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Alzheimer's patients Interaction through Digital and Arts (AIDA)

Project n.2021-1-IT02-KA220-ADU-000027077

PR1-A5- AIDA Methodology: Production of the Training Toolkit

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General Description

In recent years, as the number of people suffering from Alzheimer's Disease (AD) has increased and there has been a growing interest in rehabilitation methods that can slow down and alleviate cognitive decline. AD is a complex pathology with a wide array of contributing factors, ranging from genetic and environmental variables to previous physical and psychological conditions. AD affects almost 50 million people in the world and with a new case of AD occurring somewhere globally every 3.2 s (World Alzheimer Report, 2015; 2018). Early cognitive symptoms typically involve progressive memory loss, reduced visuo-spatial attention and topographical disorientation (Kálmán et al., 1995; Smits et al., 2012; Yew et al., 2013). Then, the disease progression spreads on a large scale (Weintraub et al., 2012), causing anterograde amnesia and significant impairment in the realm of executive functions (Perry et al., 2000; Stopford et al., 2012). AD cognitive deficits heavily affect the quality of life of both patients and caregivers while preserved autonomy in performing instrumental activities of daily living and interventions to improve cognitive functions seem to directly improve quality of life scores (Cummings et al., 1998; Bell et al., 2001; Woods et al., 2006). To this date no pharmacological treatment exists to counter this neurodegenerative disease. For this reason, is very important to look into ways and methods to slow the course of AD and to improve the quality of life and health of people affected. Moreover, in the last two years the global pandemic due to Covid-19 weighted heavily on every country national health system and on the psychological status of particularly at-risk people. This emergency added to previous difficulties encountered by caregivers and people with AD (PWAD), resulting in worse overall outcomes for their psychological health.

The aim of rehabilitation strategies is mainly to improve the autonomy of the person suffering from AD. These are rehabilitation programs that aim to establish a new personal, family and social balance; thus, in addition to increasing and preserving as much as possible the autonomy of the person

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affected by Alzheimer's, the workload and stress for the family/caregiver are also reduced.

Recent research demonstrated that older adults who are cognitively impaired are significantly less likely to be socially and cognitively active than older adults without a cognitive impairment (Johnson et al., 2014), and that engaging in meaningful activity in the early stages of dementia can help people to focus on their residual abilities and offset a sense of loss (Genoe and Dupuis, 2014). This also includes art viewing and art making, which have consistently been shown to have multidimensional benefits for people with dementia (Zeilig et al., 2014). As an example of possible benefits, results from empirical studies have indicated positive outcomes in terms of increased subjective psychological wellbeing, a sense of broadening of horizons, and social inclusion (Flatt et al., 2015; Young et al., 2015) from using art-based interventions in dementia care, while other findings demonstrated increase in sustained attention and intellectual engagement (Camic et al., 2014) and stimulation of episodic memories and communication (Eekelaar et al., 2012).

Art and museum-based interventions draw inspiration from the so-called aging paradox (Prakash et al., 2014), according to which the progressive atrophy of prefrontal regions, with consequent decline of cognitive processing, is associated with the enhancement of the preserved emotional ones (Bucks and Radford, 2004; Klein-Koerkamp et al., 2012). The channel of emotion processing becomes, for elderly people, a preferential way to reach and be reached by the external world and a way for rehabilitators to facilitate the compensation of other abilities or scaffold the decaying cognitive ones. Importantly, art appreciation and production seem to be maintained during healthy aging (Kim, 2013; Istvandity, 2017) and there is also evidence that the brain mechanisms and the cognitive processes involved in creative art activities are not irreparably damaged in PWAD (Ehresman, 2013).Taken together, results from literature seems to support that art-based and museum-based interventions are a good way to access and promote preserved abilities and functions in PWAD and that these types of

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interventions could improve the quality of life and well-being in both PWAD and caregivers.

The AIDA project created a novel methodology and procedures from the collection of the different good practices in these three fields and tested the beneficial properties of the created procedures on AD patients and their caregivers across different countries involved in the project. In particular, the AIDA project is divided into three different phases, each one addressing a different combination of digital and artistical tools:

- Art-Exploring: Guided tours in museums and places of historical/naturalistic significance; manipulation of works of art; collective discussions with facilitators and caregivers.
- Art-Making: First-person involvement in creating, digitally or analogically, art in different forms, ranging from painting to photography. Assisted by trained facilitators and guided through shared discussions.
- Personal Gallery: A small session in which participants and caregiver are showed a virtual museum of the project. For those interested, a collection of works from the previous phases will be arranged in the same virtual environment as a "personal museum", in which participantsprivatelyshowcase, assisted by their caregivers and facilitators, work of arts particularly appreciated or made by them.

