



Occupational Therapy

Learning Disabilities and Dementia

DRAFT

Introduction

This resource is written for carers. It offers some practical advice for people who have both a learning disability and dementia.

People who have a learning disability are now living longer due to advances in medicine, care and opportunities to be supported in the community. If a person with a learning disability develops dementia, they will face different and additional challenges to people who do not have a learning disability. Those with Down's syndrome, are at increased risk of developing dementia at a younger age. One in three people who have Down's syndrome develop dementia in their 50s. This increases to nearer two in three people with Down's syndrome who are over the age of 60.

Communication

Dementia can make verbal communication more difficult to follow and understand. When engaging with a person with dementia the following tips may be useful.

Useful Tips

- Use a range of non-verbal communication including gestures and body language.
- Simplify sentences and do not ask too many questions in one go.
- Listen to the person carefully and give them lots of time to respond.
- Support the person's friendships and social activities. You may need to find ways to explain to other people that the person has dementia.
- Give others tips on how to support the person.

- Encourage the person to stay as independent as possible. This may mean letting them do things in their own way (as long as they are safe).
- Use prompts and reassurance when they are doing tasks or activities that they may find difficult.
- Use pictorial cues (such as a picture of a toilet on the bathroom door). Using visual and pictorial cues to plan the person's day can be really helpful.

Pictorial Information

Useful Tips

- Use pictorial information to aid with understanding.
- Pictures, symbols or objects can be used which have meaning for the person.
- Use visual clues and planners to structure the day.
- Use visual labels on doors to help find the way around the home.

Days of the Week

- Prompt signs can also be used as suggested in the pictures.

Calendar

- A simple calendar to keep note of scheduled activities.

Information Boards

- Keep important information simple and visual and therefore acting as a prompt.
Regularly update and remove any task or event that has been completed.

Routines

Routines can be really important for people with dementia just as they are for people who have learning disabilities.

Useful Tips

- Have a routine and make sure activities happen in the same order. It can help to continue routines they are already familiar with.
- Be flexible and adapt the routine to meet their needs.
- Life story work, creating a memory box and scrapbooking (photographs with labels) can help the person to enjoy a meaningful activity.
- Support their relationships with others and support their sense of self.
- Use sensory stimulation and relaxation techniques. Gentle massage and aromatherapy.
- Listen to music. Music can be a rewarding and enjoyable activity if it is a style of music that the person enjoys.
- The person may enjoy humming or singing along to music they enjoy.

Environment

The environment can become **over stimulating** and **confusing** for the person with Dementia. Look at the environment from the person's perspective and how aspects within it can be threatening, confusing and difficult to predict.

Useful Tips

- Consider the lighting, reflections and images which can be misinterpreted or be a cause of fear and uncertainty. Keeping a light on during the night in the hallway or in the bathroom may be helpful.
- Colour Contrasts - An example of this would be dinner plates that are a different colour to the table surface. Matching carpets, suite and curtains can blend into one another which can cause problems for people in finding somewhere to sit.
- Clutter free and organised space.
- Doors can be signposted to aid with recognition e.g. bedroom, toilet etc.
- Patterned wallpapers can over stimulate and cause anxiety.
- Floors should have a dull non shiny finish. A shiny floor can be perceived as a pool of water.
- Cupboard doors may be removed from the cupboards you want the person to access.
- Fridge Prompts

- Video Intercom/Doorbell app *.....
- Consider door handles, locks and opening mechanisms. A simple change can prevent easy access.
- Accommodate wandering by securing garden area, camouflaging gates and making a path with areas for rest and which brings the person back round to the building.

Maintaining Skill Level

As the individual's skills and abilities deteriorate there is a temptation to carry out activities for the person, in doing so, the speed of the deterioration is being accelerated. Some parts of the brain are still working and need to be used.

Useful Tips

- Help break down activities into simple steps. It may be too demanding for the person to complete the activity in its entirety but they can complete steps within it.
- As the disease progresses, ongoing discussions and observations are required to guide carers and family in the best way to support the individual.

Life Story Work

This involves compiling a record of the person's life through pulling together photographs, objects, and mementos which hold meaning for the person and are significant to them in remembering their past. See attached Template from Dementia UK.

Useful Tips

- Work closely with the individual to remember their past and share it with significant others. See template below which can be edited for each individual.



Dementia_UK_Life_Story_Template-April-21

Timers

Timers can be used as a memory prompt.....

Technology.....??????

