

Dignity in Dementia

The Activity Guide



**Dignity in
Dementia**

Helping you support people with dementia

As you read this Guide, you'll notice that in the planned activity suggestions it refers to a range of groups. Clearly this is for when we are out of lockdown and groups start to run again. Until then, if you are UK based and would appreciate some support if the person you care for is struggling with the constraints that lockdown has brought, feel free to ring or email us. We'll be very happy to hear from you and hopefully offer some advice.

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INTRODUCTION

Following hugely positive feedback about our Dignity in Dementia Guide for family carers we have decided to create a much shorter version, that concentrates more on providing activities for people with dementia.

As always, we've tried hard to keep it simple and easy to follow so that you can use it to help the person with dementia that you support and care for:

- Feel happier and more content
- Continue to feel useful and valued
- Feel less stressed, which ultimately means you are less stressed too
- Feel more dignified.

When using the guide be aware that just like the rest of us, individuals living with dementia are unique with their own personalities and life histories. Additionally, the way that each person's dementia presents and progresses will be different, therefore what works for one person may not necessarily work for another. You may then need to try things out and adapt our suggestions if they don't work initially,



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WHO ARE DIGNITY IN DEMENTIA?

Who are Dignity in Dementia and why should I take notice of what they suggest?

Dignity in Dementia is an award winning Cumbrian-based Community Interest Company and not-for-profit social enterprise run by Diane Smillie and Lesley Gill. Together we have many years of experience in the social care sector. We set up Dignity in Dementia because we recognised that the dignity of individuals living with dementia and their carers could easily be compromised through lack of knowledge and confidence, and we wanted to address this.

Our approach concentrates on promoting the wellbeing of both the individuals with dementia and their carers. We know that if one is stressed the other is likely to pick up on their emotions, which can lead to them becoming upset and anxious too. Therefore, we aim to support carers by teaching them how to provide the best quality care, so that the person with dementia is happier and more relaxed.

Our work incorporates learning from some of the world's most respected dementia leads and we have seen first-hand the difference it can make. Additionally, carers who have tried our suggestions often feed back how effective they have been.



THANK YOU'S

"Thank you for helping Mum and I find each other again. Your help, knowledge and kindness has been invaluable".

"Thank you for all your efforts. You have taught me a lot and had a hugely positive impact on my husband, who is so much happier since I've been putting my learning into practice".

THE IMPORTANCE OF RECOGNISING EMOTIONS AND FEELINGS

We are all feeling beings, who experience a wide range of emotions, from happiness, joy and contentment at one end of the spectrum, to sadness, despair and hopelessness at the other.

Some people think that as a person with dementia loses their memory, they also lose their ability to feel. They are wrong. As a person's dementia progresses, their emotions, in fact, strengthen. As the part of the brain that holds memories (hippocampus) gradually fades, the part that deals with emotions and feelings (amygdala) remains intact and therefore their emotions and feelings intensify. When caring for someone with dementia, it's really important to understand this.



You need to ask:

- How is the person I care for feeling right now?
- How did they feel this morning when I raised my voice through frustration?
- How did they feel yesterday when I said I'd lay the table because they don't do it correctly anymore?

We can express our feelings and tell another person how different things make us feel. A person with dementia will feel the feelings, but won't have the ability to talk about them. They are therefore likely to communicate them through their behaviours. If they are happy, they'll smile or laugh. However, if they experience more negative emotions such as anxiety, fear, boredom or loneliness their outward behaviours may include crying, hitting out, shouting, appearing very agitated or becoming very quiet. They may also try to get away and leave the area where they have become upset.

In order to support someone with dementia effectively, it's really important to see **THE PERSON** with the dementia rather than the person with **THE DEMENTIA**

During these times carers often focus in on the dementia, believing that their behaviour is connected to the progression of the disease. They don't consider that external factors may in fact have contributed to the situation.



A WORD OF CAUTION

A majority of people with dementia can feel lonely, helpless and bored because people surrounding them think they can no longer take part in activities or carry out simple everyday tasks and so do them for them. This can contribute to them losing their confidence and becoming de-skilled more quickly than might otherwise happen.

Whenever possible, we suggest that the main family carer builds a small team around them, so that when things get tough they can call on them for support - both emotional and practical. This has several benefits:

- 1** The main carer is able to share their frustrations and off-load when required.
- 2** The team can take over the caring role now and again and provide much-needed respite to the main carer.
- 3** The person with dementia benefits from spending time with other people that they know and love, thereby reducing their feelings of isolation.