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Art-Exploring and Art-Making activities

Art-Exploring and Art-Making activities entail the following activities, three of them are chosen by availability by each partner involved:

- *Personal Expression through Mindful Colouring:*
    - A variety of colouring in sheets and art materials is set out on the tables. A range of materials is offered for colouring in such as markers, crayons, or colour pencils. The participant chooses which materials suit their mood in the moment. At the end of the session, each participant is encouraged to say something about their image to the group as a whole. The participants is encouraged to take their personal art work home with them.
- *Creative storytelling using four senses:*
    - Each participant pulls out a random object from a fabric bag and tells a short story. They select an object from the bag based on touch rather than sight. The facilitator encourages the participant to engage with the object uses their senses, sight, sound, smell and touch.As a group-based activity this can increase a feeling of social inclusion in participants.
- *Collaging colours:*
    - The idea of collaging colours is to use bright contrasting colours such as reds, oranges, mustards, purples, pinks, blues and greens to create a picture. Participants are offered a range of coloured paper cut to different sizes and shapes. They can arrange them on a sheet of paper and glue them down. They can then create a picture by drawing or colouring over the collage in markers, pencils or crayons. As a group task, this fosters a sense of self-worth and social connection to the group and gallery.
- *Choose, think, speak:*
    - An exhibit is shown to the people with dementia and with the help of facilitator they will try to develop a story together about the history of the shown object. It is possible to give the option each person to choose one object from the museum and then to develop one common story using all of the chosen objects.Each person with dementia can add something to the story and the facilitator either has to write or draw it on a sheet of paper or on a white board, so that everybody can see how the story is developing. In

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the end, the facilitator can read the story to all people with dementia and acknowledge them as creators of the story.

- *Actor for a day:*
    - The people with dementia will perform a story (they have prepared previously in the activity "Choose, think, speak") as a theatre play and they will also use the objects they have already chosen in the museum for their performance.
- *Music path:*
    - Organize tours in museums for people with dementia that are accompanied with appropriate music. In this way, by hearing music connected to the exhibits in the museums, they are stimulated to talk. The caregivers can ask them questions to help them explain better how they feel. The caregiver can also ask the person with dementia to sing/hum whichever song/melody comes to their mind when they see a specific exhibit, so that he can play it for the patient. They can sing along with the song, or they can be stimulated to talk about what the song and the object brings to their minds.
- *Draw & chat:*
    - Taking inspiration from a painting or an object at the museum, the people with dementia create a story and draw their own sketch and talk with the facilitator about their creation. Alternatively, they describe their story and the facilitator creates the drawing while they discuss the shapes, colour, ideas, emotions related to the story and the drawing.
- *Red riding hood:*
    - Different sounds and background visual stimuli guide people with dementia to adapt different roles. Walking in front of different visual effects and listening to different sounds inspires them to adapt their movement and their role accordingly.
- *Digital Museum Navigation:*
    - Different images from their hometowns or the cities they reside are provided to people with dementia. They are encouraged to discuss the pictures and recollect some memories of specific experiences they had in their hometowns/cities.
- *Nature through the artists' eyes:*

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- Being outdoors has social, physical and mental benefits. It facilitates social interaction and helps people remain active in the wider community. It also improves memory and attention, multisensory engagement, as well as a sense of well-being, self-esteem and a sense of belonging in the community. Where a number of walks in the same area are offered, participants and their carers begin to feel a familiarity with the site and become part of the community of walkers that visit the site. It expands their view of their world and increases a sense of social inclusion and community. This type of activity can promote that connection to others that relieves isolation.