Technology Charter for People Living with Dementia in Scotland.

http://www.alzscot.org/assets/0002/0289/Technology_Charter_for_People_with_Dementia_in_Scotland.pdf

Occupational therapy interventions for those with dementia

include:

- *Health Promotion.* By focusing on maintained strengths of clients and promoting wellness of care providers, practitioners can enrich their lives by promoting maximal performance in preferred activities.
- *Remediation.* Although the remediation of cognitive skills is not expected, practitioners can incorporate routine exercise into their interventions to improve the performance of activities of daily living (ADLs) and functional mobility, and to help restore range of motion, strength, and endurance (Forbes, Forbes, Blake, Theissen, & Forbes, 2015).
- *Maintenance.* Practitioners can provide supports for the habits and routines that are working well for the person with dementia, and that can be maintained to prolong independence.
- *Modification.* This is perhaps the most frequently used intervention for those with dementia, as it ensures safe and supportive environments through adaptation and compensation, including verbal cueing, personal assistance, and/or social supports.

A few specific examples illustrate potential occupational therapy interventions to promote optimal functioning for people with dementia, their families, and care providers. These examples are somewhat simplified, because during actual intervention

occupational therapists complete individualized in-depth evaluations and activity analyses to determine the typical demands of any pertinent activity. They also use critical thinking to ensure the person has the most supportive environment to enhance functioning, while promoting the person's strengths and abilities.

The following are common problematic behaviours among people with Alzheimer's disease, and potential occupational therapy and team intervention:

Person forgets what season it is when selecting clothing: Help the care provider set up limited clothing selections to fit the season, which helps avoid conflict while supporting client choice and self-efficacy.

Person gets disoriented and wanders: Set up the environment to enhance daily activity, including mobility within safe confines, and use technology to ensure safety. Sometimes a fenced courtyard with stop signs at the gates could be all that is needed to keep the person oriented to his or her own yard; for others, alarms can be installed to go off when the person opens a gate or a door.

Person has trouble communicating, along with uncharacteristic, frequent outbursts: Help caregivers identify nonverbal cues. Teach the concepts of caring, non-defensive responding techniques, and work on determining the underlying emotion that may have precipitated the client's behavioural outbursts. Avoid correcting factual errors.

Person paces or shows other repetitive non-productive behaviour: Provide opportunities for engaging in occupational tasks that fulfill the person's need to be productive and help support relationships with others. For example, if the person once enjoyed crossword puzzles, perhaps simplified puzzles or word searches would still be enjoyable. Simple, repetitive tasks like folding laundry can lead to feelings of accomplishment.

In the early stages of dementia, when the person is having difficulty with higher-level executive skills, he or she may be referred to occupational therapy for evaluation and intervention to address driving, work, and safety. In the middle stages, home safety and staying engaged in personally meaningful tasks become the paramount focus. During the late stages, when the person may be having difficulty with basic ADLs (e.g., feeding, toileting, mobility) the focus may switch to decreasing caregiver burden and enhancing basic care (e.g., safe transfers, skin protection, avoiding contractures, enjoyable sensory stimulation).

References

Alzheimer's Association. (n.d.). *What is dementia?* Retrieved from <http://www.alz.org/what-is-dementia.asp>

Forbes, D., Forbes, S. C., Blake, C. M., Thiessen, E. J., & Forbes, S. (2015). Exercise programs for people with dementia. *Cochrane Database of Systematic Reviews*, 4. Art. No. CD006489. <http://dx.doi.org/10.1002/14651858.CD006489.pub4/full>

Schaber, P., & Lieberman, D. (2010). *Occupational therapy practice guidelines for adults with Alzheimer's disease and related disorders*. Bethesda, MD: AOTA Press.

Useful resources

www.nhsinform.co.uk

www.elament.org.uk

www.makinglifeeasier.org.uk

www.firescotland.gov.uk/your-safety/hfsv-form.aspx

www.nhslanarkshire.scot.nhs.uk

NHS Lanarkshire - for local services and the latest health news visit

www.nhslanarkshire.scot

NHS Lanarkshire General Enquiry Line: 0300 30 30 243

NHS inform - The national health information service for Scotland.

www.nhsinform.co.uk

Tel No: 0800 22 44 88

If you need this information in another language or format, please contact the NHS

Lanarkshire General Enquiry Line on 0300 3030 243 or e-mail

info@lanarkshire.scot.nhs.uk

Connecting people, connecting support: The allied health professional offer to people living with dementia in Scotland will be published in 2017.