When choosing your team, make sure that everyone understands how important it is to recognise the feelings of the person with dementia. Some people just can't grasp this, as they can't see past the disease. Therefore they struggle to appreciate that a person with dementia is still the same person and entitled to the best life possible.

If someone close to you falls into that category, it's probably best not to include them in your team.



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WHAT IS DEMENTIA?

Dementia is an umbrella term used to describe a range of progressive diseases that cause problems with brain functioning. Each type of dementia will have its own set of symptoms, which relate to the specific part or parts of the brain that become damaged. The two most common types of dementia are Alzheimer's Disease and Vascular Dementia; however, there are many other types. Some people can also have a mix of the different types of dementia.

TYPES OF DEMENTIA:

- Alzheimer's Disease
- Vascular Dementia
- Lewy Body Dementia
- Frontotemporal Lobe Dementia (including Pick's Disease)
- Posterior Cortical Atrophy
- Creutzfeldt-Jakob Disease
- Parkinson's Dementia
- Mixed Dementia
- ... and many more.

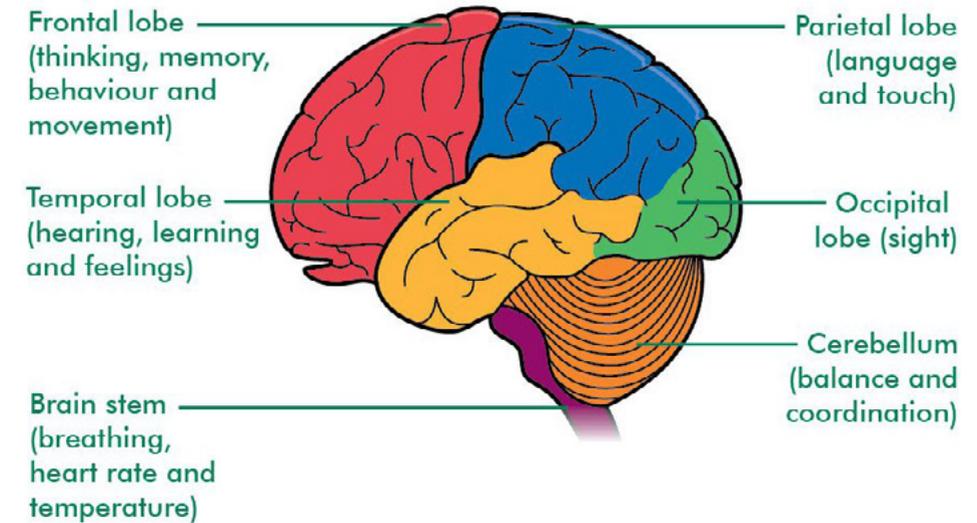
DEMENTIA SYMPTOMS:

The various symptoms of dementia can include:

- memory loss with short-term and more recent memories being particularly affected
- problems with communication and finding the right word
- difficulty with reasoning
- changes in personality and mood
- finding it hard to concentrate and thinking things through
- problems with vision.



SYMPTOMS OF DEMENTIA



The symptoms experienced by the person with dementia will be associated with the part or parts of the brain that are affected. For example, if the frontal lobe is affected, their thinking, memory, behaviours and movement are likely to become impaired and if the occipital lobe is affected, their vision and visual field will significantly reduce.

However, as mentioned in our introduction, as everyone with dementia is unique, how they experience their dementia will also be unique. Therefore it is very difficult to predict exactly how their disease will develop.



MEETING EMOTIONAL NEEDS

Love

Attachment

Identity

Comfort

Inclusion

Occupation

For us to feel contented it's essential that we feel safe, loved, purposeful, valued and stimulated. People with dementia are no different. As mentioned previously, when someone gets dementia, their emotional needs become even more pronounced. Life as they knew it is changing and, while they struggle to find the right words or sequence tasks etc, they will feel a range of emotions such as frustration, anger, despair. Helping them to feel good emotions is therefore vitally important.

Tom Kitwood, the Leader of the Bradford Dementia Group and a senior lecturer in psychology at Bradford University, listed the needs of someone with dementia as:

- Love
- Attachment
- Identity
- Comfort
- Inclusion
- Occupation.