- *On the floor:*
  - Participants are encouraged to dance in the rhythm provided by a specialised instructor.The people with dementia are asked for their favourite songs/music to dance to. Alternatively, there are provided with the music to dance to.
- *Clay your thoughts:*
  - After completing a museum tour and inspired by the museum collection, people with dementia create their own objects using clay. They can choose to work individually or in larger groups to create one larger object by connecting the different pieces they have created.
- *Sound impressions:*
  - Music produces very positive effects on people with Alzheimer's disease. The activity proposed in this scenario involves using music to stimulate participants and support them in regaining their role in society. Using local events or manifestations is a great way to involve participants in a socially familiar context and stimulate them to feel included and part of the city where they live.
- *The mask of feelings:*
  - The purpose of this scenario is to stimulate participants to share their feelings and moods. The instrument used is the mask. Participants will be asked to construct a mask in order to become part of the work being examined (a figurative work is suggested) and become the protagonist of it, together with the subjects already represented. The aim is to make them express the feelings the work conveys and share them with others.
- *Ball band:*

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- Participants will create music on Pilates balls with the help of two sticks (drumsticks or similar) and singing. The music they will play will be folk and well-known on the national level, which touches the folk heritage, because with this activity we promote the preservation of the cultural heritage. Activity can also include grandchildren, children for kindergarten, carers, family, relatives, and employees in homes for elderly.

- *Manual for daily art journaling:*
  - In the workshop, participants will draw in an art journal and receive a printed copy of the Manual for daily art journaling, to use later on. The manual guides a person with dementia to write a diary/daily journaling through expressive art therapy. Guided journaling directs focus on their memory and positive emotions, where the user draws what happened in the past day. The manual also allows a look into the past days, therefore refreshing their memories. The main two aims are to strengthen cognitive functions, as the person is invited to think about what happened during the day. At the same time, the expression of emotions through art provides relief and consequently improves the quality of life.

- *Pieces of us:*
  - The purpose of this scenario is to stimulate participants to share their feelings and moods. The tool used is photos and the reworking of works in the museum. The photos are a stimulus to encourage processes of exploration and self-knowledge aimed at change. With photographs one has access to the unconscious. It is about using photographs to communicate concepts, emotions, or experiences that are difficult to express with words. It is also a useful technique to bring out the personality of the participants so that they can recognise and identify themselves.

- *When the fairytale comes to life*:
  - Dynamic fairytale telling, including singing and art creation, strengthens cooperation, communication, and intergenerational collaboration. It is a workshop, where the participants tell their relatives, family, grandchildren, children from kindergarten a traditional fairytale, which touches the folk heritage, because this activity promote the preservation of the cultural heritage. The activity includes singing and art workshops on creating objects/persons that are the main part of the chosen fairytale.

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AIDA results

Results of the AIDA program emerged by the statistical comparison between the pre-evaluation and the post-evaluation, highlighting the effects of the AIDA program in participants.We asked both PWAD and caregivers to perform an evaluation 'Pre' AIDA activities and the same evaluation 'Post' AIDA activities. In both evaluations we used Visual Analogue Scales examining 5 different variables (i.e., Happiness, Interest, Wellness, Being Confident and Optimism).All participants were asked to evaluate on a scale their emotional status along 5 scales measuring these variables.

Analyses were conducted on a starting sample of 37 PWAD and highlighted that PWAD showed significantly increased score in the evaluation 'post' AIDA activities (Figure 1). This result indicates that AIDA activities can improve the happiness, interest, wellness, optimism and being confident in PWAD.