Resources

Alzheimer Scotland

Scotland's National Dementia Strategy 2017-2020

National Dementia Carers Action Network

Scottish Dementia Working Group (SDWG),

National Dementia Carers Action Network (NDCAN)

Focus on Dementia - Changing minds, improving lives in Scotland

<http://www.qihub.scot.nhs.uk/quality-and-efficiency/focus-on-dementia.aspx>

Alzheimer Scotland www.alzscot.org

Disabled Living Forum (DLF) www.dlf.org.uk/content/communication-aids-telecoms-and-alarms



BF-Approach-to-Activities.pdf

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POOL ACTIVITY LEVEL (PAL) PROFILE

The PAL Instrument comprises of:

- Life History Profile
- Checklist describing the way a person engages in occupations
- Activity Profile with general information for engaging the person in a range of meaningful occupations
- Individual action plan
- Outcome sheet

The PAL is a tool which can be used to determine the level at which an individual is able to participate in activities. The PAL then provides guidelines specific to the individual's determined level. Use the Pool Activity Checklist (PAL) attached to identify the appropriate level of engagement in most activities.

Below you will find different activity level of abilities broken down into:

- Planned Activity Level
- Exploratory Activity Level
- Sensory Activity Level
- Reflex Activity Level

Planned Activity Level of Ability

Name:

Date:

Likely Abilities

- Able to work towards completing activities but may not be able to solve any problems that arise in the process

Likely Limitations

- May not be able to search beyond usual places

Caregiver's Role

- Keep sentences short – avoid words such as 'and' or 'but'
- Be present to help to solve problems that arise
- Focus on activities that achieve a tangible result

Using the PAL Activity Profile to support the person

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Identify an activity of interest to the person based on knowledge of his interests, homelife etc

Example activities for Activity Plan

Exploratory Activity Level of Ability

Name:

Date:

Likely abilities

- Able to carry out familiar activities in familiar surroundings

Likely Limitations

- Less concerned with consequences of carrying out the activity and may not have end result in mind

Caregiver's Role

- Requires creative & spontaneous approach to activities.
- If there are more than 2 or 3 stages, activity will need to be broken into manageable chunks.
- Simple use of memory aids such as activity lists, calendars & labelling

Using the PAL Activity Profile to support the person

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Identify an activity of interest to the person based on knowledge of his interests, homelife etc

Example activities for Activity Plan

Sensory Activity Level of Ability

Name:

Date:

Likely Abilities

- Limited Thoughts & ideas about carrying out an activity
- Is likely to be responding to bodily sensations /make reflex responses to direct sensory stimulation

Likely Limitations

- May not have any conscious plan to carry a movement to achieve a particular end result
- May not be aware of surrounding environment or even of his body
- May have difficulty organising the multiple sensations that are being experienced
- May be relying on others to make social contact
- May become agitated in an environment that is over-stimulating

Caregiver's role

- Direct sensory stimulation can increase awareness of self and others
- Guide to carry out single step activities ie sweeping, winding wool
- More complex activities need single step supported approach
- Ensure the person experiences a wide variety of sensations (but avoid over stimulation)
- Demonstration of actions required

- To enable _____ to experience the effect of the activity on his senses and be more aware of himself
- To arouse _____ to be more aware of his surroundings
- To engage with _____ through direct sensory stimulation
- To break the activity into one step at a time
- To keep directions simple and understandable
- To approach and make the first contact with _____
- To monitor the environment and reduce multiple stimuli, loud noises and background sounds

Using the PAL Activity Profile to support the person

Position of Objects	<ul style="list-style-type: none">• Ensure that _____ becomes aware of objects and materials by making bodily contact. • Direct stimuli to the area of the body being targeted, e.g. stroke _____ arm before placing it in a sleeve. Use light across _____ field of vision to encourage eye contact.
Verbal directions	<ul style="list-style-type: none">• Limit requests to carry out actions to the naming of the action and of the object

	<p>involved, e.g. 'lift your arm', 'hold the brush'</p> <ul style="list-style-type: none"> • Use a warm reassuring tone and adapt volume to establish a connection.
Demonstrated directions	<ul style="list-style-type: none"> • Demonstrate to the person the action on the object. Break the activity down into one step at a time. • Guide movements by touching the relevant body part.
Working with others	<ul style="list-style-type: none"> • Use touch and the person's name to sustain social contact. • Maintain eye contact, exaggerate facial expression, gestures and body posture to enhance the persons understanding. Use social action which can be imitated, e.g. smiling, waving, shaking hands.
Activity characteristics	<ul style="list-style-type: none"> • The activity is used as an opportunity for a sensory experience. This may be multisensory. Repetitive actions are appropriate. • The activity focuses on a single sensation: touch, smell, sound, sight, taste.

Identify an activity of interest to the person based on knowledge of his interests, homelife etc

Example activities for Activity Plan

- Sensory box
- One-to-one sensory activities- hand massage, sensory box, smells, food tasting
- One-to-one single step activities – wool winding, wiping table

- Food tasting
- Hand massage
- Exercises
- Music and singing
- Dancing
- Wiping tables etc.

