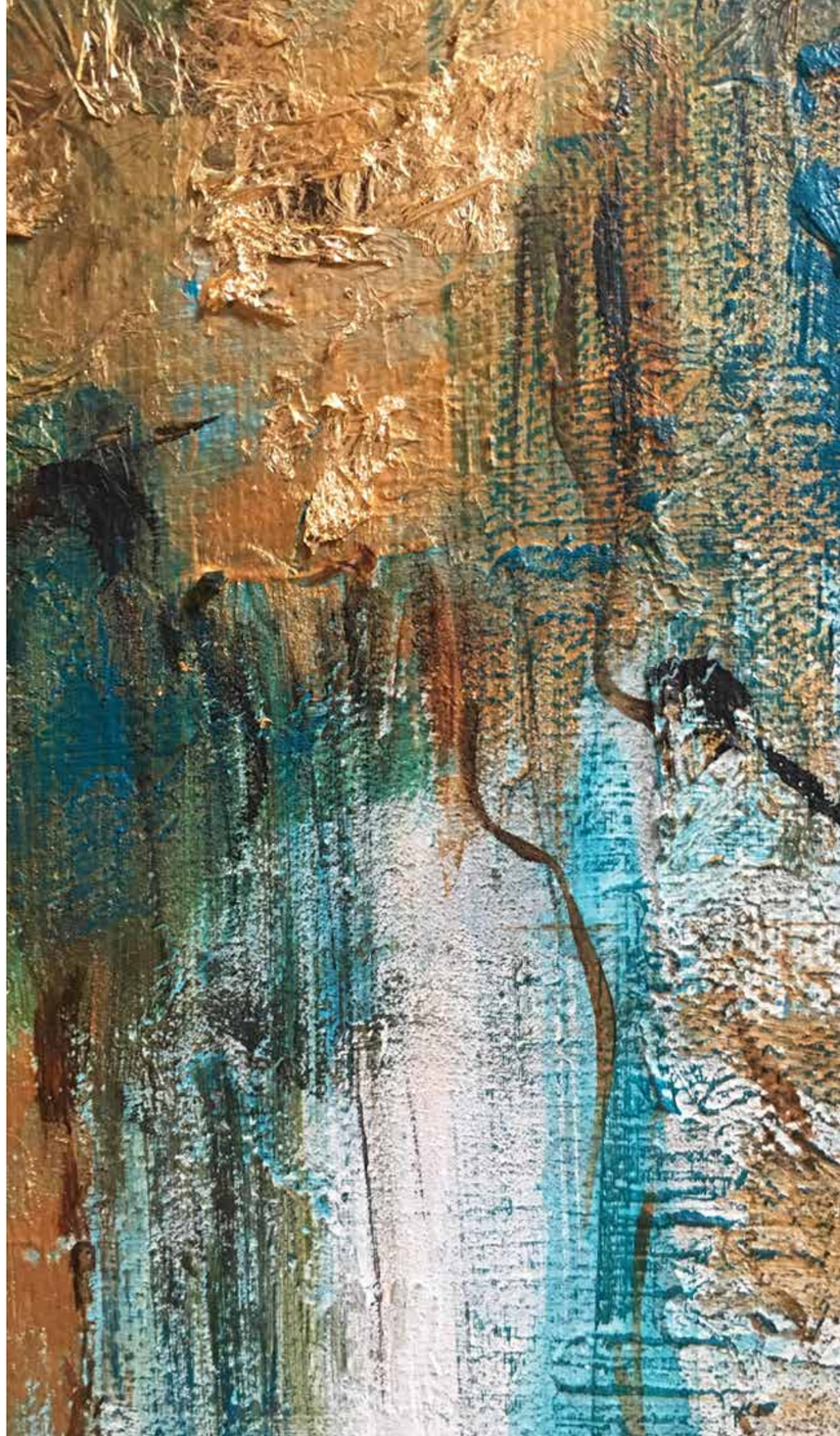
Argue with the support of the doctor

Show the prescription for the medication or tell that "Dr x", who the person with dementia sees as an authority figure, has prescribed you this medication, may be an effective way of reminding them that they need to take this medication. Having another authority figure or a person they recognise and trust may assure them that the medication will cause no harm, and can be another useful way to approach this situation.

Take your pills together

If you also take medication and the timing of it coincides, take the medication together at the same time and have a conversation about what it is that makes the person with dementia worry. This may help with the communication and make the person with dementia feel at ease.



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REFUSAL TO WASH

Washing can be a difficult activity because it is an intimate experience and people with dementia may perceive it as unpleasant or intrusive. People with dementia may be resistant to washing for a number of reasons, including: not remembering what washing is, embarrassment, lack of understanding (especially as to why you need to help them bathe), fear of water, being cold, experiencing a loss of independence, experiencing a loss of privacy, increased sensitivity to water temperature or pressure as a result of dementia.

COMMUNICATION STRATEGIES TO SUPPORT REFUSAL TO WASH

When assisting the person with dementia with bathing, **allow the person to do as much as possible.** Be ready to assist when needed, but try to offer help only when it is necessary. In the earlier stages, the person may only need a reminder to bathe. As the disease progresses, they may require more assistance.

Try to add interest to this activity by diversifying the products you are using (e.g. you can have different scented shower gel/shampoo that you might change; choose scents that you know the person with dementia would like and might prefer to use).

Help the person feel in control by offering them a choice: *"Would you like a shower or a bath?"," Would you like to wash now or in 10 minutes?".*

Give the person a role such as holding the flannel or shampoo.

Always protect their dignity and privacy. Try to help them feel less vulnerable by having a large towel available to cover their whole body while undressing and once they have finished bathing if they are dressing the top half of their body first, place a towel on their lap, so they feel more covered.

Make bathing safe by guiding the person through each step of the process. For example: *"put your feet in the tub"*, *"sit down"*, *"here is the soap"*, *"now I will rinse your hair"*. If they don't like having water on their face or eyes, provide them with a flannel to cover those areas.

Use other cues to remind the person what to do. Try using a "watch me" technique or lead by example. Put your hand over the person's hand, gently guiding the washing actions.

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WANDERING

Along with agitation, wandering seems to be the most enduring sign of challenging behaviours among people with dementia and it affects approximately 60% of this population. Different types of behaviours are included in wandering: repeatedly checking the whereabouts of the family member; trailing/stalking (extreme form of checking); pottering or rooting (walking around the house); aimless walking, night-time walking; repeated attempts to leave the house.

Reasons as to why a person with dementia may have this behaviour varies. Usually, it is an expression of how unsettled or uncomfortable they are. So, wandering can be due to an attempt to leave (exit seeking), following other people (modelling), lack of stimulation and boredom or restlessness due to side-effects of medications.

COMMUNICATION STRATEGIES TO SUPPORT WANDERING

Engage the person with dementia in other activities or sensory stimulation. For example, you can try to assign chores to keep them occupied, follow an exercise program or listen to music to redirect them from wandering.

Use technology to improve their navigation or monitor their movement. This includes technology to support safer walking, smart home technology with wandering detection or location devices.

Modify the environment to reduce hazardous areas. You can, for example, make some alterations to the physical environment to camouflage or distract the person with dementia from exiting a door.



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Remember that wandering can happen, even if you are the most diligent of family members. You can use the following strategies to help lower the chances:

• Ensure all basic needs are met.

• Identify the most likely times of day that wandering may occur. Plan activities at that time.

• Reassure the person if they feel lost, abandoned, or disoriented. Refrain from correcting the person.

• Place locks out of sight or install them either high or low on exterior doors and consider placing slide bolts at the top or bottom.

• Use devices that signal when a door or window is opened. This can be as simple as a bell placed above a door or as sophisticated as an electronic home alarm.

• The entrance door can be under camouflage, so the person with dementia feels less prone to wander.



ENGAGEMENT THROUGH STORYTELLING
IN DEMENTIA CARE

Everyone likes a good story. From an early age we are programmed to learn from and respond to stories. Stories are part of being human. They have the potential to enhance communication for the teller and the listener.

Storytelling has many benefits for both the family member and the person with dementia, through enhancing wellbeing in a non-intrusive and fun way, in using our powers of imagination we can become more present, more in the moment, and ultimately more spontaneous in our communication with each other.



ENGAGEMENT THROUGH STORYTELLING IN DEMENTIA CARE

How does Storytelling work?

How can you practice storytelling in taking care of your loved one?

HOW DOES STORYTELLING WORK

It stimulates communication

Storytelling can be both based on a real set of events or totally fictitious events. This makes them accessible for everyone. There is no obligation to be exact. They allow you to “be in the moment” without the frustration of having to remember facts. They are personal to the teller and the receiver. So, there is no right or wrong in this sharing, just endless possibilities.

It improves the mood

The mood can be enhanced dramatically by shared storytelling. For someone living with dementia, expressing themselves through a story, real or imagined, can increase self-esteem and a sense of belonging.



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ENGAGEMENT THROUGH STORYTELLING **IN DEMENTIA CARE**

How does Storytelling work?

How can you practice storytelling in taking care of your loved one?

TOM'S EXAMPLE OF USING STORYTELLING TO STIMULATE CONVERSATION AND ENHANCE THE MOOD

The challenge

Tom admits that it's difficult at times to care for his wife. "She can be difficult, and I can be difficult." Difficulty is part of their daily lives together. "Patience is not my strong point, and sometimes I feel guilty when I really dislike the one I love. This upsets me, and I can't tell anyone how I feel." He can feel very lonely and isolated sometimes. He wisely believes, "that being a carer requires a 'roll with it attitude'. On a daily basis there are new challenges. My latest is trying to get my wife to bathe."

Tom's approach

"Sometimes I make up a story and offer her a reward like telling her that we're going out for lunch, and that the restaurant won't allow us in unless we smell good. I do try and fulfil that promise, and bring Vera out to lunch, but more often it doesn't happen. We try and laugh a lot, laughter definitely helps. I make jokes out of many of the problems. Maintaining a sense of humour enables me to stay in balance. It reduces the tension."

Tom's tip

Family members are often burdened when caring for a loved one who suffers from dementia. Tom tries to care for his wife in an 'in the moment' way. He uses humour and story as a diffuser and a self-care technique.

It increases the sense of connection

Storytelling will offer you the opportunity to create and strengthen bonds. And even learn new things about each other.

Andra takes her husband for a walk most days. They like to walk especially by the shores of a local lake. On one such walk Andra picked a sprig of rosemary and offered it to her husband. And in the first complete and fully coherent sentence in months he uttered, he said, "This reminds me of your wonderful Rosemary Chicken".

Andra's tip:

A new experience and a sensory stimulus can help "in-the-moment" connections and become the stimulus for a new story, imagined or real.

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ENGAGEMENT THROUGH STORYTELLING IN DEMENTIA CARE

[How does Storytelling work?](#)

How can you practice storytelling in taking care of your loved one?

It instils a feeling of relaxation

Discussing something or someone that is familiar, can access memories and aid in reducing stress and anxiety. The imagination and creativity shared in storytelling can have great cognitive benefits, improve social interactions and can always bring great joy to both the family and their loved one.

MARY'S EXAMPLE OF USING STORYTELLING FOR CONNECTING WITH HER MOTHER AND FINDING RELAXATION

The challenge

Mary cares for her elderly mother Joan, who is in the later stages of dementia. Joan's husband is well and fit, but unable to cope with the demands of being his wife's fulltime carer. Mary does what she can to assist and meet both her parent's needs. Joan has always been a very active woman and loves nothing more than to be pottering about. Her daughter says that, "It's hard to keep up with her even at the best of times." Lately Joan has started to prepare the dinner for her husband at the most inappropriate times. Mary tells us that, "Initially, I shut her down. Telling her the facts and the reality, with the expectations that she would "get it". The whole battle was very stressful for both of us."

Mary's Approach

So, Mary tried a new approach, "this particular day I decided to be more spontaneous in my reaction, and instead of closing down the conversation I opened it up. I kind of 'played along', suggesting that maybe, we should set the table?". This time the effects were the opposite. "My mother opened up and enjoyed the process of setting the table for dinner. There was a comfort in the ritual and the familiarity in setting the table for her, and for me. I was learning to communicate in a new way with my mother. Being present and understanding my mother's needs in the moment made all the difference. We had a bit of a laugh too." Battling and reasoning gets you nowhere. When you can, and if you can, follow the person's cues. Be ready to 'play' in their reality. Being present and in the moment can be a joyful place, even under the most difficult circumstances.

Mary's tip:

Though the activity may be fictitious, the relationship and connections are real and "in the moment."

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ENGAGEMENT THROUGH STORYTELLING **IN DEMENTIA CARE**

How does Storytelling work?
How can you practice storytelling in taking care of your loved one?

HOW CAN YOU PRACTICE STORYTELLING IN TAKING CARE OF YOUR LOVED ONE?

Mary, Tom and Andra know the power of storytelling techniques. Maybe they didn't even realise they were already using these techniques on a daily basis to communicate better with their loved one. Storytelling is a natural human instinct and pastime. You are already and forever practicing it. We all have a story to tell no matter what age or stage of dementia we may be at.

With the "Sharing a Moment" activities (adventures 1, 2 and 3 from part 2) you can put your own instinct for storytelling into practice. It may even become a practice with purpose. Using these activities can be a fun way to pass some time and be "in the moment" with those in your care.



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WAYS OF RECONNECTING
THROUGH ALTERNATIVE COMMUNICATION METHODS

Alternative communication methods can help you in your supporting role, by simplifying oral or written forms of communication, usually by using visual cues which allow people with communication impairments to increase their participation in desired activities and create opportunities for social interaction through various modes of communication.

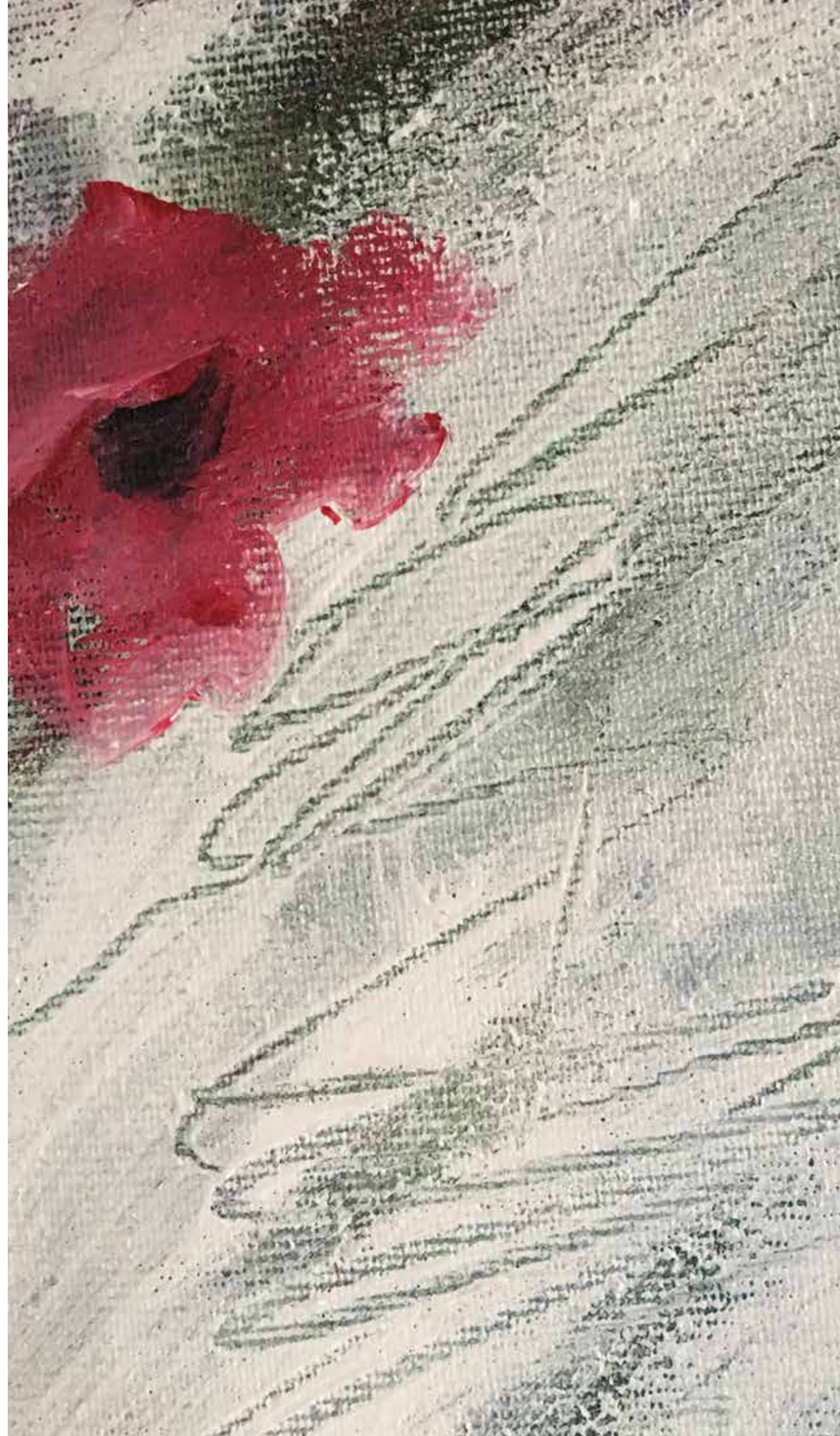
WAYS OF RECONNECTING **THROUGH ALTERNATIVE COMMUNICATION METHODS**

[Life story books](#)
[Communication wallet](#)
[Communication boards](#)
[Writing letters in the air](#)

Non-electronic or low-tech alternative communication methods make use of external aids to incorporate stimuli highly relevant to a person's daily life. These may include memory wallets, communication boards, labels, and other tangible visible symbols that provide cues for interaction.