ATTACHMENT

The person with dementia needs to feel attached to another person or a thing, especially at times of heightened anxiety. This might be their husband or wife, who they may follow everywhere around the house, or a pet, handbag, bank card or money. In the later stages of the disease it might be a doll or soft toy.

WAYS THAT YOU CAN SUPPORT A PERSONS NEED TO FEEL ATTACHED

- Having empathy and understanding of their feelings
- Acknowledging the person and recognizing them as the unique human being that they are
- Understanding the reality of the person and the 'new normal' they are encountering.

LOVE

Everybody needs love and people with dementia are no different. We need to feel love for someone or something, be it a person, a pet, an activity, religion or even a food, and we need to feel loved. Equally important is self-love /self-respect. It's important therefore that you try to ensure that the person you support feels loved by you (not always easy when they've asked you the same question 20 times, we know). With regard to helping enhance their self-love / self-respect, we hope that by following the advice in this guide, you will help them to feel this.



IDENTITY

People with dementia need to have others know who they are and who they were. They need to be acknowledged as an individual with their own identity and to be seen as special. It's vital that their individuality is recognized on an ongoing basis, for example in their food preferences, clothing, activities and recreation.

IDENTITY TIPS

It's important that those offering support connect to the person's life history and this can be achieved by:

- Accepting who the person is
- Showing respect for their past knowledge, skills, achievements and experience
- Showing respect for who they are now and demonstrating that they remain a valued member of the family / community and society.

INCLUSION

People with dementia want to feel they belong and that they are part of something. Some want to belong to a group and be a member. You can support the individual to feel included by:



- Including them in conversations and seeking their opinions (but not in the form of questions)
- Recognising their uniqueness
- Ensuring they feel they belong in the family, group or wider community etc
- Generating laughter and using fun whenever possible.

COMFORT

We all need to feel comfortable. Think back to a time when you felt uncomfortable. Perhaps your jeans were too tight, you felt too hot or too cold or you had a tooth-ache.

It goes without saying therefore, that the person with dementia you support needs to feel comfortable too. They need to have a full-stomach and not be thirsty, to be dry and clean, not be too hot or cold, have quiet when they want it and have any pain dealt with.

They also need to have their anxiety calmed, to have a sense of tenderness, closeness, and bonding with others. This requires a deep understanding of the person and of their likes and dislikes.

Remember, if you create a family team to support the person with dementia, make sure that everyone is aware of the person's likes and dislikes.

SOME FURTHER CONSIDERATIONS

- Demonstrating affection will help to make the person feel safe and secure.
- Create as calm an atmosphere as possible and do things at a more relaxed pace. For example, if your previous routine involved having lunch out after doing the weekly shop and then visiting a friend, consider spreading these activities out so that your family member doesn't feel overwhelmed.
- Ask your GP for regular medication reviews to check that the prescribed medications are still effective and not causing side effects.
- Remember that the person you care for may not be able to tell you they are in pain, so consider this if their behaviour suddenly changes.

OCCUPATION

It's important that people with dementia are occupied (have something to do). Just like the rest of us, they need to feel there is purpose and meaning in their life, to feel needed and valued. Think



what it would be like to sit doing nothing all day. Imagine not being allowed into your kitchen when you know a meal has to be prepared or told to stay out of the garage when you've always tinkered about making things. Think about how you'd feel if you were told to just sit down.

Therefore find ways that enable the person you're caring for to get involved in tasks they've always done.

They may only be able to do one small part like put a few of

the ingredients into the making of a cake, spend a long time peeling a potato, polishing shoes or cleaning a window. It's very likely that the completed task won't be to their previous standard and it may need doing again (when they aren't around), but it's important to let them do what they can and not criticise.

YOUTUBE

If you have access to the internet, it's worth watching Teepa Snow's short video, '*Why Activities Matter*'. You can find it on YouTube at www.youtube.com/watch?v=OWheW1MR4Q8

ACTIVITIES

There are 3 types of activity to consider:- meaningful activity, spontaneous activity and planned activity.

Things to consider when choosing an activity:

- The mobility of the individual.
- The person's type of dementia and their willingness to take part in activities. Often if you ask someone if they want to do something they will say no, but if you start an activity next to them they are likely to become curious and then get involved.
- Their familiarity with meaningful tasks.
- Did they used to do/like doing the hobby?
- Is it too much of a risk? It is important to find the balance in allowing the person to take a risk and not being over protective. Ask yourself how you would feel if you were stopped from doing something you had always done – possibly frustrated, angry. You need to find that all important balance.