Reflex Activity level of ability

Name:

Date:

A person at a reflex activity level may not be aware of the surrounding environment or even of his/her own body. He/she is living in a subliminal or sub-conscious state, where movement is a reflex response to a stimulus. Therefore people wishing to enter into this person's consciousness need to use direct sensory stimulation. By using direct stimulation the person's self-awareness can be raised. A person at this level may have difficulty in organising more than one sensation which is being experienced at the same time. Excessive or multiple stimuli can cause distress; therefore crowds, loud noises and background clamour should be avoided. Activities at this level should focus on delivering a single sensation to the person. Caregivers interacting with a person at a **reflex** activity level need to use all their communication skills to enter the world of the person. Language skills tend to play only a minor role and should be kept to single-word directions, although the use of facial expression and of a warm reassuring tone and volume can be vital in establishing a communication channel.

The Profile suggests that the following guidelines should be considered when offering activities to the person at the reflex level of ability. These are

generalised guidelines and should be considered alongside knowledge of the individual.

Likely Abilities

- The person can make reflex responses to direct sensory stimulation.
- Direct sensory stimulation can increase awareness of self, and others.
- The person may respond to social engagement through the use of body language.

Likely Limitations

- The person may not be aware of the surrounding environment or even their own body.
- The person may have difficulty organising the multiple sensations that are being experienced and may become agitated in an environment that is overly stimulating.

Care Givers role.

- To enable the person to be more aware of themselves.
- To arouse the person to be more aware of their surroundings.
- To engage the person and reduce multiple stimuli, loud noises and background sounds.

The PAL offers the following suggestions when supporting a person within the Reflex level.

Position of objects	Direct stimuli to the area of the body being targeted e.g. stroke the person's arm before placing it in a sleeve. Use light across the person's field of vision to encourage eye movement.
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Verbal directions	Limit spoken directions to movement directions e.g. “Lift”, “Hold” , “Open”. Use a warm, reassuring tone and adapt volume to establish a connection with the person.
Demonstrated directions	Guide movements by touching the relevant body part.
Working with others.	Maintain eye contact, make maximum use of facial expression, gestures and body posture for a non-verbal conversation. Use social actions which can be imitated e.g. Smiling, waving, shaking hands.
Activity characteristics	The activity focuses on a single sensation: touch, smell, sound, sight, taste.

Suggested Leisure Activities

- Identify an activity of interest to the person based on the knowledge of their interest, likes/ dislikes, home life etc
- As a starting point the following could be offered :
- Smells, food tasting, hand massage, music, lights, textured objects, chimes, other sensory activities.

Any activity offered to the person should aim to arouse conscious awareness of self and the immediate environment using single senses of sight, sound, touch, taste, smell and movement.

Below are suggestions to consider when offering an activity to a person at a REFLEX level. The example here uses the leisure activity of gardening but the same principles would apply to the person’s preferred activities.

GARDENING –REFLEX ACTIVITY LEVEL

- Position the person next to you when you carry out the gardening task. Ensure that he/she is comfortable and can see what you are doing.
- Keep equipment that is not being used out of a person's line of vision.
- Offer a plant to the person to smell by placing your fingers over theirs and, together gently crush the plant. Raise the person's hand to his/her face and suggest that he/ she smell the plant.
- Use your body language of smiling and nodding to reinforce that this is a pleasant experience for you.

Promoting Person-Centred Care at the front line (Innes A, Macpherson S, McCabe L 2006)

Service users identified the following as being key:

- Patience
- Compassion
- Sensitivity
- Empathy
- Skills to help perform their role are also valued
- Listening to service user & carer views which may be contrary to our own

Value of using the Pool Activity Level (PAL)

- Recommended in the National Clinical Practice Guidelines for Dementia (NICE 2006)
- Studies show reasonably easy to complete
- Useful practical resource for care staff to enable people with dementia to engage in meaningful activities (Pool et al 2008)
- Contains outcomes sheet to assist with adapting to change in function

- All members of the care staff can see their input; therefore is empowering for staff resulting in them being more likely to engage in implementation (Brooker 2004)

Thoughts to consider

- See the person behind the illness (Kitwood 1997)
- Value people's uniqueness and individuality
- Use validation to acknowledge people's feelings & emotions in their communication (Feil 1993)
- Power with not power over the person
- Build effective networks with other OT's and services to provide a better quality of care and access to services
- Focus on quality of life & wellbeing throughout the OT process
- Promote a positive social environment (Brooker 2004, McCormack 2004))

Identify the person's agenda and reconcile it with your own

- Focus on providing a positive social environment to enable the person with dementia to experience relative well-being. (Brooker 2004)
- Assist person to maintain 'aspects of self' (Sabat 2006)
- Support staff – if they are not treated in a person-centred way, they will have difficulty doing this with service users (Jacques and Innes, 1998; Ryan et al., 2004)