One value of alternative communication methods for conversation between people with dementia and their family members is that the tools offer visual and literal joint reference to create common meaning for social interaction. Whether the tools consist of single words written in large block letters on cue cards, videos of family events that can be used for reminiscence, or communication books that contain pictures and words to help with daily routines, these visual tools create common cues to support communication.

Below are some examples of alternative communication methods you can use with your loved one.



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WAYS OF RECONNECTING **THROUGH ALTERNATIVE COMMUNICATION METHODS**

Life story books
Communication wallet
Communication boards
Writing letters in the air

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LIFE STORY BOOKS

The inability to recall incidents and events, especially when symptoms of dementia become more prevalent and severe, can cause a person to experience a loss of self or to have doubts about their identity. Life story books, as their name indicate, can be helpful in supporting your loved one recall their autobiographical memories.

For the person with dementia, using a life story book can have the following positive effects: enhance mood, reduce the feelings of disorientation and anxiety, improve self-confidence, improve their memory, and enhance social interactions and their overall quality of life.

A life story book offers a record of a person's history and could be extremely helpful throughout the progression of the disease and as the memory declines. It includes information and photographs of friends and family, interests, likes, dislikes, and occupation.

A life story book can be started immediately after the diagnosis of dementia. Creating a life story book will be especially helpful if you are finding yourself at the beginning of the caring journey, as it will offer a quick reference guide of your loved ones preferences, as well as an accurate and deep understanding of historical events which might influence their reactions to particular stimuli and circumstances.



WAYS OF RECONNECTING **THROUGH ALTERNATIVE COMMUNICATION METHODS**

[Life story books](#)
Communication wallet
Communication boards
Writing letters in the air

JEAN'S EXAMPLE OF USING LIFE STORY BOOKS TO FIND MEANING AND JOY

The challenge

Mary, an 80-year-old widow at the moderate stage of dementia, has been living at a residential care home for the last 2.5 years. Even though Mary's sister (Jean) was reluctant at first to participate, she finally agreed to help Mary create a life story book. Jean brought all photos and other tangible documents to depict Mary's life story.

Jean's approach

Throughout the life review process, Mary talked about the difficulties she had in her youth and explained the reasons for her working at a very young age. An unhappy event in her life was the early death of her spouse some years after their marriage. There were times throughout the process that Mary expressed sorrow about the death of her spouse. However, it also evoked many cheerful memories of her life with her husband through her wedding album and invitations. Mary did not get married again and moved to her parents focusing on her career.

At the last session Mary was requested to evaluate her overall life experiences and said:
"When I look back at my life (long pause) ...I have no regret...all looks fine.... I'm happy...no need to change anything.... only one thing....my husband.... he died.... what can I do? Can we do anything? Overall, I'm happy with my life."

Jean's tip:
Even if some ideas might seem too much, try them out. It can attract the interest of your loved one and bring them some joy.

If you wish to create a life story book for your loved one, you will find step by step instructions and resources in Part 2, Adventure 4.



WAYS OF RECONNECTING **THROUGH ALTERNATIVE COMMUNICATION METHODS**

Life story books
Communication wallet
Communication boards
Writing letters in the air

COMMUNICATION WALLET

A communication wallet is an effective tool to help keep your loved one on-topic and make relevant contributions to the conversation. It consists of a set of pictures and sentences about familiar people, places, and events that they might have difficulty remembering.

The wallet can include facts that are important for the individual (e.g. information they want to talk about, facts they often get confused about) or for you as a care partner (e.g. activities of daily living, common topics of conversation, and problematic issues).

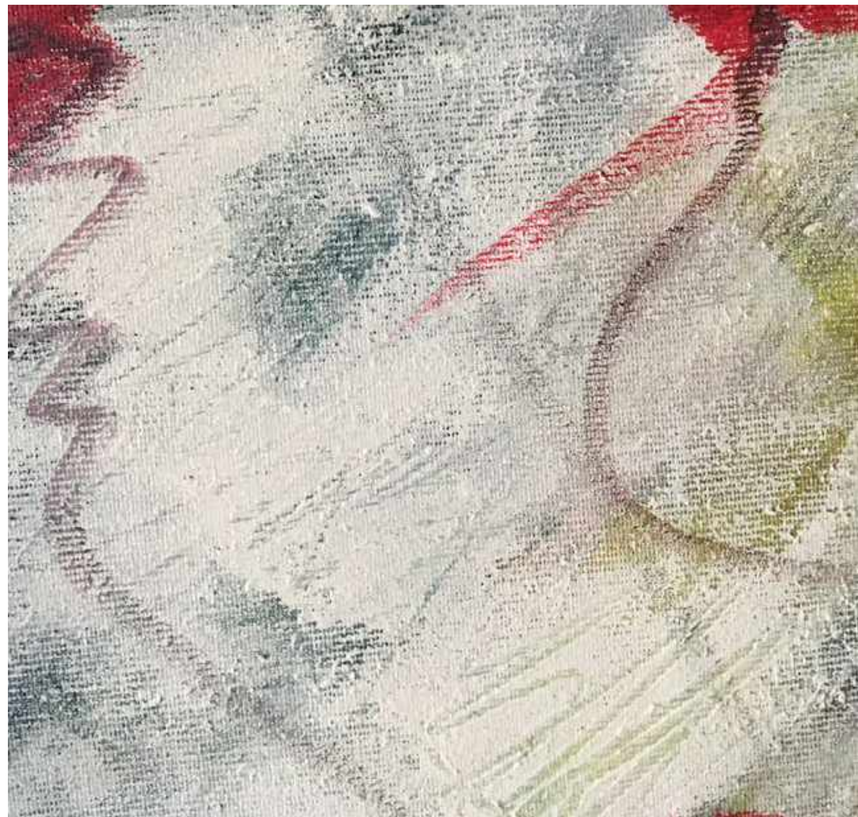
MARIA'S EXAMPLE OF USING THE COMMUNICATION WALLET TO TRAIN COMMUNICATION

The challenge

Mihai is 67 years old and lives at home with his wife Maria. Mihai was diagnosed with Alzheimer's disease a few years ago and lately he has started to have communication difficulties. Maria wants to help him maintain his communication skills for as long as possible and she has created a communication wallet for Mihai that she uses five times a week for 15 minutes sessions.

Maria's approach

When she is training with Mihai she generally starts by encouraging Mihai to use the wallet. She starts by saying "Now we are going to practice having a conversation. This wallet has pictures and sentences that you can look at to help you remember what you want to say. Open the first page." Then she starts by asking about one of the three topics, switching the order from session to session, for example "Let's talk about your day. Tell me about your day".



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WAYS OF RECONNECTING **THROUGH ALTERNATIVE COMMUNICATION METHODS**

Life story books
Communication wallet
Communication boards
Writing letters in the air

When Mihai manages to read the sentence on the card (e.g. I woke up and dressed), she praises him and then stimulates him to make an additional comment by asking something like "What else can you tell me about that?". When Mihai cannot come up with a new comment, Maria says something to help him such as "You are wearing your favourite blue shirt today, aren't you?". When Mihai still fails to come up with a new comment, she asks Mihai to turn the page, points at the sentence on the new page and says "Wait, read this").

Sometimes, Mihai has difficulties to begin reading and Maria starts by reading the first word then she pauses for Mihai to continue. Maria has been using this to facilitate communication with Mihai for the last five weeks. While Mihai still has difficulties correctly reading some of the sentences, she has observed that he has additional comments for every second index card and sometimes even short anecdotes.

Maria's tip:
Being able to have a conversation is the aim here rather than reading all the sentences. Keep a light attitude and focus on what the person does right.

If you wish to create a communication wallet for your loved one, you will find step by step instructions and resources in Part 2, Adventure 5.



WAYS OF RECONNECTING **THROUGH ALTERNATIVE COMMUNICATION METHODS**

Life story books
Communication wallet
Communication boards
Writing letters in the air

COMMUNICATION BOARDS

Communication boards can help you maintain or improve conversation with your loved one by using visual cues, such as cards.

Using communication boards can allow your loved one to share their immediate needs and preferences and, as a result, to feel less confused, anxious, or frustrated. It will help you get answers to common and real time questions about the food they would like to have, in which activities they would like to be involved in and whether they feel any pain. Boards can also be used as reminders for daily living such as taking a shower, going for a walk, or napping and can be used even when speech impairment is present.

You can also use communication boards to maintain or improve conversation with your loved one if you construct your board around conversational topics such as hobbies, family, travel, work, home, sports, religion and/or animals.

It usually consists of a “board” which can be as simple as a printed piece of A4/A3 paper with time categories such as “Now” or “Not now” and smaller simple visual cards with one picture and one word per card. The visual cards reflect different situational categories such as food, activities, pain and daily living.

JOHN’S FAMILY EXAMPLE OF USING COMMUNICATION BOARDS TO FIND OUT HIS PREFERENCES

The challenge

One day, John’s family realised he could no longer talk, did not remember who his wife was, and did not like his lifelong passion of music anymore.
First, they asked John if he could read some information. John was able to, so they knew we could try to communicate using the communication board.

John’s family approach

They asked John to read the board which had ”Always”, “Sometimes”, and “Never” as the categories. Then they asked John some questions. First, “Do you feel any pain?” John was shown the chest pain card and asked, “do you have chest pain always, sometimes or never?” John replied “Never” this was followed by other cards such as headache, toothache etc.
Next John was asked about what he liked to do, “John do you like music always, sometimes or never?” John put the music card on always. It was realised John had been saying “no” when his family asked if he wanted music on, so they assumed he had moved past this,

WAYS OF RECONNECTING **THROUGH ALTERNATIVE COMMUNICATION METHODS**

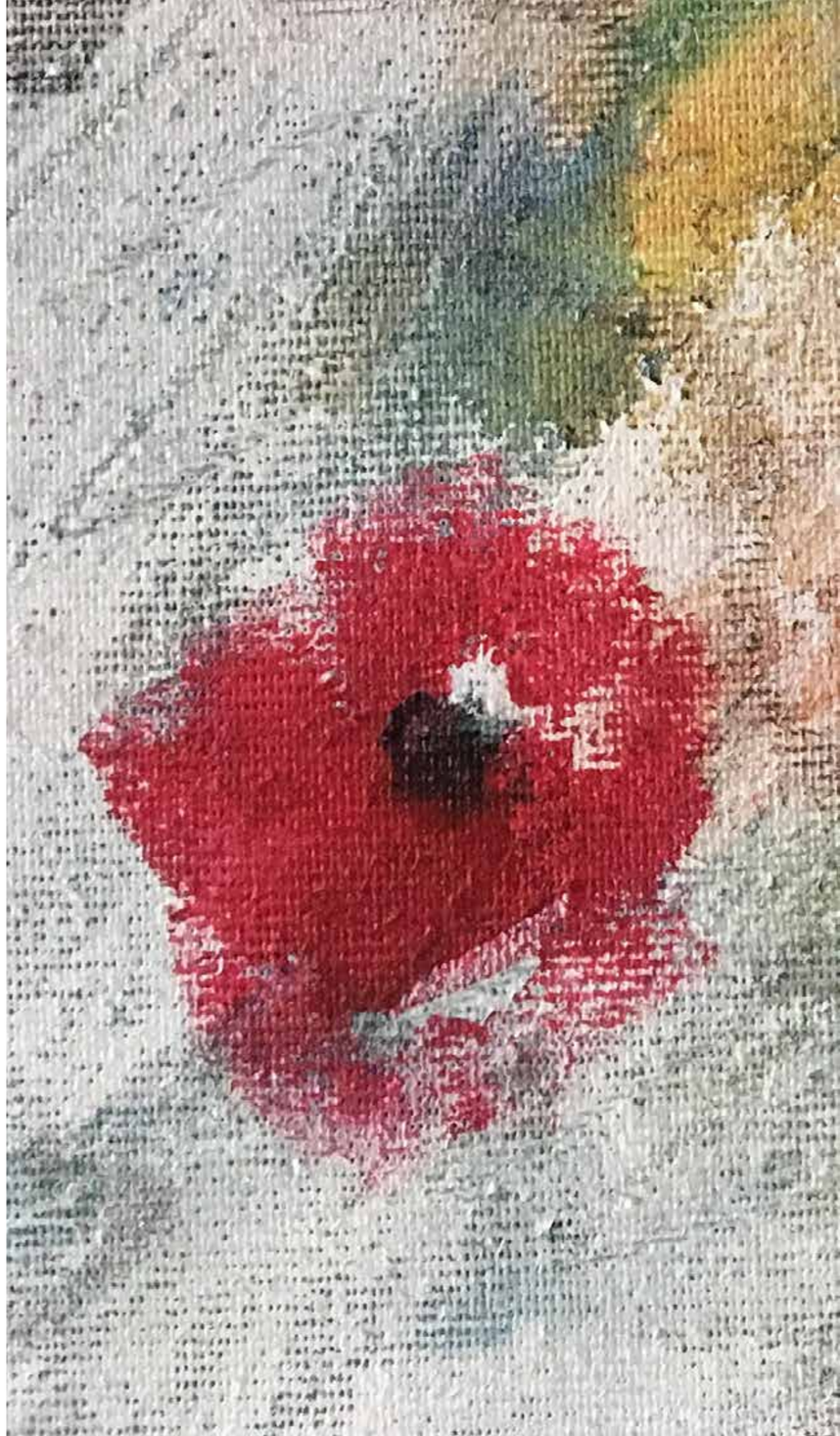
Life story books
Communication wallet
Communication boards
Writing letters in the air

however this enabled his family to see he did still like music, as well as walking and family visits. It can be common for people with dementia to reply "no" to many questions, as it is one of the first words that is learnt and it is very protective language.

Using the board helped John's family to see that John can still understand conversation, read, understand the pictures and that he is able to communicate his preferences and needs more effectively by using the board than before.

Tip from John's family:
If using 'Now', 'Not now' and 'later' categories to agree a schedule for that day, put the board in an easy place to see and use it to remind you and the person you care for what you have agreed as your 'now', 'next' and 'later' activities to do.

If you wish to create a communication board for your loved one, you will find step by step instructions and resources in Part 2, Adventure 6.



WAYS OF RECONNECTING **THROUGH ALTERNATIVE COMMUNICATION METHODS**

Life story books
Communication wallet
Communication boards
Writing letters in the air

WRITING LETTERS IN THE AIR

People with dementia often require alternative communication approaches for differing periods of time. They can temporarily or permanently lose the ability to speak and need alternative means to express basic needs efficiently and effectively.

The main purpose of expressive communication is to provide the individual with a means to express their basic physical needs or vital information, and to increase the amount of interactions between them and family members to reduce isolation and fear.

Writing letters in the air means using natural forms of communication that uses the human body, with no other equipment required. The physical act of air-writing the letters creates a big cognitive impression and helps cement the word in the memory.

GEORGINA'S EXAMPLE OF WRITING LETTERS IN THE AIR TO LEARN ABOUT NEEDS

The challenge
Maria is 76 years old and has moderate stage dementia. Maria is living with her daughter, Georgina, her care partner for the past 5 years. Lately, Maria is experiencing communication problems, she is no longer able to express herself verbally, to say the words she wants.

