Dementia Champions







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About BJF



BJF champion positive ageing. We listen to, learn from, and share people's stories of ageing.



We support people to stay connected, growing friendship groups, during times of bereavement and ill health.



We offer free advocacy support for people with dementia, making sure people's choices and rights are protected.

Dementia Champions

Dementia Champions help to make people with dementia feel welcome in their community and in situations in everyday life:

We share information, experiences and stories to help raise awareness and change attitudes of dementia in communities.

We reduce the fear and stigma of dementia by helping people to understand how dementia affects people and what can help.

By making small changes to the environment, we help people with dementia to feel comfortable.

The impact of living with dementia

The word 'dementia' describes a set of symptoms that may include memory loss.

Dementia is caused by a number of diseases that affect the brain.





Dementia progresses in a way that is unique to each individual.

www.alzheimers.org.uk

Signs of Alzheimer's and Dementia	Typical Age-Related Changes
Poor judgment and decision-making.	Making a bad decision now and then.
Inability to manage a budget.	Missing a monthly payment.
Losing track of the date or season.	Forgetting which day it is and remembering it later.
Difficulty having a conversation.	Sometimes forgetting a word.
Misplacing things, being unable to retrace steps to find them.	Losing things from time to time.

The impact of living with dementia



Someone develops dementia every three minutes.



1 in 2 of us will be affected by dementia in our lifetime.



1 in 14 people over the age of 65 have dementia.



1 in 6 people over the age of 80 have dementia.



2 out of 3 people with dementia live in the community.

www.dementiauk.org

Each person is unique and will experience dementia in their own way.



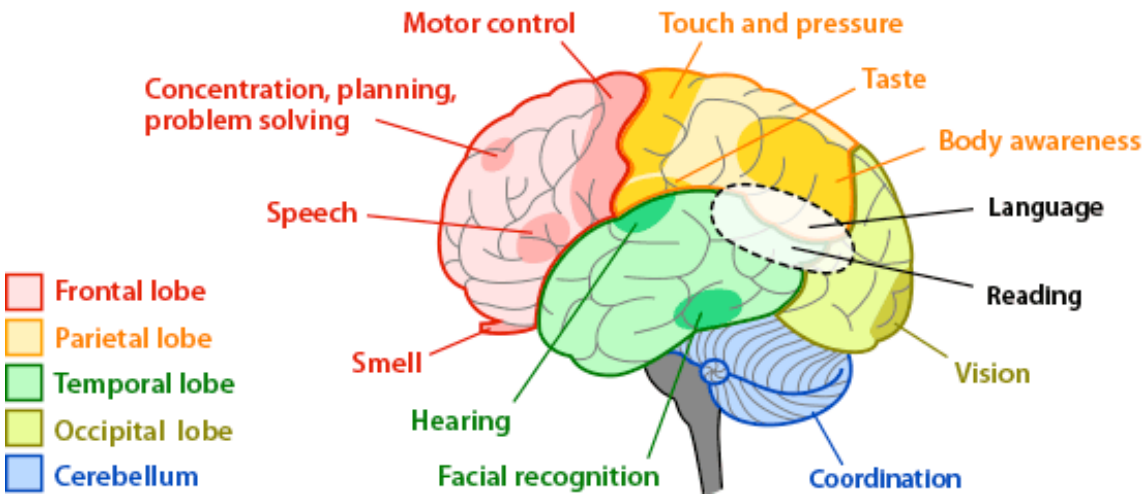


What do you think day to day life might feel like for the person with dementia?

The impact of living with dementia

People with dementia often feel vulnerable and need reassurance and support. Carers, friends and family need to do everything they can to help people to retain their sense of identity and feelings of self-worth.





- Alzheimer's disease primarily affects memory then language and reasoning.
- Vascular dementia can impact thinking, planning and problem-solving.
- Frontotemporal dementia often affects behaviour, personality and mobility.

Compassionate Communication

Words matter; words that mainly focus on problems will overshadow the person. Addressing stigma starts with understanding a person's challenges and strengths. Being person-centered means asking who this person is, what hopes do they have.



Focusing on a person's strengths means we ask:

- what can this person do for themselves?
- what can this person do if they have the support?
- what does this person need others to do for them?

Words are powerful and should reflect the whole person rather than just focusing on the disability or illness that a person is experiencing.

People living with dementia identified words that should never be used:

- Dementia sufferer
- Demented
- Senile / Senile dementia
- Victim
- Wanderer
- Delusional
- Burden

People living with dementia prefer these words and phrases:

- Person/people living with dementia
- Person/people with dementia
- Person/people living well with dementia

Compassionate Communication



A person with dementia may understand far more than they can communicate, Try:

- focusing entirely on the person
- smiling and saying their name
- speaking clearly in short sentences
- listening carefully with empathy
- giving plenty of time to answer
- use gestures, photos or images.

Important To and Important For:

- Skills and abilities
- Community presence
- Continuity
- Choice and influence
- Individuality
- Status and respect
- Partnerships and relationships
- Wellbeing

Chris Sterling, CPI

Finish the sentence...