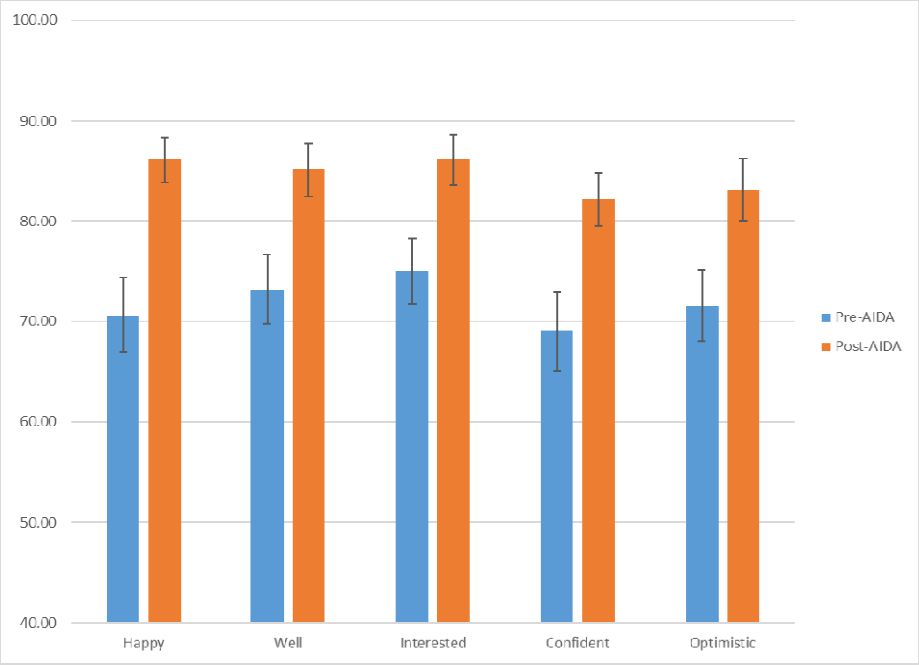

Figure 1. In blue mean scores of PWAD in the Pre-AIDA evaluation. In orange mean scores of PWAD in the Post-AIDA evaluation.

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Performing the AIDA program

In this section of the toolkit we will explore all the practical and logistical details to know when approaching the organization of sessions of art-viewing and art-making examined in the AIDA program. We will divide all tips and advices from our experience in the 'Who', the 'How' and the 'Where'.

Who:

In this paragraph we will examine who are the primary beneficiaries and participants of the AIDA program, their characteristics and some advices to keep in mind when recruiting them.

First of all, for each session the participants are:

- at least one Facilitator
- at least 5 Caregivers
- at least 5 PWAD

Facilitators:

Facilitators should lead and perform the learning scenarios with the group of PWAD and caregivers. Every partner can freely choose how manyfacilitators they need for the piloting according to their needs and chosenlearning scenarios.

Facilitators:

- are responsible for the course of learning scenarios;
- are responsible for managing the group discussions and activities;
- should provide a safe and pleasant atmosphere;
- encourage social interaction between participants and caregivers;
- provide intellectual stimulation and extra information if needed;
- focus on the wellbeing of the individuals in the group;
- should give practical assistance to participants and caregivers ifneeded;
- ensure the inclusion of all members of the group during activities,focusing particularly on the safety of the participants, used tools andobjects.

Caregivers:

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Each PWAD should have their own caregiver during thepiloting phase. The caregiver is the person who is responsible for PWAD's mental and physical wellbeing.The caregiver should know well the PWAD beforehand (inorder any stress to be avoided). He should also have information about thephysical and mental state of the PWAD(in order to be ready toprovide any help during the activity, if needed). Any additional knowledgeconnected to the PWAD's background (experience, hobbies,jobs) that the caregiver has, will be beneficial for the activity.The relatives/caregivers who are responsible for the PWAD must also give their consent for the person with dementia to beincluded in the program.

The following personal qualities of the caregiver must also be consideredwhen choosing participants for the activities:

- personal qualities such as: patience, responsibility, empathy, positiveattitude, creativity, etc.;
- appropriate approach towards the person with dementia: the caregivershould know how to communicate with him (asking simple questions,giving time for rest, respect the PWAD's desires, etc.);
- ability to deal with unexpected situations (as the PWAD is put in an unknown for him environment and he can get irritated, lost,etc.).

An important aspect when choosing a caregiver must be whether he is willingto participate in the activities and whether he has a motivation to do so.Therefore, it is important incentives to be provided such as educational,financial, moral, etc. The piloting requires more responsibilities and tasks forthe caregiver and if he is not willing to accept them, he should not be forced.A plus will be if the caregiver has technical and/or artistic background or interest and if he is trained on how to implement the activities.

People with Alzheimer's Dementia:

It is important that the participants are aware of what kind of activities they willbe included and are willing to take part in them. They should not be forced toparticipate. The participants should be either people with dementia from nursing homesor people with dementia who are taken care of informally. If the people withdementia know each other, the experience will be more beneficial for thembecause it will turn into a more social event.

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The following things must be considered when choosing appropriateparticipants for a certain cultural site and learning scenario:

- the PWAD's art preferences (type − singing, painting,listening to music, sculpturing, etc., style, epoch, culture);
- the PWAD's background (his job, way of life, etc.).

Where:

AIDA activities are designed to take place in cultural venues (museums,archaeological parks, galleries, castles, etc.). Regardless of which venue ischosen, the first fundamental element to pay attention to is logistics.