Georgina's approach
Georgina is feeling that she cannot understand her mother's needs, and an alternative communication method like "writing letters in the air" can be help support communication difficulties. Georgina can write words on cards or use printed card with words on, and use these to exercise writing letters in the air following the words written on the cards with her mother. In this way, Maria will learn to use this system when she wants to express her needs or wishes non-verbally.

Georgina's tip :
You can use a flash card on which a word is written. The flash card needs to be held at the individual's eye level. We want to make sure that the individual is focused on the written word on the flash card, not on your face or mouth.

If you wish to try out this alternative method of communication with your loved one, you will find step by step instructions and resources in Part 2, Adventure 7.

PART 2
ACTIVITIES FOR PRACTICE

This part consists of communication activities, detailed with step by step instructions and designed to be practiced together with the person with dementia.

1. ENGAGEMENT THROUGH STORYTELLING “SHARING A MOMENT”

2. WAYS OF RECONNECTING THROUGH ALTERNATIVE COMMUNICATION METHODS



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WHAT IS **STORYTELLING?**

Everyone likes a good story. From an early age we are programmed to learn from and respond to stories. Stories are part of being human. They have the potential to enhance communication for the teller and the listener.

Adventure 1: Exploring the senses to create a poem
Adventure 2: Creating an original story from postcards and pictures
Adventure 3: Creating a character story in a poem



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SHARING A MOMENT ADVENTURE 1: EXPLORING THE SENSES TO CREATE A POEM

BEFORE

Setting up Tips:
Preparation is key - Storing all you need in a "Sharing a Moment" box is recommended.

1



Choose a relaxed setting e.g. at a kitchen table, coffee table etc. where you and your loved one feel comfortable and where materials can be put on a table.

3

2

HAVE YOUR MATERIALS SOURCED AND READY IN ADVANCE:

- "Sharing a Moment" Box;
- Balloon;
- Pens;
- Notepaper for writing on;
- 6 bags approx. (cotton, linen, paper bags) to hold the individual sensory items (lavender, tea bags, soap etc., and any items you think the person might like or connect with).

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IN THE MOMENT

Introduce what you are going to do together in a relaxed and fun way.

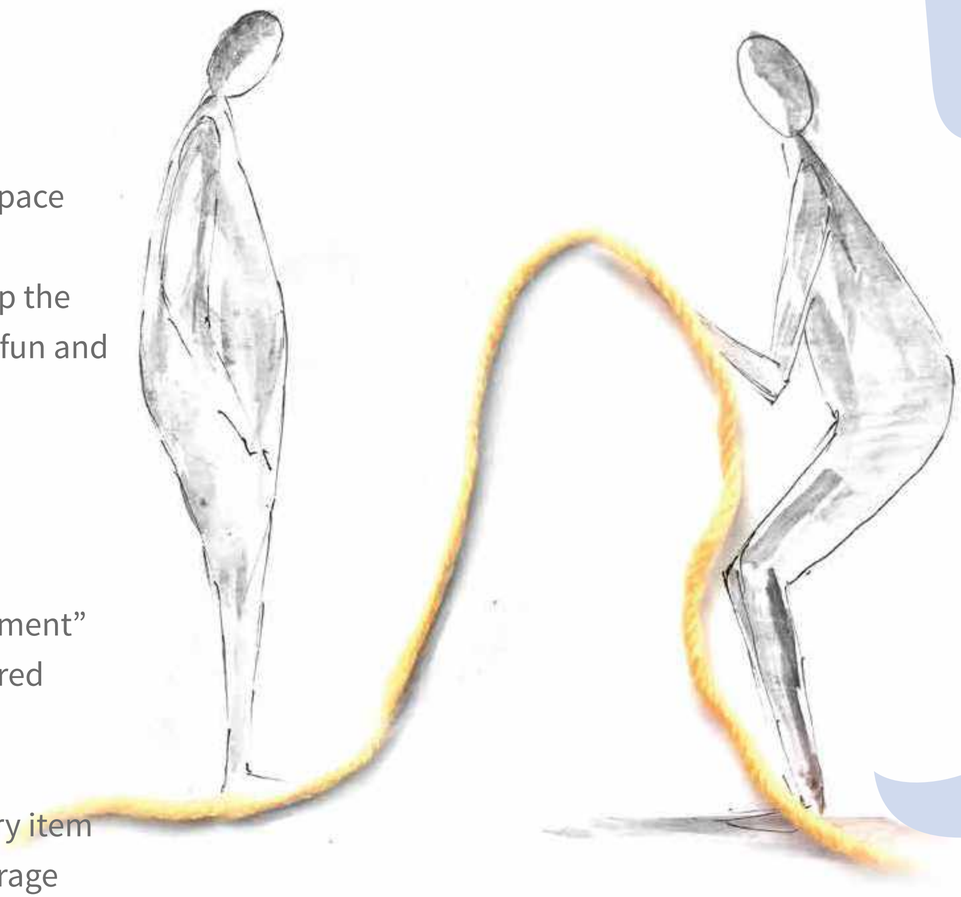
ACTIVITY 1 - BALLOON (OPTIONAL)

This exercise can take place at the table or in a space separate to the table.
Pat balloon up into the air. Work together to keep the balloon in the air and encourage the element of fun and laughter.

ACTIVITY 2 - SENSORY BAGS

Sit at the table and introduce the “Sharing a moment” box. Inside are the sensory bags you have prepared earlier for stimulating the senses.

Take out the bags. Each bag contains one sensory item each. Give one bag to your loved one and encourage them to explore the item inside, through touching, smelling, listening to and finally looking at the item. Repeat with the other bags.



NOTE: If you do not have bags, you can hand the items one by one.

Chat about each item after it has been introduced and investigated or wait until all items have been introduced to chat about them. Respond to the their willingness to talk about the items and go with the moment.

Chat about the feel, smell, memories of taste, sound and appearance of items.

Chat about the knowledge the person with dementia has about the items, their connection and experience with them. Listen to any memories the person with dementia may want to share about them.
You can share your thoughts too. Now you are both sharing your thoughts and experiences together; you are connecting with each other around the items and senses associated with them.

ACTIVITY 3 – FROM SENSE TO SENTENCES

You are now going to write a poem together about "Summer" or another season theme.
First, you both write sentences related to the senses that you both associate with summer.

Pick "Taste". Write a line about a taste you associate with summer and encourage the person with dementia to do the same. Eg. Taste…. The taste of chilled wine on the back porch. Taste…. The taste of blackberries on the bushes.

Now you have 2 different lines about the taste of summer.

NOTE: If your loved one cannot read or write you can write their sense thoughts down for them. If he/she only writes one word, you can encourage them to expand on it, creating a sentence.

Now, at the same time, write more "taste" lines separately.

Repeat this until you have a written collection of shared tastes associated with the theme of Summer.

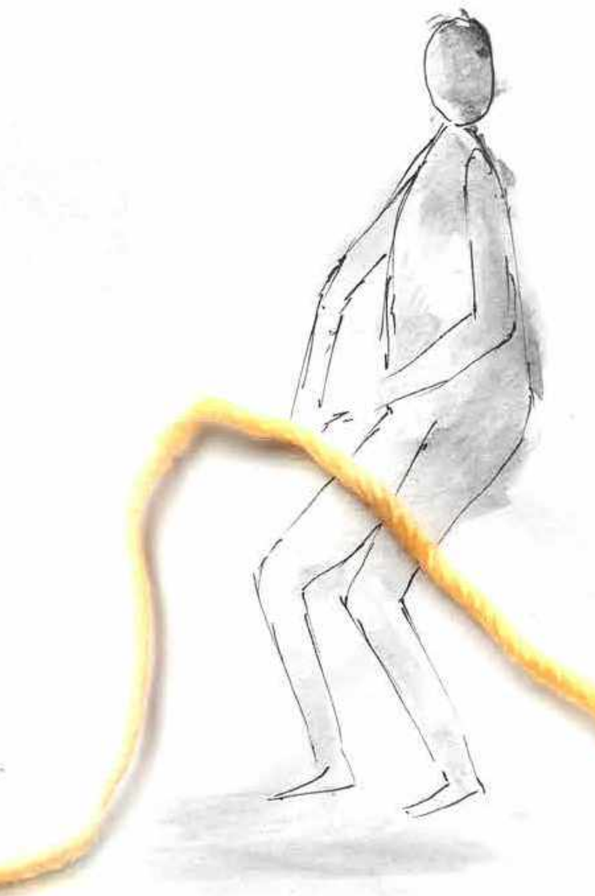
Repeat the same activity with the other senses e.g.

See… the roses in the garden

Hear… the ducks quacking in the park pond

Smell… the smell of grass

Touch… the feeling of a light breeze from the sea



When you have your full collection of shared written senses completed, read them aloud together, taking turns if you like.

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ACTIVITY 4 – WRITING YOUR SENSORY POEM

You are going to create a poem together using the sentences you have both just written. Be creative in your approach; there is no right or wrong way to create this poem. You already have the material (i.e. the lines), now you just need to decide on the sequence of putting them together. You can create verses around one sense or using random senses.

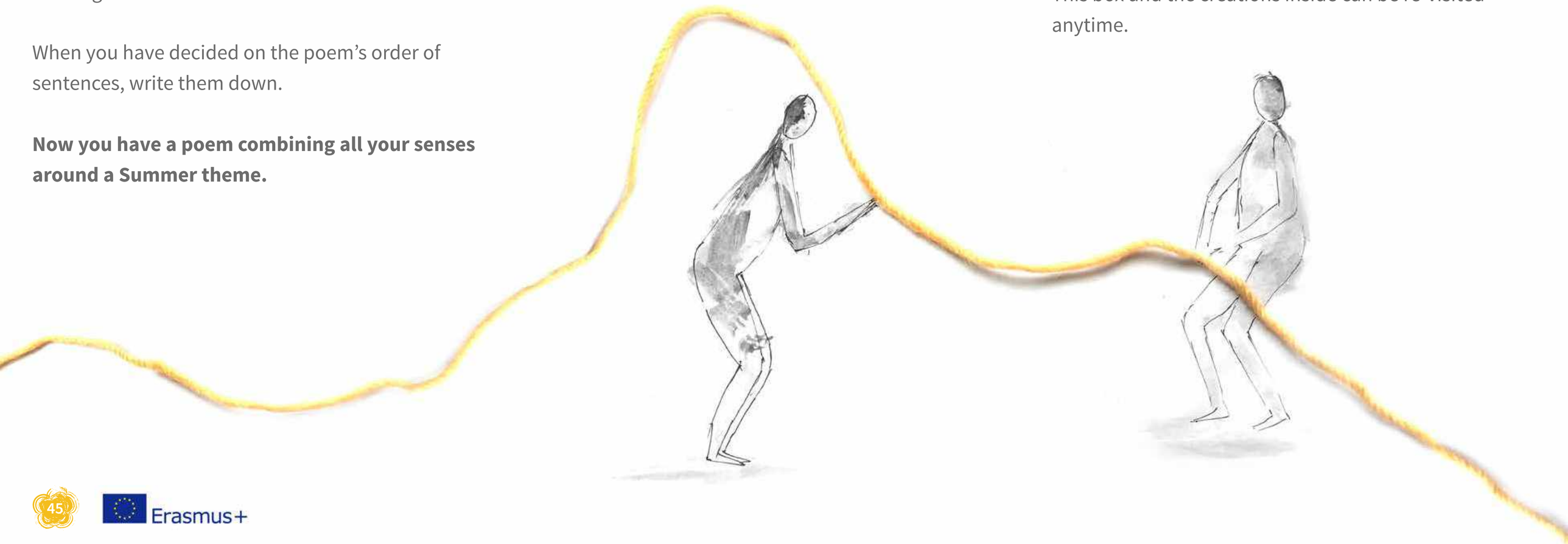
When you have decided on the poem's order of sentences, write them down.

Now you have a poem combining all your senses around a Summer theme.

Read the poem aloud.

Give the poem a title together.

As authors, now sign the poem.



AFTER

Congratulate each other on a job well done creating the poem.

To finish your story adventure together, pack everything up and put it all into the "Sharing a Moment" box.

This box and the creations inside can be re-visited anytime.

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Ask yourself:

• What worked well for me?

• What worked best for the person with dementia?

• Were there moments that stood out? If so, what were they?

• Did I encounter any difficulties or challenges? If so, when and how? How might I improve this for the next time?



COMMUNICATION

Did we communicate well together?
What worked well for me?
What worked best for the person with dementia?
Did we use our imaginations? If so, how and when?

CONNECTIONS

Did I learn something new about the person with dementia?
Has that changed my outlook?

MOOD

Did we have fun together? If so, how?
Did the activity improve the person with dementia's mood? If so, when and how?
Did the activity improve my own mood? If so, when and how?

RELAXATION

Was the activity a relaxing and enjoyable experience? If so, when and how?
Contemplate on how you will use these reflections to help your day to day interactions with your loved one, and how will you apply these new insights into your next Storytelling Adventure together.

TIME FOR REFLECTION

In your own time, think about the activity you completed together

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FAMILY MEMBER'S EXPERIENCE WITH **THE ACTIVITIES**

Anna asked her mother to find some jars of herbs from the kitchen. Her mother brought her the jars and Anna started a conversation with her about the herbs. Anna asked her what herb was in each jar and then she asked if she had any memories connected to each herb. Her mother participated to the conversation and started sharing her knowledge and her connections to each herb.



Tip for family members:
Use this activity as an opportunity to create a connection with your loved one rather than striving for a result.

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SHARING A MOMENT ADVENTURE 2: **CREATING AN ORIGINAL STORY FROM POSTCARDS AND PICTURES**

BEFORE

Setting up Tips:
Preparation is key - Storing all you need in a "Sharing a Moment" box is recommended.

1



Choose a relaxed setting e.g. at a kitchen table, coffee table etc. where you and your loved one feel comfortable and where materials can be put on a table.

3

2

HAVE YOUR MATERIALS SOURCED AND READY IN ADVANCE:

- "Sharing a Moment" Box;
- Postcards and/or pictures;
- Balloon;
- Notepaper;
- Pens;
- Sensory poem and sensory bags with items from "Sharing a Moment - adventure 1".

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IN THE MOMENT

Introduce what you are going to do together in a relaxed and fun way.

ACTIVITY 1 - BALLOON (OPTIONAL)

This exercise can take place at the table or in a space separate to the table.
Pat balloon up into the air. Work together to keep the balloon in the air and encourage the element of fun and laughter.

ACTIVITY 2 - RECAP AND REFLECT

Materials i.e. Sensory bag items and poem from previous activity session have already been placed on the table. Reflect briefly on what you explored and created together in the last session.
Read the sensory poem aloud and honour your achievement together.

ACTIVITY 3 - PICTURE-PICK

Place postcards and pictures from the “Sharing a Moment” box onto the table.

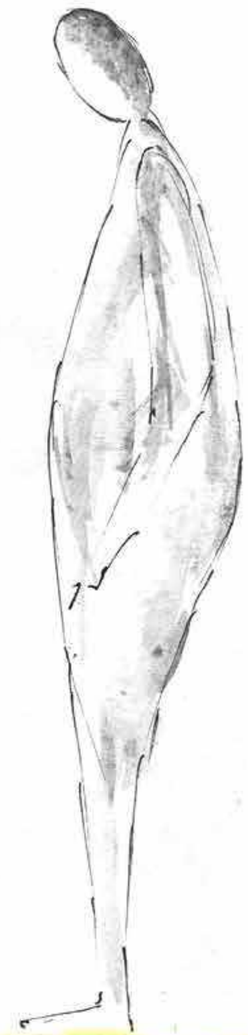
NOTE: Postcards and pictures should be of landscapes, ports, airports, countryside and towns or cities. Include some pictures with unknown people in them. Choose vintage postcards e.g. From the 1950’s/ 60’s/ 70’s. Choose pictures which are relevant to your own country and ones that you think will resonate with the person with dementia.

Now ask the person with dementia to choose and look at different pictures. Give them some time to do this, whilst you do the same.

Ask the person with dementia to choose a postcard or picture and to reveal their thoughts or connections related to the image and why they chose it.

You can participate in this exercise too, choosing a picture and sharing your thoughts.