If I can no longer tell you what I want, this is what is important to me...



Compassionate Communication

Think about what need the person is communicating, what is the cause of distress and what you can do to help:

- If the person is asking to go home
- When a person asks for their parents
- If the person talks about going to school or work
- When the person has difficulty following conversations
- If the person doesn't remember you or why you are here
- When the person is angry/upset and can't explain why

Support should be sensitive to the person as an individual.

Concentrate on what the person feels, rather than what they remember.

The person may experience a world that is very different to people around them.



Try to see things from their perspective.

Positive support and strategies

- Keep things simple.
- Be curious, what need is the person expressing.
- Check if the person is comfortable.
- Don't argue or try to reason with the person.
- Focus on the person's feelings rather than words.
- Three r's: **right** (meet in their reality), **reassure** (build trust and rapport), **re-direct** (change the subject or environment).
- Create a calm environment, use calming music and aromas.
- Avoid loud noises, shadowy lighting, patterned flooring.
- Use colour contrast to help people understand the environment.
- Have a regular routine, exercise and meaningful activities.
- Good heart health, reduce risks of strokes (vascular dementia).



Reflections :
What can help a person with dementia to feel safe and valued?

Supporting decision making

As a person's dementia progresses, their ability to process information decreases and their communication is affected.

People may find it difficult to remember the meaning of certain words or may take time to find the right word.

People may go about most aspects of daily life independently, but they may find it difficult to hold a conversation.

In later stages of dementia people may rarely speak, friends and family find different ways to communicate with them.



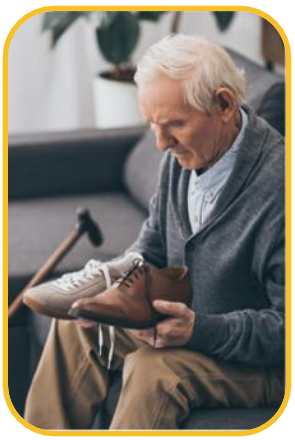
How many choices do you think you have already made so far today?

(Research shows we make thousands of choices everyday).

- Break information down into smaller chunks using clear words.
- Make time, listen and be creative when sharing information.
- Offer a choice of either or, as the person may feel overwhelmed by information and the many choices available.
- Use symbols, photos, objects of reference that the person may be familiar with.

Understanding Advocacy

Advocacy is based on fairness, dignity, equality and respect: speaking up for ourselves, making our own decisions and making sure our rights are respected by others.



Living our lives with as much choice and control as possible is important to everyone.

Advocacy also happens when we:

- support people to have their voice heard
- ensure people's wishes are genuinely considered
- involve people in plans and decisions about them.

Advocacy helps people to explore options, choices and consequences, and supports people to speak up and to be involved in decisions about them.



All human beings
are born free and equal
in dignity and rights.

The Universal Declaration of Human Rights
Article 1

Understanding Advocacy

Dementia is a progressive condition which brings with it the need to adapt to new challenges and to think about the future.

From making daily choices to bigger life decisions, it is important that people living with dementia are supported to keep as much control over their own lives as possible. An understanding of human rights and advocacy is important in planning ahead.

The Mental Capacity Act 2005 states that:



- Every adult has the right to make his or her own decisions and must be assumed to have capacity to do so unless proved otherwise.



- A person must be given all practicable help before anyone treats them as not being able to make their own decisions.



- People have the right not to be treated as lacking capacity because they make a decision that others deem ‘unwise’.



- Anything done for or on behalf of a person who lacks mental capacity must involve the person and be done in their best interests.



- People must be involved in decisions about them and any decisions must be the least restrictive to the person’s rights and freedoms.

Dementia-friendly places and spaces

Taking part in meaningful activities can help to:

- Improve eating and sleeping patterns.
- Reduce restlessness and anxiety and ease distress reactions.
- Improve socialisation and co-operation and delay deterioration.
- Achieve a sense of pleasure and increase well-being.





A dementia-friendly community is a place where people with dementia are understood, respected and supported. Dementia-friendly spaces :

- Are accessible, friendly and supportive with a choice of meaningful activities on offer.
- Decorated using colour contrast to help people understand and navigate the environment.
- Avoid reflective surfaces, shadowy lighting and patterned flooring.
- Staff and volunteers are ready to greet people, offering reassurance and a warm welcome.
- People are available to listen and can signpost people to support and services in the community.

Dementia-friendly places and spaces

A dementia-friendly community is place where people with dementia are understood, respected and supported.

Too often, people with dementia can be left feeling lonely and 'cut off from society' (Age UK).



Even if the person is struggling with memory problems, their capacity to feel frightened or at peace, loved or lonely, and to feel sad or secure remains.

Activities for a person with dementia should be meaningful to them, and tailored to their needs, wishes and biography. They should be structured, but also flexible.

Spaces should be quiet, well lit and uncluttered, with clear signage.



- Allow the right amount of time for the activity.
- Consider the space, lighting and temperature.
- Focus on taking part rather than end results.

With the right support, people can continue to live a fulfilling life and have a valuable role in their community, even years after diagnosis.