

TOP TIPS FOR SUPPORTING A PERSON LIVING WITH DEMENTIA



JEWISH CARE

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We know how difficult it can be to understand how to support someone living with dementia.

This booklet aims to provide some top tips. Caring for someone living with dementia doesn't come with a handbook holding all the answers. There is however support and advice to hand.

If you have questions, want some support, a friendly person at the end of the phone to talk to or information about services available, call the Jewish Care Direct helpline on 020 8922 2222

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1. SEEING THE PERSON FIRST AND THE DEMENTIA SECOND

Once a person develops dementia, the danger is that their identity becomes all about the dementia. Remember they are still your grandma, mum, dad, brother etc...

They still have their likes, hobbies, routines and character. They may change their behaviour, personality and language, but deep inside they are still that person.

2. GETTING AN EARLY DIAGNOSIS

This can be particularly advantageous for both family carer and the person with dementia:

- There is medication that may slow down the process for some people in the early stages of Alzheimer's disease
- It gives you a chance to discuss hopes and wishes whilst the person with dementia can still express theirs
- You can receive advice and information from support agencies and groups
- It can help both the person with dementia and their carer to understand what is happening
- It gives you the time and opportunity to set up legal instructions. e.g, a Will and Lasting Power of Attorney (LPA).

3. ENTER A PERSON'S WORLD

A person with dementia may have a perceived reality that is not the same as people around them.

- They may see themselves as a 35 year-old woman who has a young family and a husband who is at work. She may get agitated in the afternoons and feel that she needs to be somewhere else – such as collecting the children from school.



Different approaches work for each individual. For some, it's about reassurance that the children are being taken care of, for others it may be a good time to go for a walk around the block to distract her. It may also be an opportunity to get photos out of the children when they were little. Talk to her, reminisce.

- When she asks for her mum..



Suggested responses could be: "She's not here today" or "Let's talk about that later". Don't say that her mother is dead. This can cause shock and grief.

Talk about her mum; look at photos, have a cup of tea, do something that may distract her. Validate feelings: it may be because of how she is feeling that makes her think about her mum. Try to find out what could be troubling her. Is she lost, lonely, hungry, in pain, confused or disorientated?

4. DON'T TRY TO CORRECT

She may mix up the names of her brother and son.



It is very hard for a person with dementia to keep up with who's who. The best approach is to just go along with it. It could potentially distress YOU even more when you try to correct them whilst they struggle to grasp the information and it can be really upsetting for them to be corrected. Be prepared and accept hearing stories and facts that are all mixed up.

5. SIGNAGE



It can be helpful to label the cupboards in the kitchen: cups, plates, larder etc... Similarly, labelling items in the wardrobe can also help: socks, bras, jumpers etc.

You could use pictures and words like this:



socks



sweaters

Signs around the house can help a person to:

- find what is inside cupboards
- avoid having to ask all the time for something
- be more independent
- orientate them

A useful tip is to use a notice board to write up what the day, month and year is. Indicate the seasons, if there is a festival or occasion and what is happening that day.

6. ROUTINES

Try to keep a person in their routine for as long as possible.

- If Wednesday has always been a day to go to Tesco followed by lunch with a friend, try to encourage and support the friend to continue this.
- Bridge on a Tuesday - contact the bridge group to see whether your mum can still be invited even though she can't play by the rules anymore.
- Going to the tennis club. Same idea as the bridge club.
- Lighting the candles on a Friday night. Keep the tradition going even if she has forgotten the blessing.
- She always has a bath before bed: care workers CAN be flexible.
- Challah on a Friday. Even the outing to buy it can give purpose to the day.

Routines help a person to know what day and time of year it is, and may orientate them with day and night. Rather than stopping their routines, consider how you can help them to continue for as long as possible.

7. INTERESTS, HOBBIES AND LIFE HISTORY

A person with dementia may still be able to carry on with their interests and hobbies; but you may need to adapt how they do this. It is the familiarity of participating that is the important part. They may like to carry on with painting although the end result may not be to the same standard as it used to be.

If a person used to be a dressmaker, just feeling and folding off-cuts of material may occupy them for a while. If they used to be a book-keeper, having a log book to write numbers down gives a purpose to their day and keeps them occupied with an activity that is meaningful to them. Just because a person has dementia doesn't mean they can't prepare food, do the dusting or set the table. They may just do things their way and need a little more support.

Encourage them to do the things they have always done and enable them to learn new skills.

Creating a life history book, with photos throughout their life, brief details of what they have done and people they've met along the way, and including facts throughout their lifetime of national and international history, titles of songs, advertising slogans etc can be a wonderful prompt and a way to hold a conversation and share memories. It can also give a feeling of well-being to the person with dementia and remind carers of who they were/are.

8. REPETITIVE QUESTIONING AND CONTINUOUS PHONE CALLS

One of the many challenges of being with a person with dementia is hearing the same thing over and over again, getting phone calls throughout the day and night, and hearing constantly repeated questions.



Try to see the world from where they are coming from. They will have no memory of having had that conversation. To them, it is as if they are telling you this for the first time. They cannot retain information. Short term memory is often affected more than long term.

Try to be patient and recognise that it is not their fault.
Write it down – consider using the notice board!

9. REFUSING PERSONAL HYGIENE

A person may not recognise the need to wash, shave or to go to the toilet regularly. All of these issues can be made worse when you try to suggest, coerce or even force the person to do these things against their will.

There are no golden answers; but changing or lowering expectations, being creative and recognising the changing needs can help you develop strategies to manage and cope. Quite often these behaviours demonstrate ways a person with dementia still tries to have some control over their life and to assert themselves, whilst they are aware that they are losing so much.

Try to put things in perspective and not to worry. Does it really matter if they don't shower today? What is the worse thing that could happen if they only showered every other day? Consider a solution to offer - that they can have a sponge wash in the bedroom on alternate days.

10. FOOD AND MEALTIMES

Eating habits and tastes can change as a person develops dementia. Your mother may never have eaten fish but recently her favourite meal has become fish and chips. What happened in the past, may not be applicable today.

People with dementia may not feel the need to eat or have no memory of having eaten, and may ask for lunch even though they have just had it. Suggested strategies could be to leave snacks and finger foods easily available for them to help themselves without realising that this is a meal.

If they particularly enjoy breakfast, then make the most of that meal; perhaps turn it into brunch and don't worry too much about lunch. Quite often a person has phases and what is an issue this week may be something very different next week.

11. SUPPORT FOR THE FAMILY

Don't be afraid to ask for help.

Being open and honest about your situation makes it easier for others, both personally and professionally to support you.

It's better to ask for help rather than struggle on your own

- Jewish Care and other agencies are there to help
- There are support groups for family carers
- There are creative activities to go to. For instance 'Singing for Memory' and 'Memory Way Cafés'

For support, advice and information about the range of support services available for people living with dementia and their families call the Jewish Care Direct helpline on 020 8922 2222

Jewish Care works in collaboration with a number of organisations, charities and individuals to enhance the quality of life for their clients living with dementia. These include:

- Music for Life (Wigmore Hall and Dementia UK)
- Singing for Memory
- The Eden Alternative
- The Dementia Action Alliance
- Mobility London
- Community Focus (Barnet Arts Depot)
- Gardening Projects
- Choirs and singing groups
- Dance movement therapy
- Salmagundi Films-digital arts and animation
- World music percussion
- Story telling
- Textile Art
- Intergenerational Arts Work
- Reminiscence and Storytelling-Oral History Groups
- Musical theatre workshops
- Drama therapy
- Puppetry