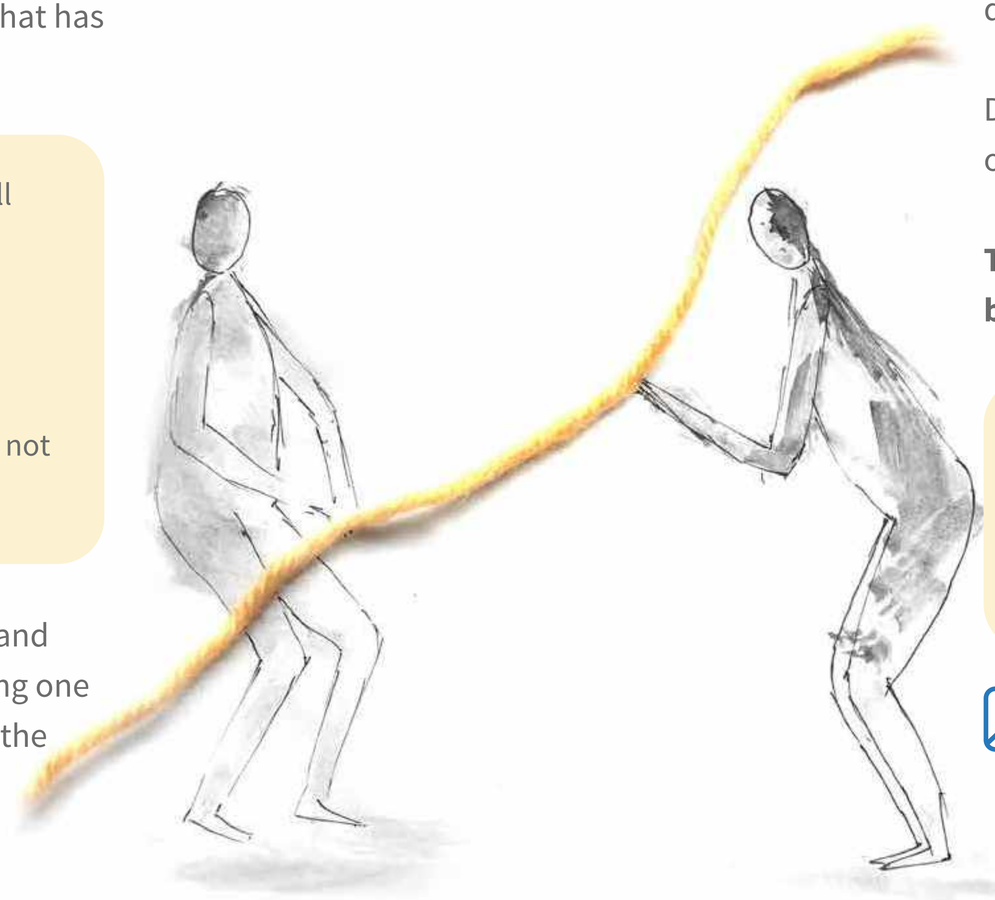
Now you can both share your knowledge, connections and memories around the other pictures and postcards also.



ACTIVITY 4 – PICTURE STORY

Now choose one picture or postcard together that you will now create a story around. Ideally pick one that has an unknown person or people in it.

NOTE: Tell the person with dementia that you will be creating a fictional or "made-up" story about the picture. (It is likely the person with dementia will create personal connections to the pictures and this is welcomed, but persevere to keep the developing story fictional. Just remember; this is not a reminiscence activity.)



To begin, ask your loved one to hold the picture and begin telling the story they see in the picture using one sentence e.g. "There were once 2 children out in the field with their cart."

You can then add another sentence to the story.

Continue like this, each taking turns to develop the story.

Concentrate on the beginning of the story first for a few sentences, then the middle, then the end. If it is very short, you can go back over the story encouraging more detail for each beginning/ middle / end section.

During or after a re-cap of the story, write the sentences of the story down on a piece of paper.

The story can be added to at any time until you are both happy with the outcome.

NOTE: As an alternative, you may begin and say the first sentence of the story and the person with dementia follows with the second sentence and so on.

Attach the picture/postcard to the story.

Give the story a title together.

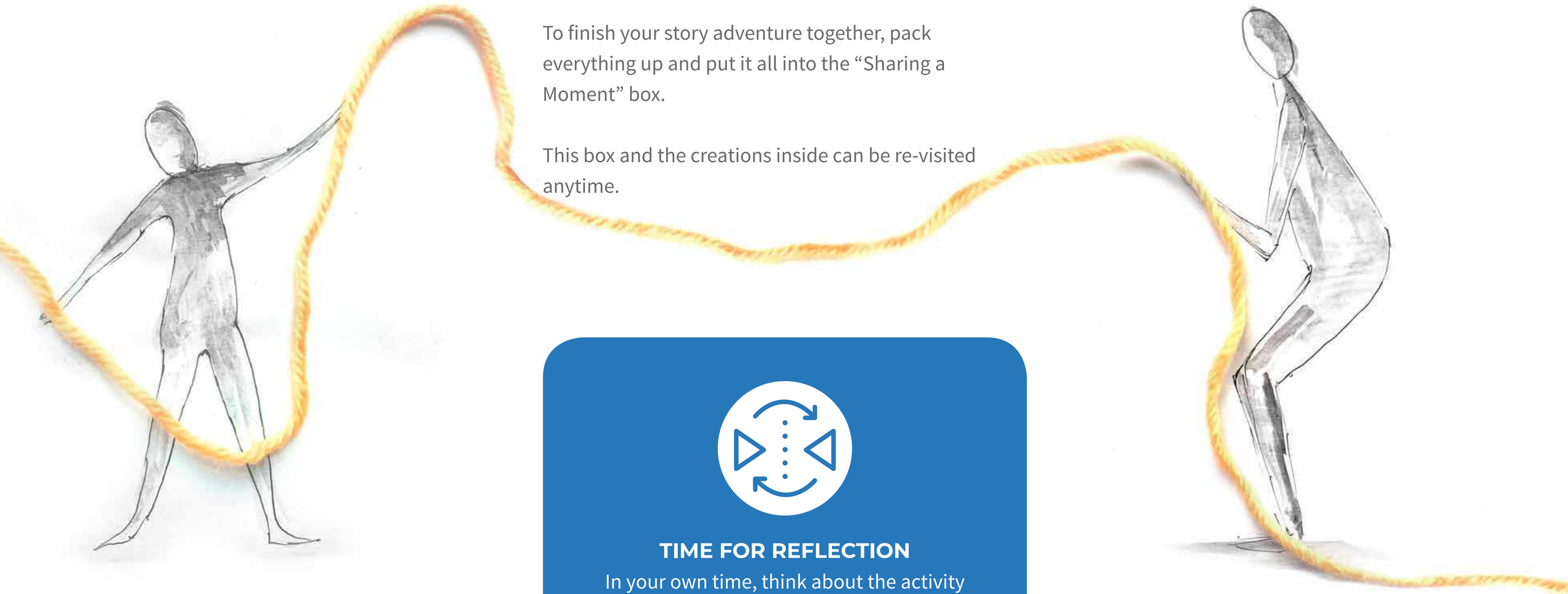
As authors, now sign the story.

AFTER

Congratulate each other on a job well done creating the story.

To finish your story adventure together, pack everything up and put it all into the “Sharing a Moment” box.

This box and the creations inside can be re-visited anytime.



TIME FOR REFLECTION

In your own time, think about the activity you completed together.

See Reflection time in Adventure 1.

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SHARING A MOMENT
ADVENTURE 3
CREATING A CHARACTER STORY IN A POEM

BEFORE

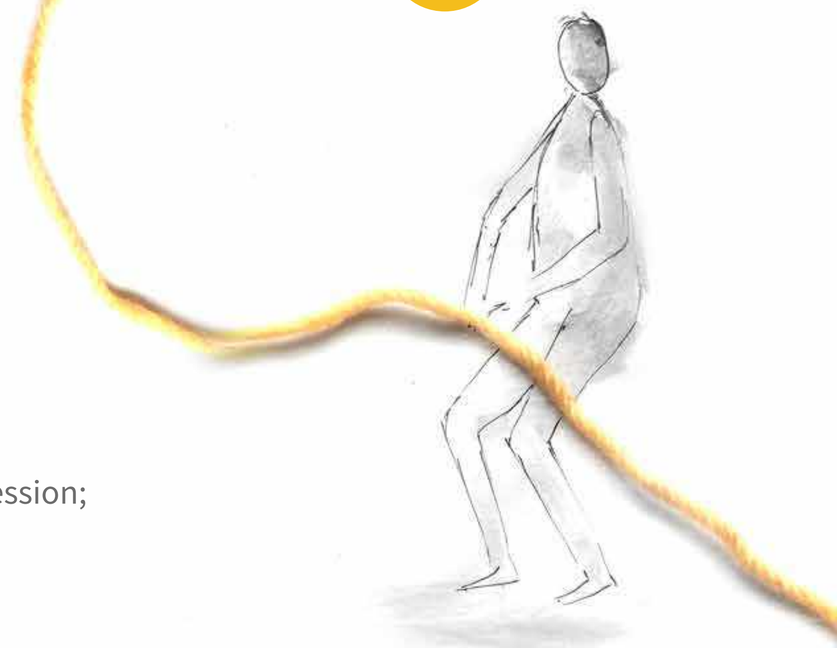
Setting up Tips:
Preparation is key - Storing all you need in a "Sharing a Moment" box is recommended.

1



Choose a relaxed setting e.g. at a kitchen table, coffee table etc. where you and your loved one feel comfortable and where materials can be put on a table.

3



2

HAVE YOUR MATERIALS SOURCED AND READY IN ADVANCE:

- "Sharing a Moment" Box;
- Balloon;
- Pens;
- Note Paper;
- Postcards and pictures from previous activity session;
- Picture Story from previous activity session.

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IN THE MOMENT

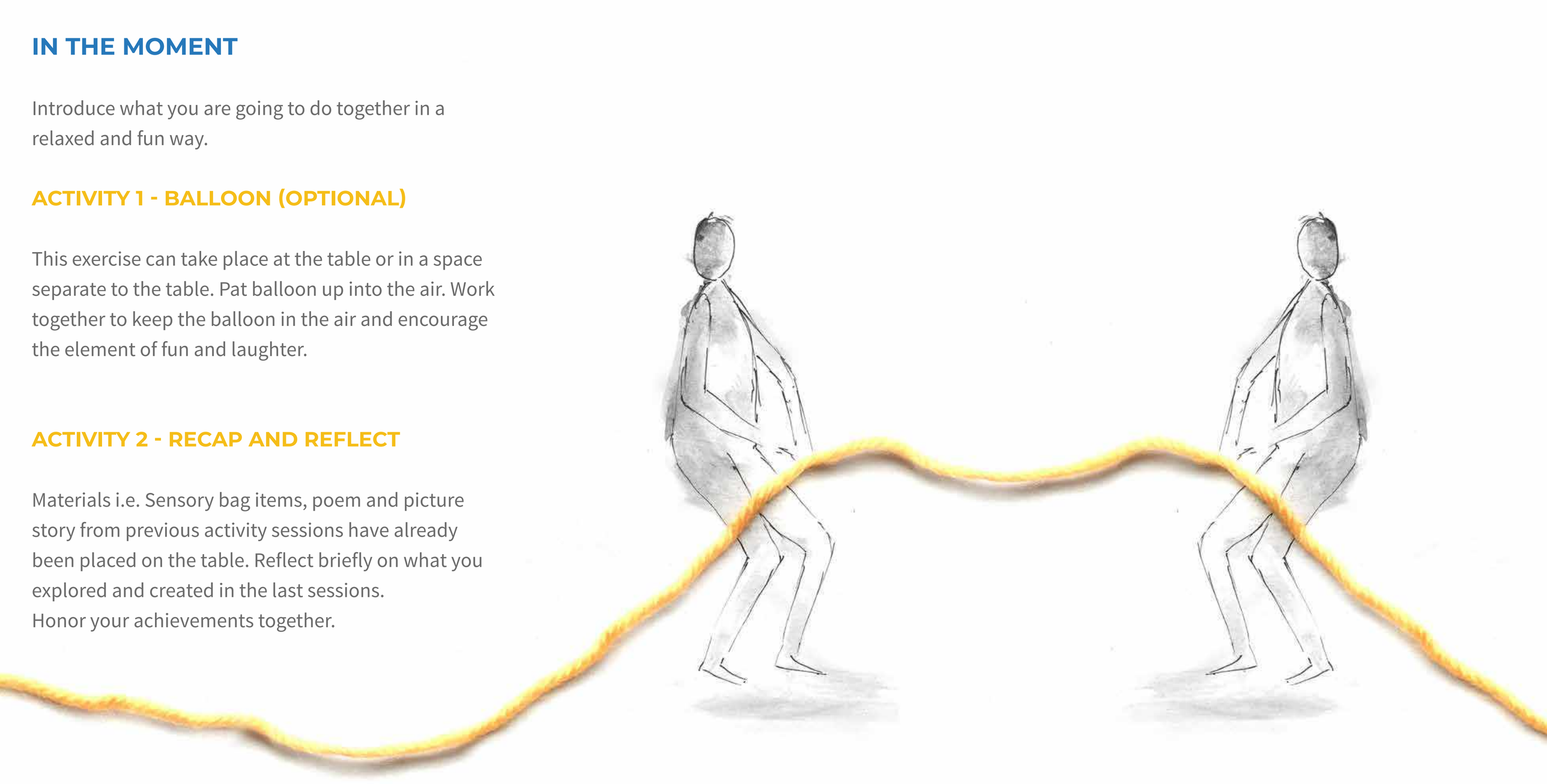
Introduce what you are going to do together in a relaxed and fun way.

ACTIVITY 1 - BALLOON (OPTIONAL)

This exercise can take place at the table or in a space separate to the table. Pat balloon up into the air. Work together to keep the balloon in the air and encourage the element of fun and laughter.

ACTIVITY 2 - RECAP AND REFLECT

Materials i.e. Sensory bag items, poem and picture story from previous activity sessions have already been placed on the table. Reflect briefly on what you explored and created in the last sessions.
Honor your achievements together.



ACTIVITY 3 - HAND RHYTHM CLAP EXERCISE

Remember, this is a fun activity; it's not about getting it right. Mistakes are encouraged and celebrated.

1. Pat the table in turn with both hands i.e. Start- Left hand- pat table, right hand- pat table.
2. Now, ask the person with dementia to repeat the short sequence - Left hand- pat table, right hand- pat table.
3. Repeat the activity, asking the person with dementia to go first and you copy.
4. Take turns over and over so that you and the person with dementia are copying and creating pat rhythms together.
5. Repeat the above, adding in claps i.e. Pat pat pat, clap clap, pat.
6. Take turns to lead and follow as before.