Specifically, the following aspects need to be checked:

- confirmation of meeting date and time
- organisation of transport
- parking
- management of unforeseen events

Let usnow focus on organising the space. First of all, it is necessary to identify alarge and welcoming space, it could be:

- conference room: there must be the possibility of arranging the chairs ina way that is appropriate and useful for the activity. It is important tohave a PC and a projector to be able to share in large size the image ofthe work on which the workshop will focus.
- one of the rooms in the museum: there must be the possibility ofarranging the chairs. If you decide to organise the activity in a room ofthe museum, it is always important to bear in mind that the work mustbe visible and located in an easily accessible and welcoming area ofthe museum, possibly away from other exhibits which could distractvisitors during the activity.
- outdoor space: make sure that the space is usable and free of hazards(overhanging branches, damp ground, weather conditions, etc.). Again,it must be possible to organise the space with chairs and to have areproduction (also photographic) of the work on which the meeting iscentered.

As a general rule, whatever space is chosen, it must be accessible, if possible

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close to the toilets and welcoming.

The room has to be prepared before the start of the meeting. It is necessary toknow the number of participants so that the right number of chairs can beplaced in a semicircle. It's important to know in advance if there areparticipants with reduced mobility so that everything can be prepared toaccommodate them properly. The room will certainly need a table on which toplace the materials that will be needed during the workshop/workshop phase.In addition, it is useful to know beforehand who will be attending, so thenames of the participants will be communicated to the museum beforehandso that cards with their names written on them can be prepared, a very usefultechnique to establish contact between the group and to make them feelmore "at home". On the day of the activity, guests are welcomed to thecultural heritage place.

Even for this brief moment, it is necessary to find a place that has thefollowing characteristics:

- is relatively small;
- is accessible to wheelchairs;
- has a coat rack or cloakroom nearby;
- has toilets nearby;
- has a room for rest to provide participants with a quiet place for taking abreak;
- is as close as possible to the car park and entrance;
- is free of disturbing noise;
- has enough chairs or benches to allow participants to sit comfortablywhile waiting for the start;
- is within walking distance of the hall where the activities will take placeor is close to the lifts.

Upon arrival, participants should be welcomed by the facilitators.These have to be the same ones who took part in the first meeting at the daycenter for recruiting. They introduce themselves briefly and simply, explain to thosepresent where they are, and what they are going to do, and hand out nametags to be worn by all group members. Throughout the visit, both

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thecaregivers and a member of the medical staff are present, who mingles withthe group and observes, notes and photographs the activity.

To prepare an environment that it is safe and comfortable, you should follow a few steps:

- Choosing the room to host the workshop/laboratory: this must be ascomfortable and least distracting as possible. As already explained, it isfine to organise the workshop in the room of the museum where thework which is the protagonist of the activity is exhibited, but this must beaway from other works which could catch the attention of the guestsand place in a suitable position to be observed.
- Seating arrangements: it would be useful to know in advance the exactnumber of participants, to organise the right number of chairs. It isrecommended that chairs be placed in a welcoming manner, e.g., in asemicircle or horseshoe shape. In this way, participants can easilyobserve the work/play and see each other face to face. Furthermore,positioning in a semicircle or horseshoe shape gives a sense ofinclusion and promotes the feeling of being in a 'protected' space. Ifthere are participants in wheelchairs or with reduced mobility,arrangements must be made accordingly. One should ask in advance ifparticipants are provided with support (wheelchair, crutches, cane, etc.)
- Lighting: this should be optimal in terms of comfort. It should not be toointense or of different colors (e.g., strong colors such as red, andyellow, could be annoying for photosensitive or cognitively impairedparticipants). The light should be fixed, not subject to changes in hue orintensity. If the chosen environment allows it, favor natural light.
- Temperature: as with lighting, the temperature should also be stableand appropriate to the season. If a low temperature must necessarily bemaintained in the rooms of the cultural venue for the preservation of theexhibits, then it is advisable to organise the activity/workshop in anotherspace, where it can be set and maintained at the necessary degrees.
- Noise: this aspect is certainly the most complicated to manage. Ifactivities are carried out during the opening hours of the cultural

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venue,it will be more complicated to keep the environment quiet and peaceful.In this case, visitors should be warned that project activity is takingplace in a specific room. At the same time, they will be asked to payattention and politely be quiet when they meet the group. If the culturalvenue should organise itself to ensure the presence of these supports.