MEANINGFUL ACTIVITIES

The person still needs to feel needed and one of the best ways to help them with this is to involve them in a routine task they previously did. For example:

- Household tasks – washing up, cleaning, dusting, cleaning windows, vacuuming, ironing sweeping, etc
- Gardening tasks – sweeping, pruning, raking, planting seeds/bulbs, watering etc
- Simple DIY tasks – sanding, painting, changing a battery, sorting screws or nails etc
- Puzzles – Suduko, crosswords, Japanese memory test (see www.gloriousopportunity.org), jigsaws

- Sorting photos into categories and creating a photobook/album eg holidays, Christmases over the Years, etc
- Listening to music – a personalised playlist works especially well as it evokes positive feelings – check out Playlist for Life at www.playlistforlife.org.uk
- Exercise – indoor – chair exercise with a DVD, dancing
- Exercise – outdoor – walking, jogging, cycling, digging
- Being outdoors provides a multi-sensory experience (light, wind, change in temperature, sound, smell, touch) that can improve the wellbeing of the person with dementia. Daylight is also important for aiding sleep
- Nature – looking at plants, trees, birds, wildlife etc
- Singing – there are many singing groups to join
- Painting/drawing – sometimes this skill can lie dormant in a person and can be reinvigorated if encouraged
- Researching where the person used to live together and creating a scrap book



- Cooking – peeling vegetables, baking, icing cakes, stirring stews or sauces, mashing cooked potatoes
- Experiencing reminiscent smells eg. mint, lavender etc
- Apps for people with dementia eg, MemorC, My house of memories, Remind me care, Daily Sparkle
- Caring for plants or a pet. A dog could be borrowed from a family member or neighbour and looked after for an hour or two
- Brass/silver polishing
- Polishing shoes or boots
- Knitting – a square to make a blanket is a good suggestion or winding wool from an old jumper into a ball
- Playing a musical instrument
- Stacking things
- Caring for things – animals, plants and, in later stage dementia, dolls for people who have had a caring role.



SPONTANEOUS ACTIVITIES

These are activities that happen on the spur of the moment. They can be used to make an instant connection or to distract a person if their mood is starting to deteriorate. See Distraction at the end of this leaflet.

- Create a Memory Box of things that mean something to the individual and pick something out of it to talk about
- Sing a spontaneous song together or do a little dance
- Watch the birds/wildlife out of the window
- Read a poem/short story/newspaper article
- Watch a pre-recorded TV programme or DVD
- Talk about a mutual funny memory
- Listen to radio/audio book/CD
- Paint the person's nails
- Give them a hand massage
- Use an App, as in section above



PLANNED ACTIVITIES

Planned activities are something you plan in advance. They may be weekly groups that you attend or a routine visit out. Examples include:

- A walk - there are a number of friendly dementia walks now being arranged in different localities
- Swimming
- Singing in a local singing group
- Dancing group
- Music group



- Local History group
- Local activities
- Crafting groups such as knit and natter
- Afternoon tea out
- Cinema - some local cinemas offer dementia friendly viewings of old well know films
- Museum trip
- Drive to a local favourite place
- Facetime/Skype/WhatsApp a family member
- Visit a local nature reserve
- Local National Trust property/garden
- Create a life history book



ACTIVITIES... A FEW THINGS TO REMEMBER

- Rest is also an important activity, especially after a meal.
- Sometimes just part of an activity will be all your loved one can do, so think carefully about breaking it down and get them involved in an achievable step.
- Give just the right amount of help because you want the activity to give purpose and be meaningful.
- An activity could be as short as 5 minutes before they tire. Fifteen minutes is probably long enough unless they are really enjoying it.
- Decide the best time of day to do the activity.
- Choose activities that fit the person's interests.
- Be creative and remember that the key is to make the person feel important, needed, and productive.

DISTRACTION

Distraction is a great technique to use when a person with dementia starts to become anxious, agitated or attempts something that could put them at risk. It involves trying to change a behaviour by directing the person's focus onto something or someone else. The aim is to maintain a harmonious, peaceful and safe relationship.



We hope you have found this guide useful. If you wish to purchase our full Guide or learn more about Dignity in Dementia, please visit our website at www.dignityindementia.org or contact us at info@dignityindementia.org.

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