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ACTIVITY 4 – CALL AND RESPONSE RHYME

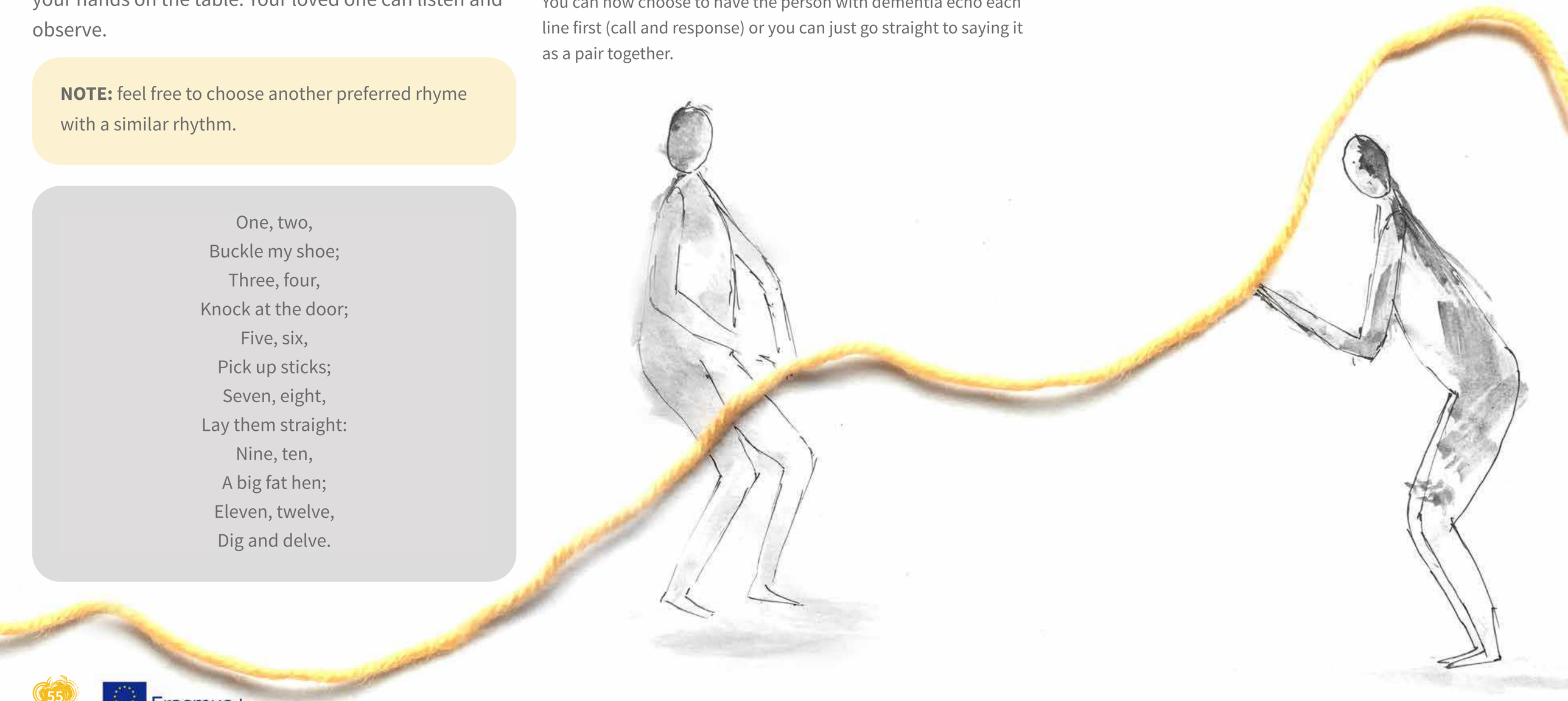
Now say the following well-known rhyme, as you pat your hands on the table. Your loved one can listen and observe.

NOTE: feel free to choose another preferred rhyme with a similar rhythm.

One, two,
Buckle my shoe;
Three, four,
Knock at the door;
Five, six,
Pick up sticks;
Seven, eight,
Lay them straight:
Nine, ten,
A big fat hen;
Eleven, twelve,
Dig and delve.

Now, say the rhyme again and have fun incorporating actions, clapping, pats etc. encouraging the person with dementia to copy.

You can now choose to have the person with dementia echo each line first (call and response) or you can just go straight to saying it as a pair together.



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ACTIVITY 5 - CALL AND RESPONSE POEM

Now read the following poem to the person with dementia once.

“The Glass Eye” by Patricia A Stephens

The Joke was very funny
She laughed a lot of tears
When suddenly her eye fell out
And landed in her beer

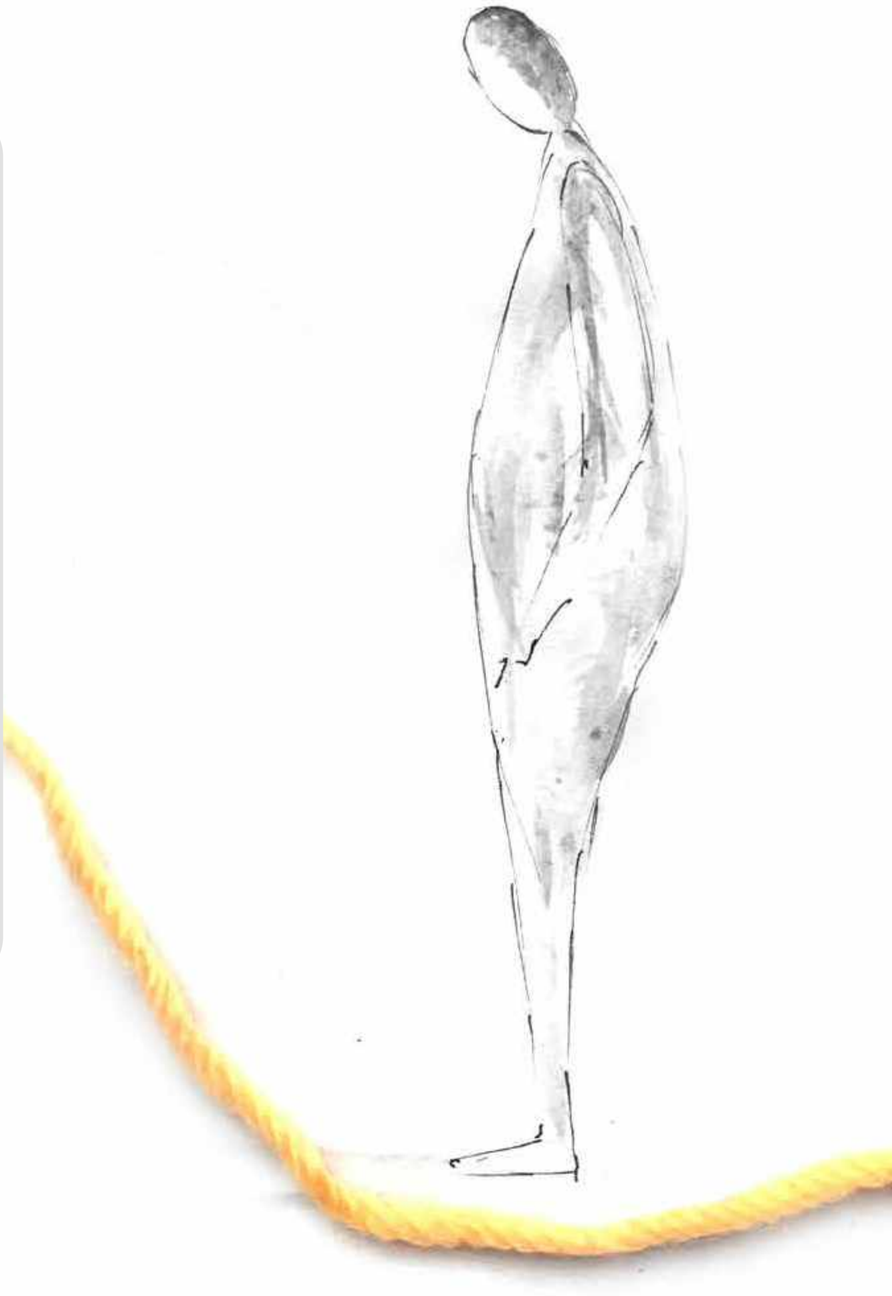
She fished around
with her pudding spoon
But it just stared back
Through the beery gloom

She tried again
with her fountain pen
but she only saw it
Now and then

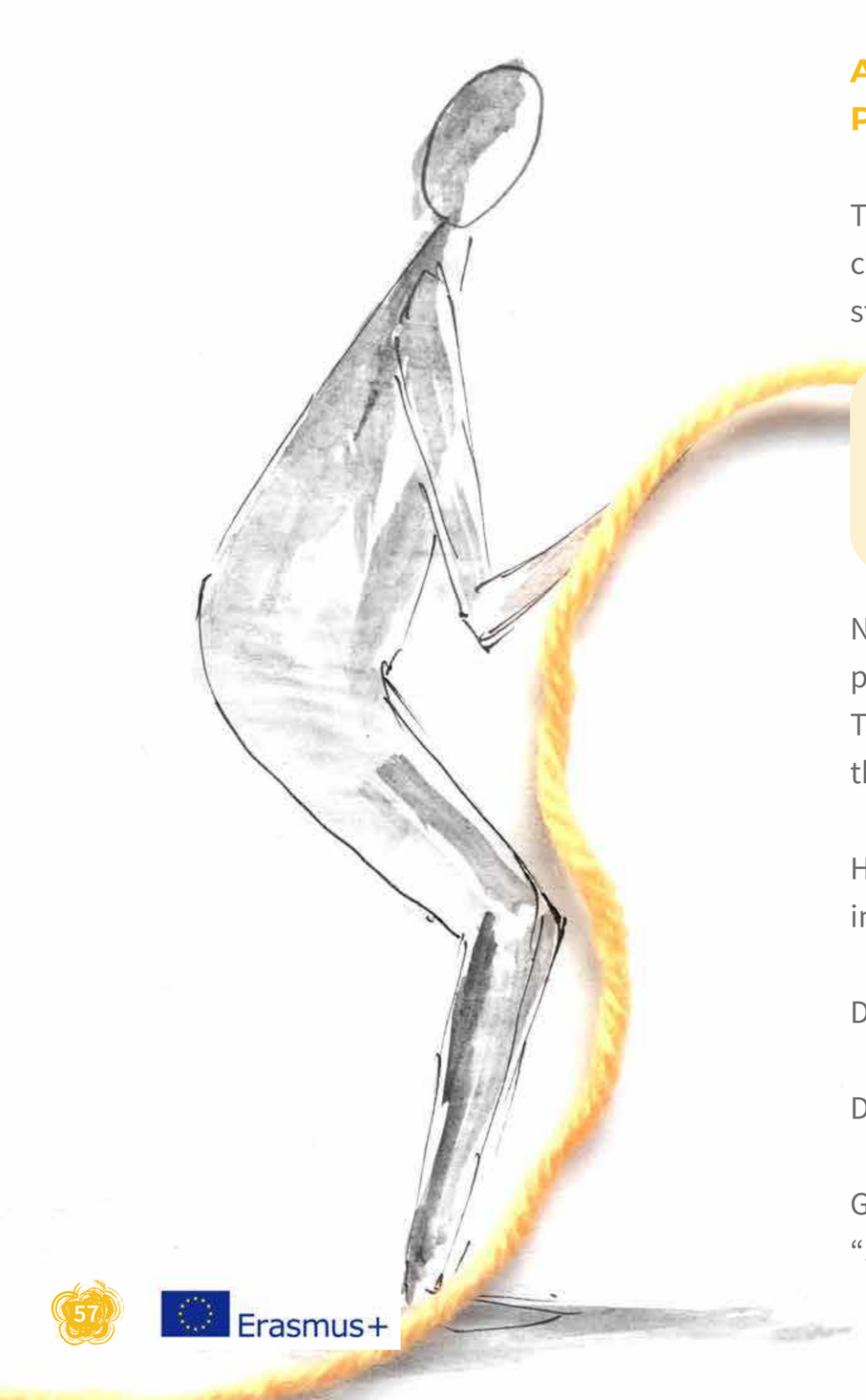
What to do
She tried to decide
Pondered and pondered
Sighed and sighed

In a fit of madness
She downed her drink
Swallowed her eye
With not even a blink

I believe she’s still waiting
It’s playing hide and seek
So she’s had to buy another eye
To see her through the week.



Now read each line of the poem again encouraging the person with dementia to chant each line back.
(Call and Response)
This can be repeated, adding actions, claps, expressions etc.



ACTIVITY 6 – CREATING A CHARACTER POEM

The character poem will be based on one of the characters that you created together in the picture story in “Sharing a Moment: Adventure 2”.

NOTE: The poem can be something funny or silly, similar to the poem they have just recited. There is a theme of mischief.

Now read and remind the person with dementia of the picture story you previously created.
Together you will now create a poem about something that happens to a character from your picture story.

Have a general discussion first about the event or incident that happens in the picture story.

Decide the event.

Decide the character’s name.

Give a title to the poem based on name and event e.g. “Scarlet - The day she fell into the pigsty”.

Now use the following prompts to write the character poem together:

- Describe the day;
- Introduce and describe physical appearance of the character (e.g. red hair), yellow dress;
- Describe the personality of the character (e.g. Kind, funny);
- Describe feelings of the character;
- What happens (e.g. She fell into the pigsty);
- What happened after;
- The end.

NOTE: Rhythm is encouraged but is not a necessity in writing the poem.

Read the poem out, line by line, encouraging the person with dementia to chant back the lines as before.

As authors, now sign the poem.

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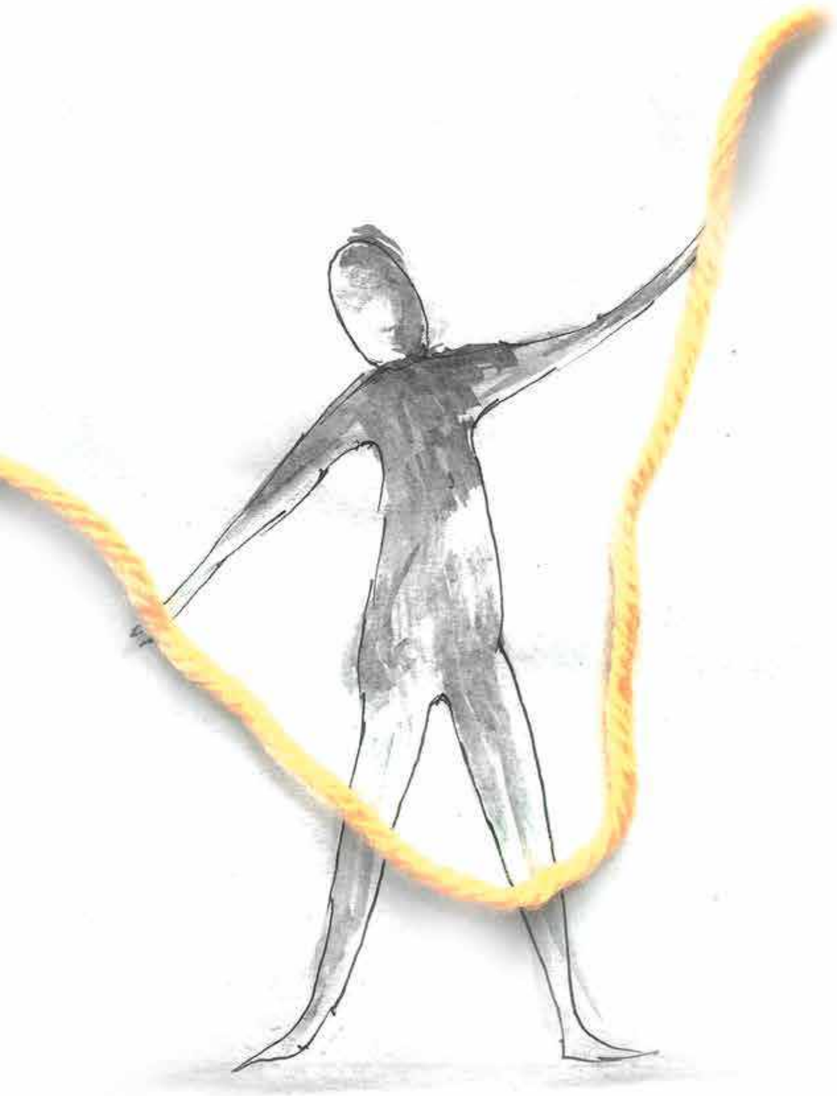
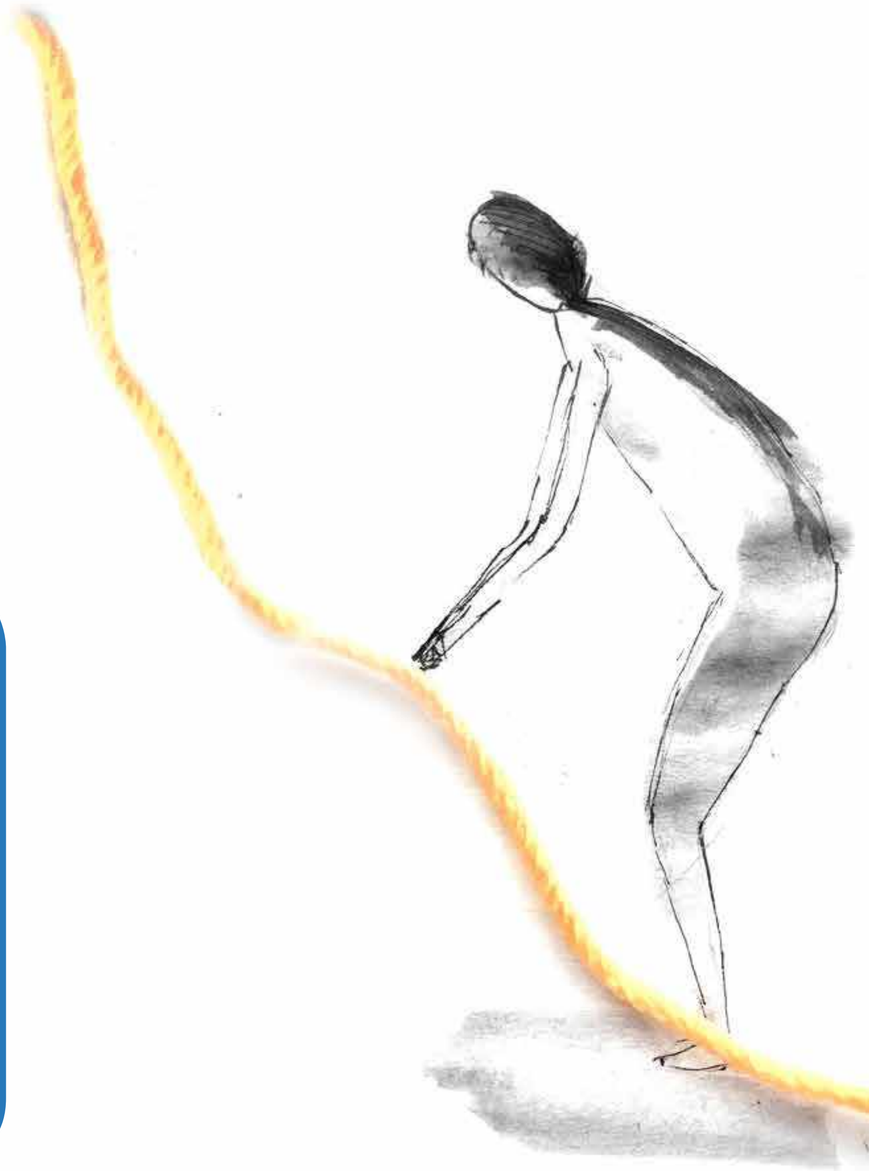


AFTER

Congratulate each other on a job well done creating the poem.