- Workshop materials: AIDA activities all start from art-viewing and art-making activities developed to be implemented within cultural venues. These serve asguidelines for organising and setting up activities involving people withAlzheimer's and their caregivers. One will have to organise in advance topurchase what is needed, considering the number of participants. Oncethe materials needed have been found, they will be placed on the tablepreviously positioned in the workshop room. It may happen that, duringthe start-up phase of the workshop, there is a need to help participantsstart their projects by assisting them at whatever level is necessary.

Clear instructions should be given and repeated as often as necessary.Make sure to balance the program objectives with the particular moodand interests of the group and do your utmost to accommodatedistractions of all kinds.Finally, make sure you have enough materialfor everyone.

How:

In this paragraph we will examine how to optimally perform the AIDA program, highlighting possible issues and how to solve or prevent them.

First of all, the best number of participants to have a good amount of people attending the session and to ensure a calmer andmore receptive environment without confusion and chaos is 5 participants affected by mild-to-moderate ADplus their 5 caregivers.

Secondly, it is important to keep in mind that, when working with people with dementia, there might be difficultiesconnected to communication and understanding each other. People withdementia usually find it hard to express themselves and understand others.Their behavior sometimes is hard to be understood.A few reasons for these difficulties in communication and comprehensioninclude:

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- PWAD have difficulties connected to verbal expressionsuch as: finding the right words; creating a sane sentence; keeping thetrain of thought; organizing words logically; they may repeat words orinvent new words to describe familiar objects. They may even speakless or rely on nonverbal gestures.
- PWAD find it hard handling their emotions. Due toinability to express themselves properly or to communicate theirthoughts as well as inability to perform everyday tasks, people withdementia may feel frustrated, angry and depressed.
- Even if PWAD cannot express themselves properly, theystill have emotions and inner world and need to receive respect, warmthand attention.

In order to communicate beneficially and positively with the PWAD, there are a few tips you can follow:

- The first goal of communication with PWAD should behelping the person communicate his thoughts and feelings whilepreserving his dignity and emotional wellbeing.
- The later the stage of dementia, the more noticeable thesecommunication and behavioral problems are. However, you shouldapproach the PWAD without indulgence and should tryto keep the conversation as natural as possible.
- You should avoid criticizing, correcting and arguing. Be calm andsupportive, using a gentle, relaxed tone of voice. You should be patient,flexible and understanding when communicating with a person withdementia. It is recommended to maintain eye contact but if not possibleat least use positive, friendly facial expressions. The idea is to keep theinteraction positive.
- During the activity show that you are listening and trying to understandwhat is being said. Encourage the PWAD to continueexpressing thoughts even if he is having difficulty. Be careful and do notinterrupt. Try to keep the environment not too distracting and help theperson focus on the object in front of him. Do not push him to speakabout things that are unfamiliar or hard to speak about (for example, toocomplex topics or memories he does not remember).

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- When giving instructions speak slowly and clearly. Break instructionsand tasks into clear, simple steps. You can explain the whole activity tothe person with dementia, but when he has to execute a number oftasks, focus only on the present exercise. During the activity, you canremind to the PWAD what he needs to do. You can show him through gestures, pictures, personal example and otheralternative tools what the task is.
- Ask one question at a time. Allow enough time for a response to thePWAD. Yes-no questions are always a good idea if thePWAD finds it hard to communicate his thoughts.
- However, depending on the stage of dementia, a more complexconversation is possible if the person is able to express himself throughwords.
- During the testing phase, be sure that the PWADunderstands the questions by asking additional questions or askingquestions using all communication tools (gestures, examples, pictures,etc.) if needed.

It is important that, even if PWAD find it hard to communicate, this does not meanthat they do not have feelings or a right of a choice. All in all, when working with a PWAD, you should always use only encouraging wordsand never make him feel as if he has not managed to perform the task. Youshould show him that you are trying to understand him and you should givehim the tools to be understood (by asking simple questions and questionswhich help him to express his emotions and thoughts, suggesting words,using a lot of gestures and facial expressions). At the same time, youshould not make him feel disrespected (by being too indulgent). You shouldrespect his ability to perform certain tasks and to decide whether to take partin an activity or not.To conclude, you should approach the person with dementia in the way youapproach any other human being − with positivity, warmth and respect, andhe will respond in the same way.

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