To finish your story adventure together, pack everything up and put it all into the “Sharing a Moment” box.

This box and the creations inside can be re-visited anytime.



TIME FOR REFLECTION

In your own time, think about the activity you completed together.

See Reflection time in Adventure 1.

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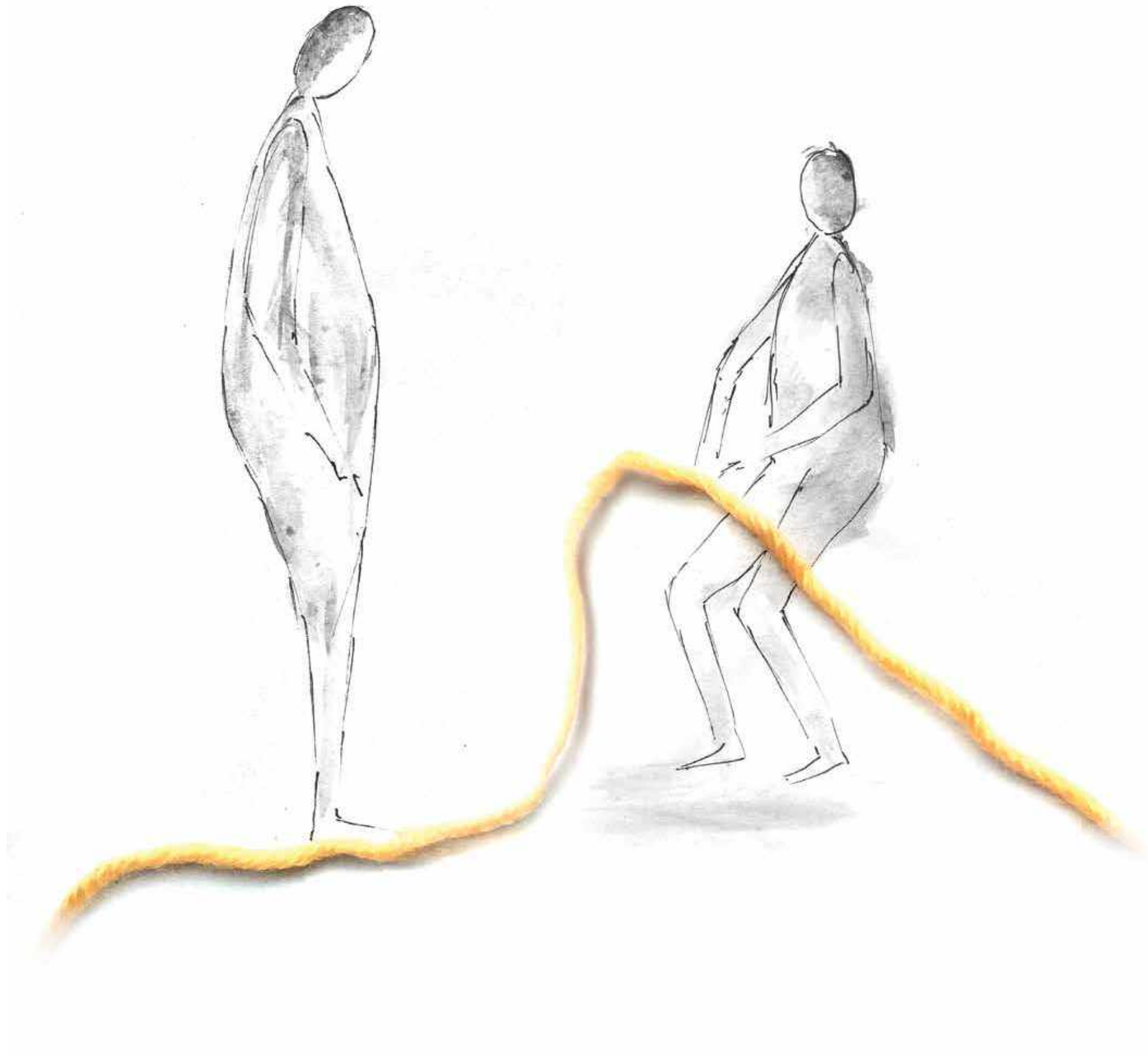
WHAT IS **ALTERNATIVE COMMUNICATION METHODS?**

Alternative communication methods can help you in your caring and supportive role, by simplifying oral or written forms of communication, usually by using visual cues which allow people with communication impairments to increase their participation in desired activities and create opportunities for social interaction through various models of communication.

Adventure 4: Life Story Book
Adventure 5: Communication wallet
Adventure 6: Communication boards
Adventure 7: Writing letters in the air



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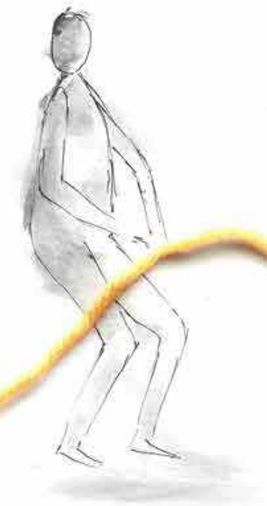
ALTERNATIVE COMMUNICATION METHODS ADVENTURE 4: LIFE STORY BOOK

BEFORE

Setting up Tips:
Preparation is key

1



Choose a relaxed setting e.g. at a kitchen table, coffee table etc. where you and your loved one feel comfortable and where materials can be put on a table.

3

2

HAVE YOUR MATERIALS SOURCED AND READY IN ADVANCE:

- A large book with empty pages to place the photos and to write the descriptions on it;
- Glue or sellotape to stick the pictures in the Life Story Book;
- Photos of your loved one, their friends and family;
- Photos from the person's life events and timelines. This could be pictures from holidays, birthdays;
- Pens/ biros.

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IN THE MOMENT

Introduce what you are going to do together in a relaxed and fun way.

ACTIVITY 1 - SELECTING PICTURES

This exercise can take place at the table or in a space separate to the table.
Select the photos you want to include (one per page).

Go through all photos with your loved one and try to organize the photos in a chronological order.

You will need to caption every page; discuss with the loved one the context in which each photo was taken and what would be the most appropriate caption for each picture.

NOTES:

• Use extra-large photos of persons' faces; it will help your loved one to see clearly the individual in the photo and to recognize him/her easier;

• Use photos that tell a story about the person with dementia (e.g. if the individual was a policeman you could use a picture where he wears his uniform);

• Don't use photos of deceased people; it may upset your loved one as they might not remember that the person has died and might re-live the sad moment.

ACTIVITY 2 - CREATING LIFE STORY BOOK

Glue the photos in the book and write a short description near each photo.

Leave enough space near each picture in order to write a short description.

Refer to the individual's name in the photo.

In case the person in the photo does something (e.g. painting), you also need to refer to the activity he does **Example: 'Here is your sister Ann and she is painting.'**.

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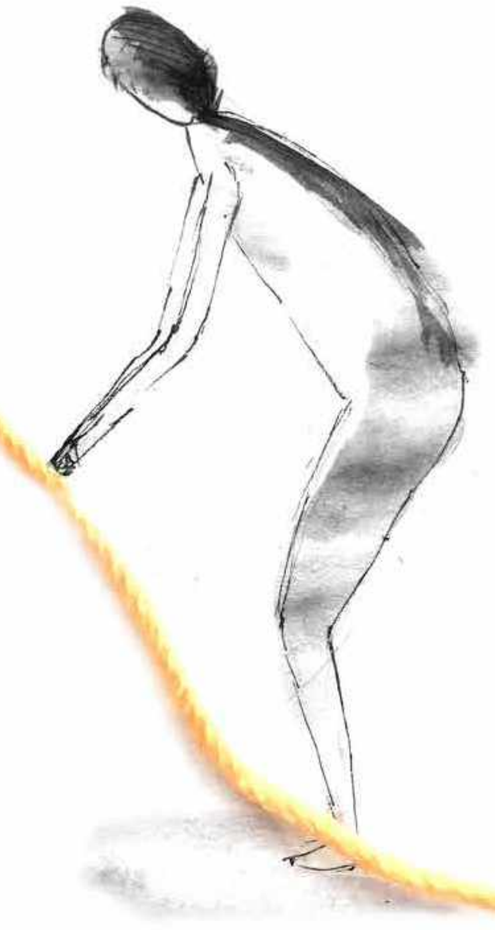
AFTER

Congratulate each other on a job well done creating a life story book.





TIME FOR REFLECTION

In your own time, think about the activity you completed together.

See Reflection time in Adventure 1.

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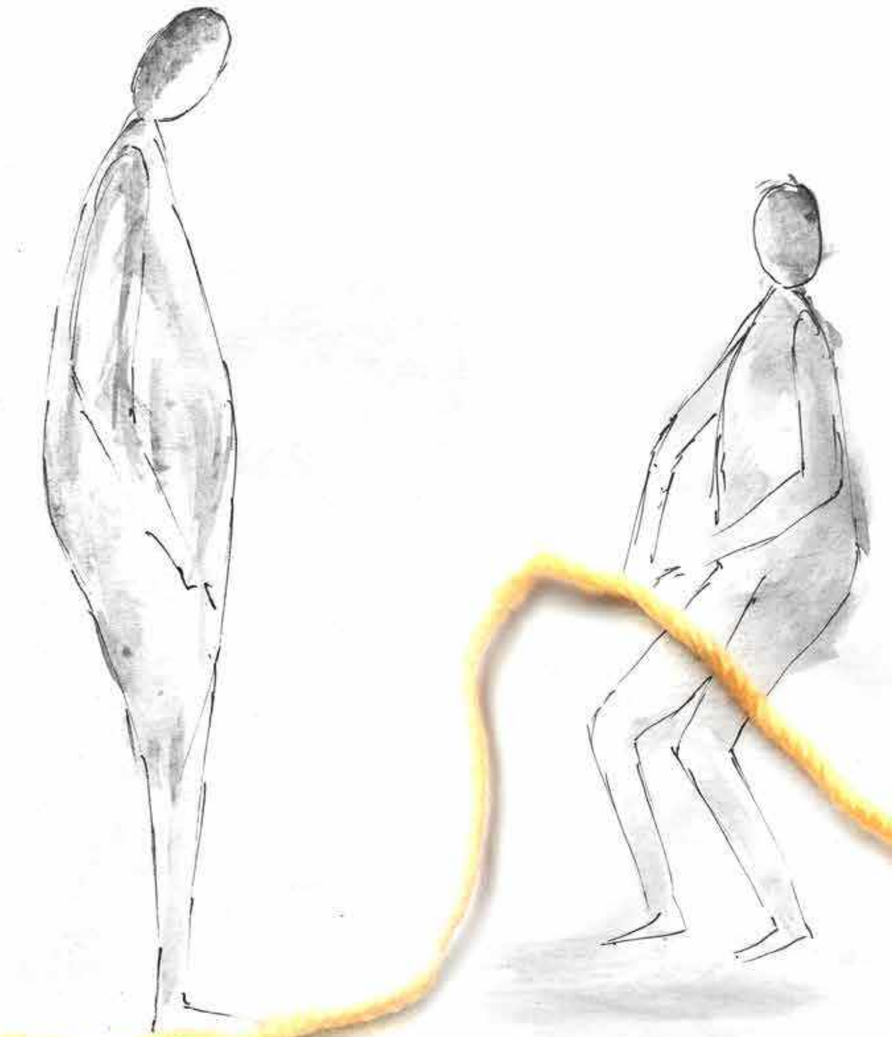
FAMILY MEMBER'S EXPERIENCE WITH **THE ACTIVITIES**

"It's something I have wanted to do for months. Amazing number of photos and memories. We have found it interesting and fun so far (...); have got about 80 photos, some words put together, we have had some good discussion and fun putting it together so far (...). I am really looking forward to completing it because I hope it will be a good interest for my wife. Also thinking about memorabilia items for discussion at the same time, I got some ideas."

Tip for family members:

Take your time with this Adventure. You don't have to finish in one session and as long as it is fun you can select pictures over several sessions.



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ALTERNATIVE COMMUNICATION METHODS ADVENTURE 5: **COMMUNICATION WALLET**

BEFORE

Setting up Tips:
Preparation is key

1

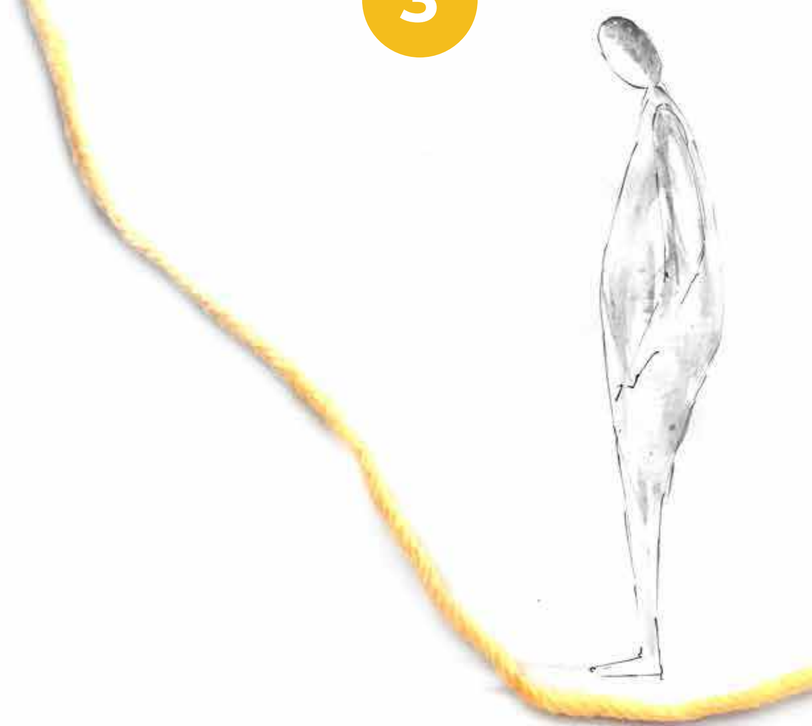
2

HAVE YOUR MATERIALS SOURCED AND READY IN ADVANCE:

- Paper and pen (or computer with printer);
- Index cards;
- Family photos or other pictures (as needed);
- Plastic wallet or small portfolio;
- Plastic dividers with color-coded tabs.

Choose a relaxed setting e.g. at a kitchen table, coffee table etc. where you and your loved one feel comfortable and where materials can be put on a table.

3



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IN THE MOMENT

Introduce what you are going to do together in a relaxed and fun way.

ACTIVITY 1

First, identify the top 3 topics of conversation where your loved one is experiencing significant memory difficulties.

Example:

MY DAY | **MY LIFE** | **MYSELF**

Create a master list of facts of personal relevance specific to each of these 3 areas.

Example: for the topic “My day” these could be:
When do they wake up?
What do they do next?
What do they like to have for breakfast?

ACTIVITY 2

Choose the top 10 relevant facts for each topic of difficulty and create 10 simple, declarative sentences to represent these facts.

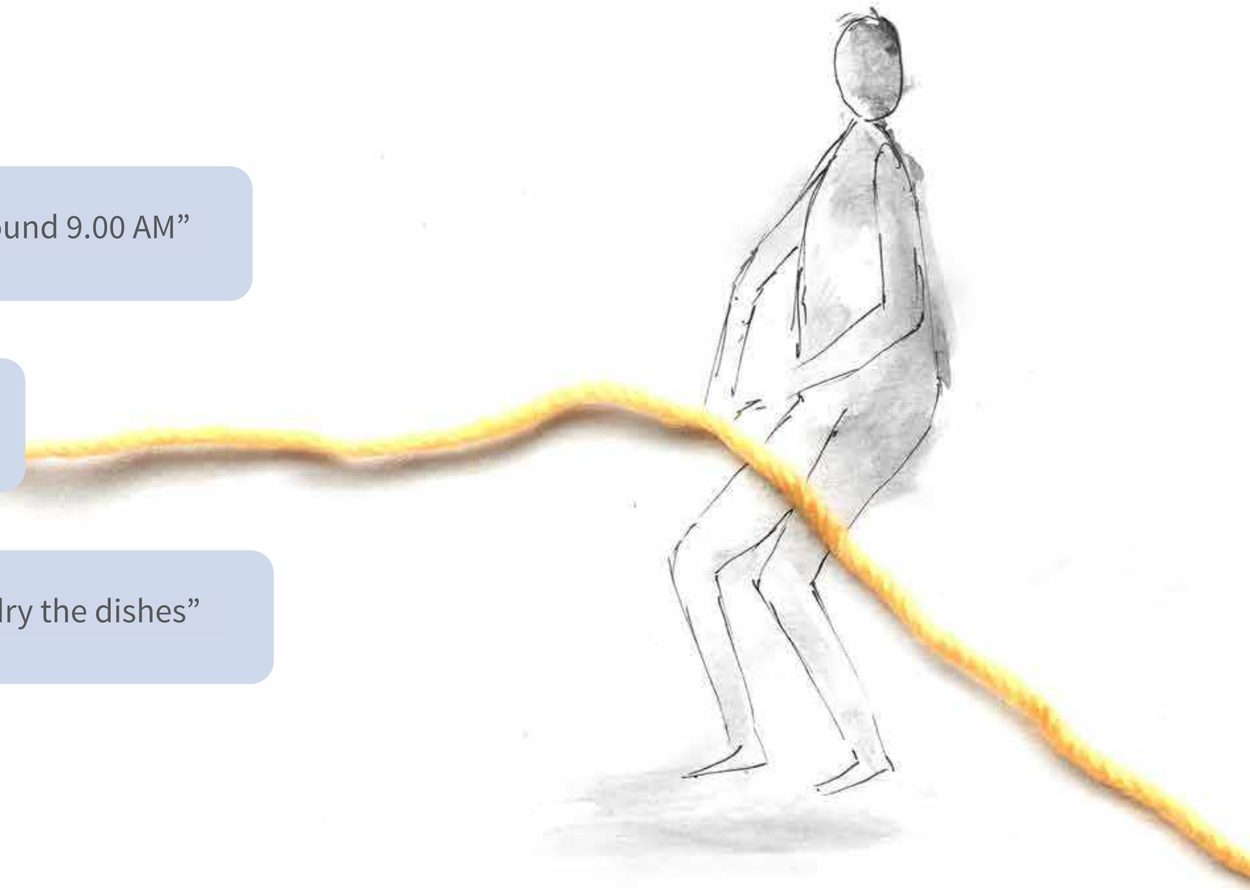
Example:
For the topic “My day”

1. “I get up and dressed around 9.00 AM”

2. “Then I eat breakfast”

3. “After meals I wash and dry the dishes”

4. etc



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ACTIVITY 3

Choose photos from family photo albums to pair with each of the 10 simple sentences.

For topics that are difficult to represent with a family photo (like breakfast or doctor, for instance), drawings or clipart pictures can be used instead.



I get up and dressed around 9.00 AM



Then I eat breakfast



After meals I wash and dry the dishes

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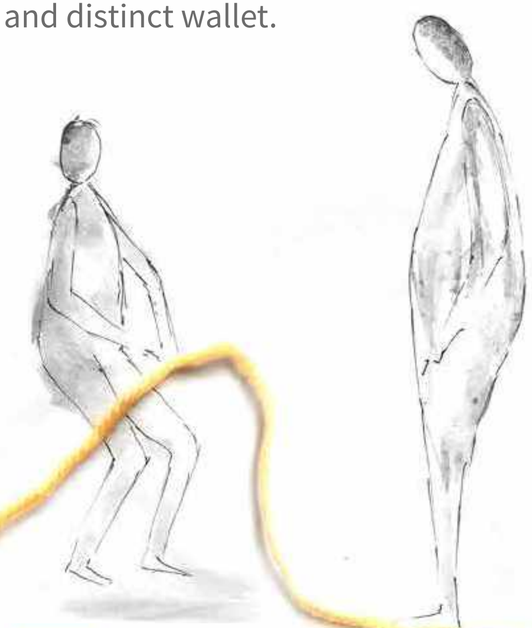
ACTIVITY 4

Assemble the wallet

- Arrange the sentences and pictures onto index cards.
- Insert into a plastic wallet or small portfolio.
- Use plastic dividers with color-coded tabs to separate each of the three topics.
- In the case of someone who can't manage a tab system, each topic can have its own separate and distinct wallet.



ACTIVITY 5

Support your partner how to use the wallet

- Start by saying: "Now we are going to practice having a conversation. This wallet has pictures and sentences that you can look at to help you remember what you want to say. Open it to the first page. Let's talk about your day. Tell me about your day." (The underlined phrase can be substituted with one of the topics you have chosen for your wallet).
- Praise your partner for accurately reading the phrases and for making accurate elaborations about the stimulus sentences and expand on them if possible.
- If the communication breaks down after this, prompt them to read the next related sentence to continue to topic of conversation (say "Wait, read this.").
- If they are still unable to contribute to the conversation, read the next sentence aloud to them, encouraging them to participate and read along.
- Continue to practice this until your loved one is comfortable using the wallet to read all 10 sentences for each of the 3 topics in response to a request for conversation.

NOTES:

• Encourage your loved one to use the communication wallet often, with as many conversational partners as possible;

• Be sure to consider the other communication techniques you have learned to support your communication even when using the wallet;

• If you like the idea and it's working for you, there's no need to stop at 3 topics. Feel free to make more and involve family and friends to help out.

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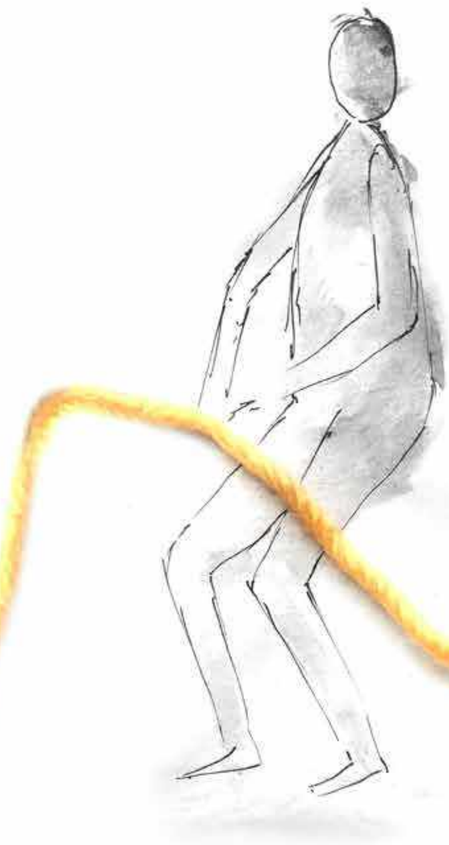
AFTER

Congratulate each other on a job well done creating a communication wallet.

TIME FOR REFLECTION

In your own time, think about the activity you completed together.

See Reflection time in Adventure 1.



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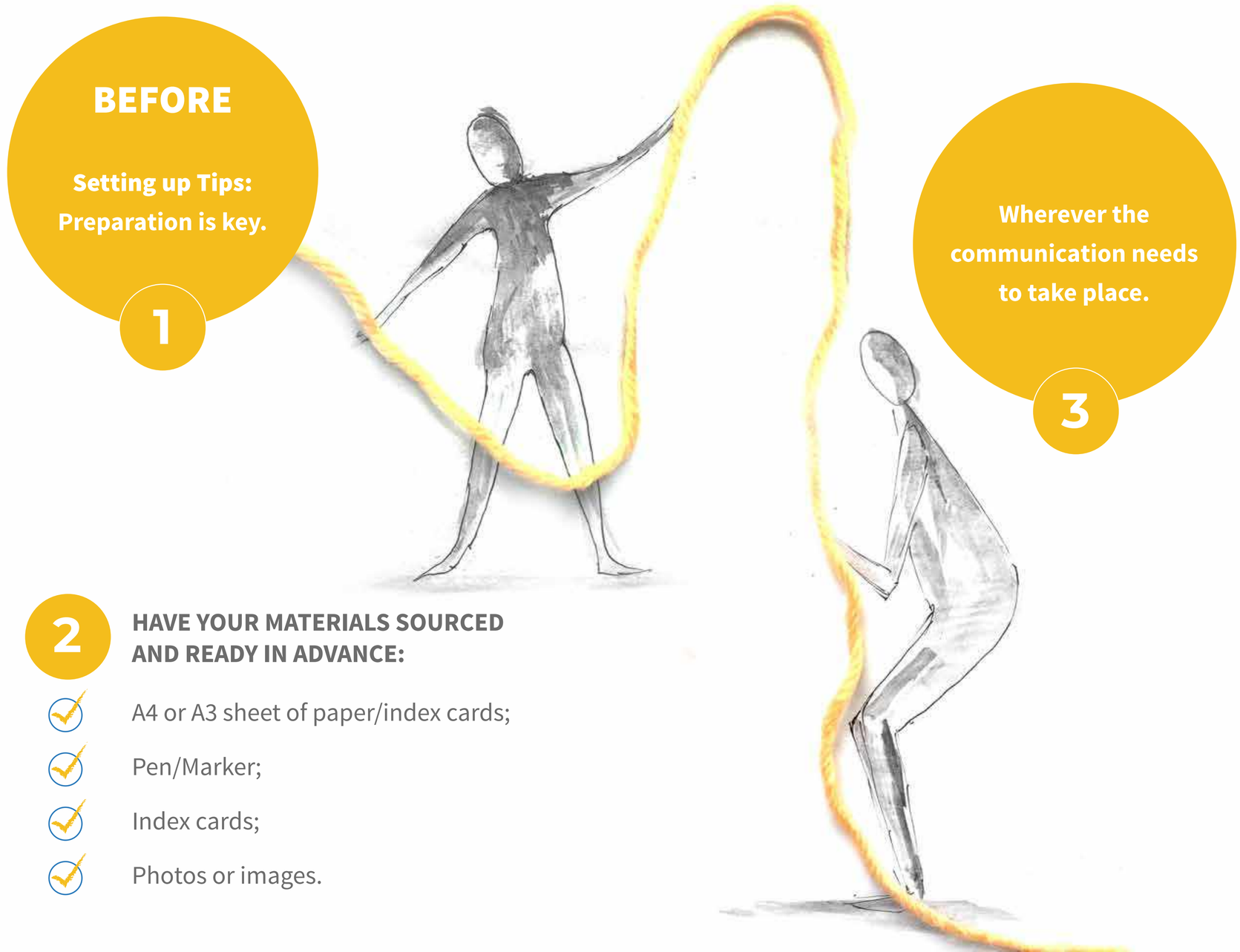
ALTERNATIVE COMMUNICATION METHODS ADVENTURE 6: COMMUNICATION BOARDS



BEFORE

Setting up Tips:
Preparation is key.

1

Wherever the communication needs to take place.

3

2

HAVE YOUR MATERIALS SOURCED AND READY IN ADVANCE:

- A4 or A3 sheet of paper/index cards;
- Pen/Marker;
- Index cards;
- Photos or images.

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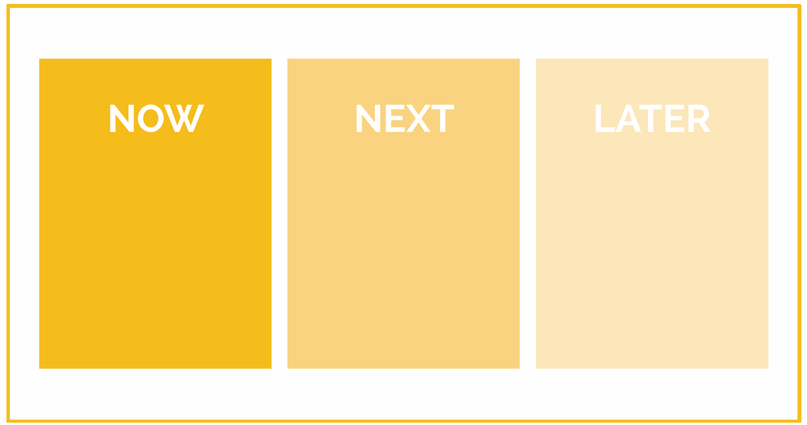
IN THE MOMENT

ACTIVITY 1

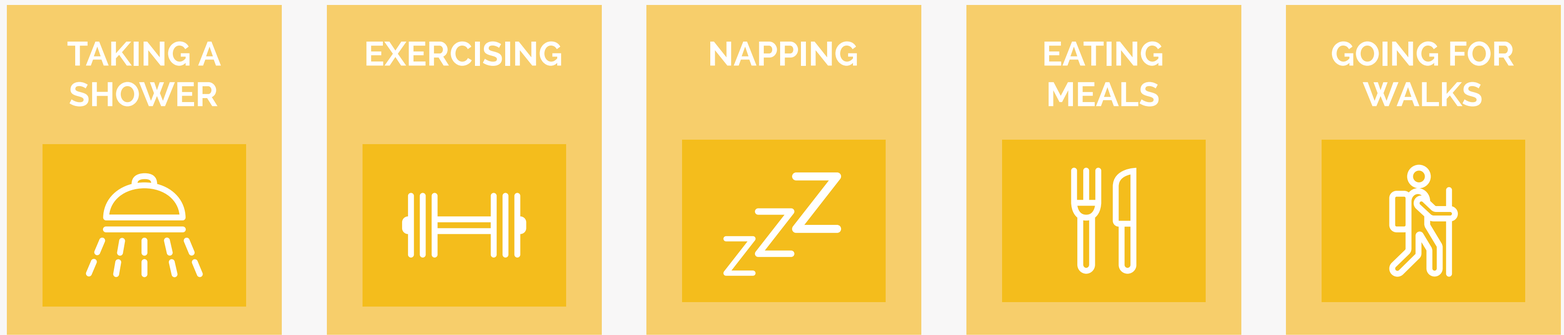
On an A3 sheet of paper/card draw boxes labelled ”Now”, “Next” and “Later” OR “Now” and “Not Now”.



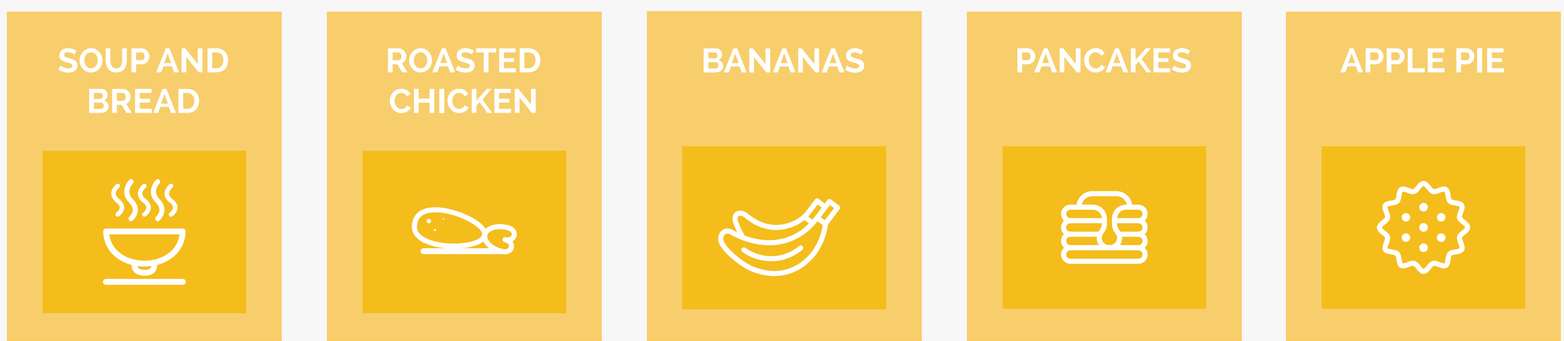
ACTIVITY 2

Create several visual cue cards with both written word (in bold, large, and easy to read font) and a picture.

CATEGORY: DAILY LIVING



CATEGORY: FOOD



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ACTIVITY 3

Use the communication board

Ask the person what they would like to do now,
Example: Ask “Would you like to wash now or later?” and show the visual cue card for “Taking a shower” while asking the question;

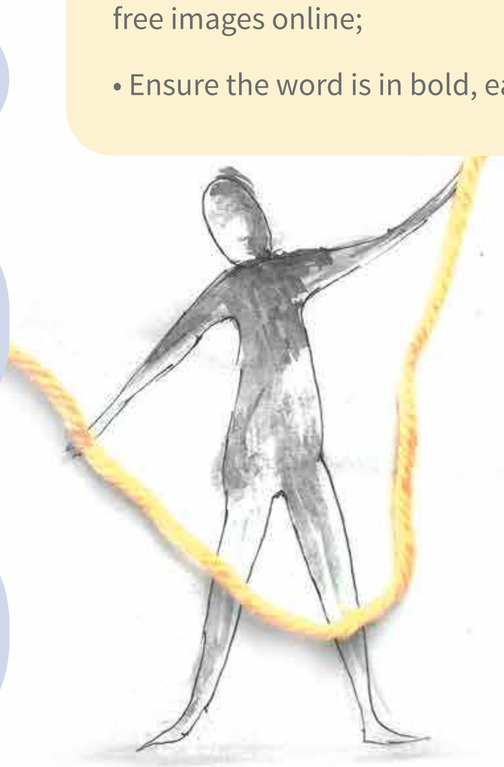
Let them answer or point if they would like to do that “Now”, “Next” or “Later”

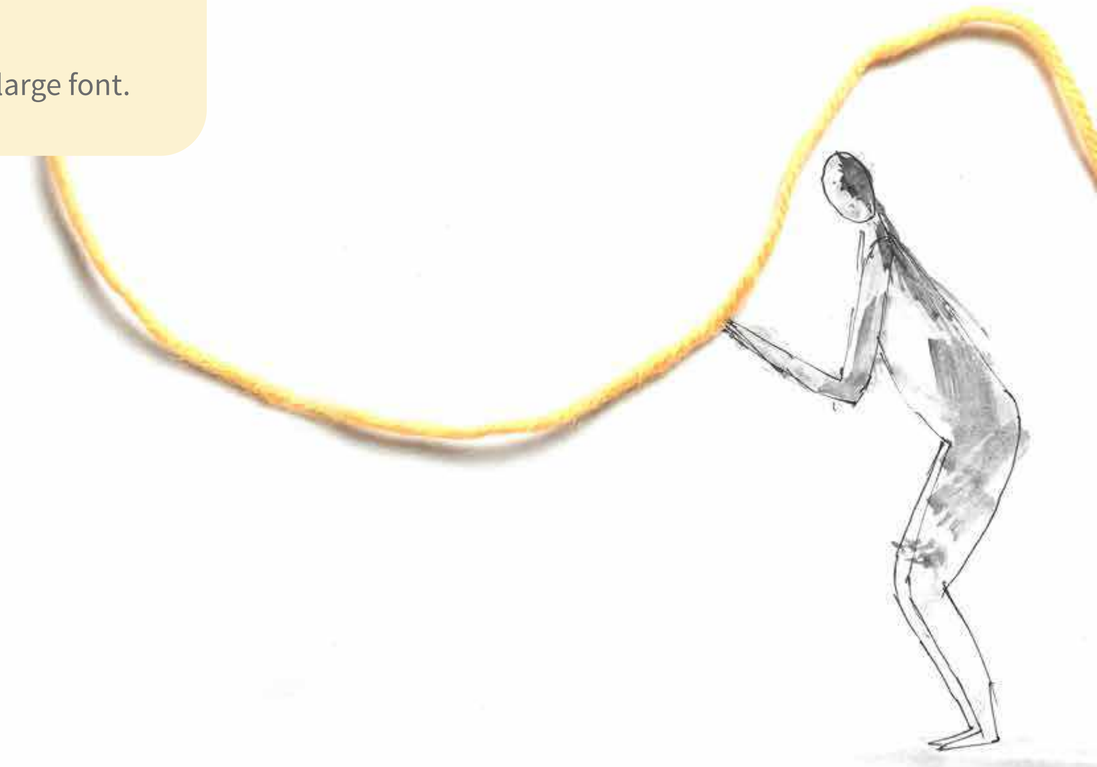
If the person said they would like to wash next or later, ask them what they would like to do now, for example “Would you like to go for a walk now?”

If the person said they would like to wash now, ask them what they would like to do next and later, for example “Would you like to go for a walk next?”

NOTES:

- The cue cards could either be designed on a computer and printed, or simply written on plain or coloured paper;
- You can use photos, draw pictures, or download free images online;
- Ensure the word is in bold, easy to read large font.





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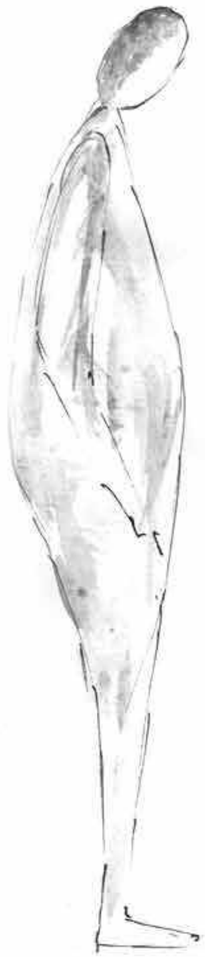


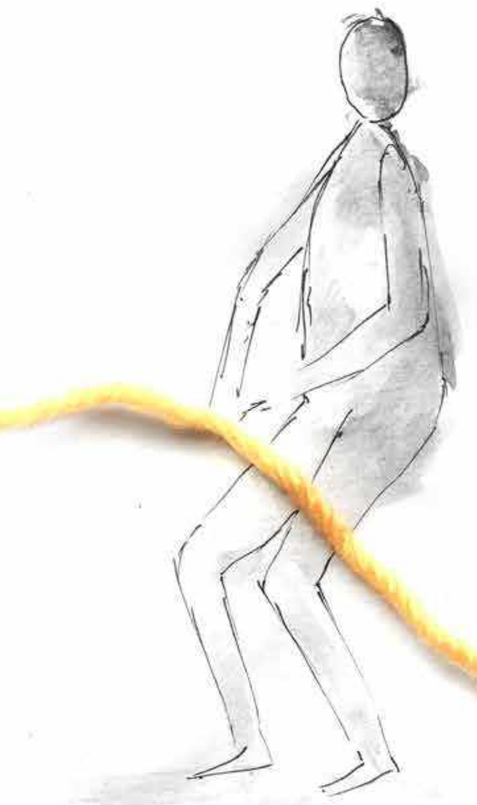
AFTER

Congratulate each other on a job well done creating a communication board.

TIME FOR REFLECTION

In your own time, think about the activity you completed together.

See Reflection time in Adventure 1.



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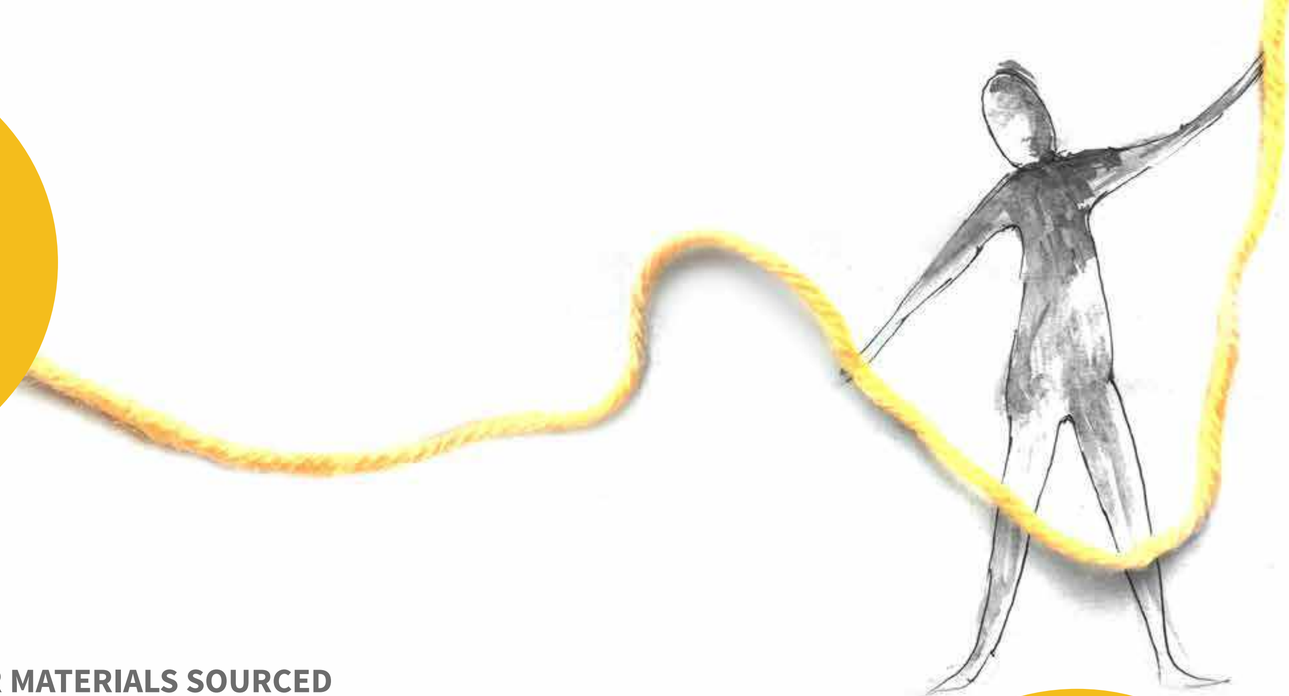
ALTERNATIVE COMMUNICATION METHODS ADVENTURE 7: **WRITING LETTERS IN THE AIR**



BEFORE

Setting up Tips:
Preparation is key.

1

2 **HAVE YOUR MATERIALS SOURCED AND READY IN ADVANCE:**

- Flash cards on which the words you want to train are written;
- Images of foods eaten at breakfast;
- Prepare flash cards on which the words of the breakfast items are written, such as:

TOAST	EGGS	BACON	JUICE

Prepare images with items usually offered for breakfast, as in the right image:



Wherever the communication needs to take place.

3

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IN THE MOMENT

Explain that the aim of the activity is for the person with dementia to practice expressing their food preferences, for example for breakfast.

ACTIVITY 1

Say the word you wish to train while “underlining” it, using two fingers of your right hand to trace the arrow that runs from left to right underneath the word on each flash card, and in the same time having the real food item – toast, in front of the person and showing it to her/him.

ACTIVITY 2

Spell the word out loud, using two fingers of your writing hand to “air-write” each letter as you say it.
You will air-write the letters underneath the printed word on the flash card, but do not actually touch the flash card.

ACTIVITY 3

After air-writing the word, say the whole word one more time, again tracing the arrow to “underline” the word from left to right, in the same time showing also the real toast.

ACTIVITY 4

Your loved one will form the letters in the air. You and the person with dementia should both air-write below the word on the flash card so that your fingers don’t block her/his view of the letters.

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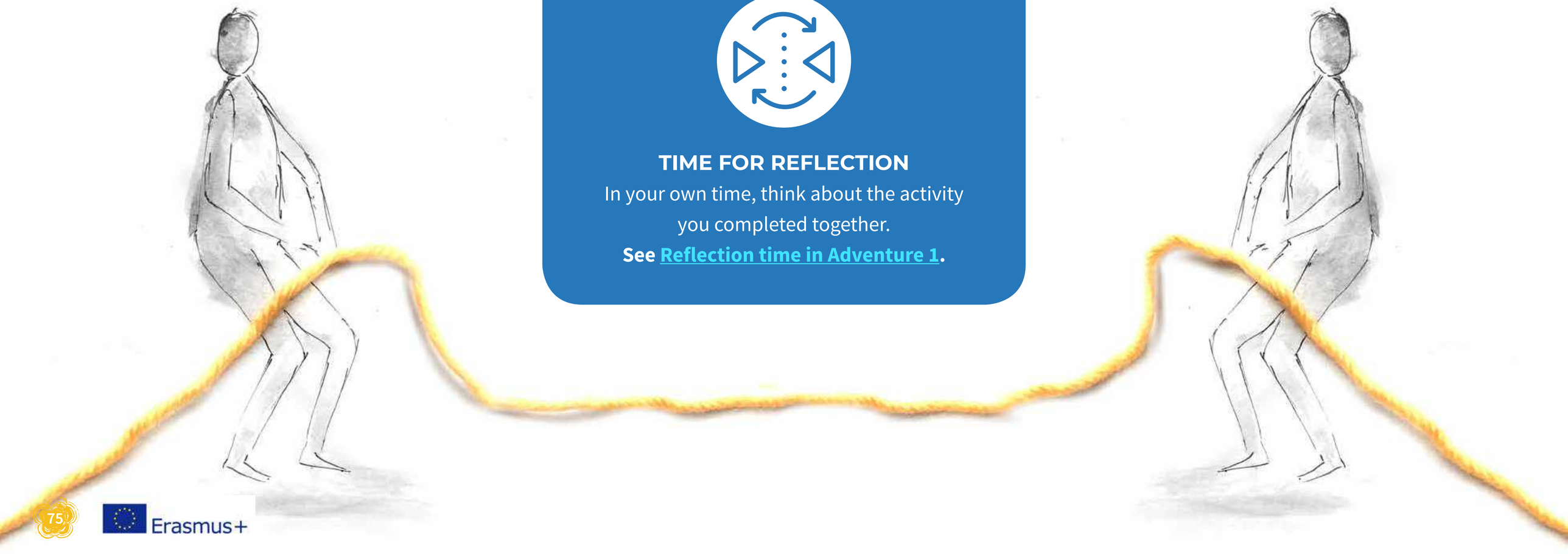
AFTER

Congratulate each other on a job well done in training the person with dementia to write letters in the air.



TIME FOR REFLECTION

In your own time, think about the activity you completed together.

See Reflection time in Adventure 1.

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RESOURCES:

No.	Video resources topic	Link	Source
1	**Memory book**	Click Here	Ohio Council for Cognitive Health
2	**Making a memory book**	Click Here	NIHSeniorHealth.gov
3	**Communication Boards**	Click Here	
4	**Communication boards, Voice My ChoiceTM tool**	Click Here	Daughterly Care

No.	Other resurces topic	Link	Source
1	**Lifes Story Book** The template demonstrates a list of common questions and prompts which could be used to produce a Life Story Book. Generally, it is recommended to use positive information in the book eluding any sad situations that might distress an individual.	Click Here	Dementia UK
2	**Making a memory book**	Click Here	Best Alzheimer's Product
3	**Cue cards for Dementia Care**	Click Here	Golden Carers
4	**Communication wallet**	Click Here	
5	**Refusal to wash**	Click Here	Alzheimer's Society
6	**Bathing**	Click Here	Alzheimer's Association
7	**Tip Sheet for Bathing**	Click Here	Family Caregiver Alliance
8	**18 tips for helping someone with dementia shower or bathe**	Click Here	Verywell Health
9	**Repetitive behaviours**	Click Here	Alzheimer's Society
10	**Repetition**	Click Here	Alzheimer's Association
11	**Wandering**	Click Here	Alzheimer's Association
12	**Hallucinations**	Click Here	Alzheimer's Association
13	**Coping with dementia behaviour changes**	Click Here	NHS

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