

# Condition Insight Report (CIR)

## Dementia

VERSION 1.0

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[Slide 2 – Overview](#)

[Slide 3 – Fluctuations and reliability](#)

[Slide 4 – Sensitivities and customer care](#)

[Slide 5 – Functional impact 1-3](#)

[Slide 6 – Functional impact 4-6](#)

[Slide 7 –Functional impact 7-9](#)

[Slide 8 – Functional impact 10-12](#)

[Slide 9 – Additional reading/ resources](#)

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# Overview

## What is the condition usually called/ any abbreviations used?

Dementia.

There are over 100 different causes, but the most common types are: Alzheimer's or Alzheimer's disease, Vascular dementia or stroke-related dementia or Binswanger's disease, Parkinson's disease dementia, Mixed Dementia (usually Alzheimer's and vascular mixed).

## Brief overview of the condition

Dementia is an umbrella term used to describe a range of progressive neurological disorders, that is, conditions affecting the brain. The brain is made up of nerve cells (neurones) that communicate with each other by sending messages. Dementia damages the nerve cells in the brain so messages can't be sent from and to the brain effectively, which prevents the body from functioning normally.

Dementia is more common in over 65s but can develop in people in their 20s or 30s. The profile of dementia is different in those of working age, with less common forms such as Frontotemporal dementia (FTD), Dementia with Lewy bodies (DLB) and alcohol related brain damage.

## What is the generally preferred term for someone with this condition?

'People affected by dementia' or 'people living with dementia' (though some people would prefer memory problems). Not 'sufferer'.

# Presenting Symptoms

Dementia is a 'hidden' disability because the person looks unrestricted. Over a short period, they may speak and behave "normally", although with time it may be apparent that they are struggling with certain things. The person may also have problems with vision or hearing which exacerbates their dementia.

No two people will show the same symptoms. People struggle most with new things (learning a new phone or TV remote) and less with familiar things that they have learned historically.

The loss of some skills may be exacerbated by psychological distress leading to an inability to carry out tasks that were previously possible. Likewise, an unfamiliar environment or routine can cause confusion or distress.

All the dementias listed are progressive. How quickly, or slowly dementia progresses, varies greatly from person to person.

Symptoms of dementia are usually divided up into:

- Cognitive – poor memory, lack of executive function, problems with language and so on
- Mood – apathy, stress/depression, irritability, anxiety
- Perception – delusions, possibly hallucinations
- Behavioural – restlessness, agitation, sleep disturbance
- Physical – problems with coordination

Dementia in people of working age is less likely to manifest as memory problems. Much more likely are problems with executive function, concentration, visuospatial problems and behavioural changes (e.g. apathy, poor judgement, loss of social conventions).

People with working age dementia report 'autobiographical disruption' which means the plans that they had for the future life are now very different, leading to anxiety and depression and often changes in family dynamics.

# Fluctuations



Typical for people to have good days when they are less impeded and bad days when they appear more disabled. Particularly true of dementias that affect younger people (i.e. people of working age). Also characteristic of dementia with Lewy bodies, in which symptoms can fluctuate hour by hour.

## Think about exploring things like:

- Are they orientated to time, place, person, occasion?
- Do they require prompts around the property?
- Do they utilise a routine to manage their memory? If so, is this independently managed or are they prompted by a person/alarm/calendar etc.
- Are there any hallucinations or paranoia? If so, how often, to what extent and how long does it last? How is it managed?
- How consistent is their presentation e.g. with memory – can they always remember what day it is or who people are, how frequently does this change?
- **How has the condition been over the past 12 months?** What changes have they seen, over what period of time did they experience any deterioration, what has this meant for their functional ability now compared to previous?

Watch **Hat's story**  
about living with  
Alzheimer's **HERE**.

# Reliability

What specific areas should be covered to ensure a complete, reflective report?

**S**AFETY



Do they have any symptoms which could cause a safety consideration?

Due to their memory regression in some places, they can lose the ability to coordinate certain tasks or that they used to enjoy them at all. They can become easily distracted and forget stages in a process which can lead to dangers. Ensure you fully understand how this is managed.

**T**IMELY



For any activities where restriction is reported how long does it take them to complete these activities? Has how long it takes them changed over time?

Activities can take much longer if they become distracted whilst doing a task and cannot remember why they are doing it or are unable to initiate it all together. When there is a lack of orientation to time or place this can affect their ability to complete a task as they may not feel it is appropriate to have a wash if they think they are at work, or if it is the middle of the day etc. Many rely on strict routines and support.

**A**CCEPTABLE  
STANDARD



How have they adapted to completing tasks over time – is this different to what might be considered 'normal'?

As dementia progresses, whilst an individual may be able to complete tasks with a routine, they still might need small reminders around the residence to support them e.g. on the cupboard doors for its contents etc. Get sufficient detail about the support networks in place so you can determine if things like prompting are sufficient to meet their needs.

**R**EPEATEDLY



Are they able to repeat a task as often as required? Is this the same every day?

This is a key feature of many living with dementia that they may be able to do some activities one day and not the next. The variance between days makes it so that ability to complete activities is not consistent or dependable meaning they require support to complete all tasks to ensure reliable outcome.

# Sensitivities

What areas might they find difficult to mention or perhaps understate the impact of?

- Anyone with dementia can lack insight into their condition or be in denial; this is more common in Alzheimer's than vascular dementia.
- If 'exposed' they may become distressed or angry and embarrassed. This can result in behaviours that others find challenging
- A carer/family member/supporter may also be reluctant to discuss these things if the claimant can hear them and may be afraid to distress or anger them



# Customer Care

How is it best to ask about any sensitive topics and what are the common courtesies?



## In general

- Some people may be reluctant to discuss their diagnosis and may even prefer not to use the word 'dementia'. An alternative phrase may be 'memory problems'. They may (incorrectly) use 'Alzheimer's disease' to cover all forms of dementia

**REMEMBER: You are there to explore function rather than diagnosis so ensure you do not push for correct terminology.**

- Stick to one point at a time using straightforward questions
- Allow extra thinking time
- Having too many choices can be overwhelming
- Try describing things in a different way (if not understood) using simpler words if necessary
- May need support to express or understand verbal or written information. This problem may be exacerbated if they feel that they are under pressure

## During face to face interactions

- Make eye contact and smile
- Look for non-verbal cues
- Sit at the same level as the person
- Talk to them rather than asking someone else to answer for them
- Use the same language they do to refer to their condition
- Give them time and stop for a break if they need it



## During telephone assessments

- Remember the claimant cannot see you so you must ensure you provide reassurance, especially if allowing for silence to type.
- Ensure any companions are dialled in if requested and that your report is an accurate representation of who said what.

# Functional Impact

*A brief summary of the functional impact those living with this condition may experience*

## Activity 1: Preparing food

Dementia can present as problems with executive functioning, concentration, visuospatial problems and behavioural changes which may impact someone's ability to cook. A dementia sufferer will often struggle with concentration, memory and thought process impacting their ability to safely cook. They may also lack the understanding of how to use items in the kitchen and have difficulties with control and coordination of their movements

### Remember in PIP...

The risks that are often linked to this activity must be fully considered. Are they safe with knives or the hob? Can they tell food is cooked or remember to turn the oven off? Do they need supervision due to their difficulties? Do they require prompting to commence the task? Can they safely use the microwave? Have they had any incidents in the kitchen?

## Activity 2: Taking nutrition

Dementia may impact someone's ability to remember to eat. Sufferers may also have difficulty recognising hunger or how to appropriately use cutlery, chew and swallow.

### Remember in PIP...

You need to establish the individual's ability to be nourished, by cutting food into pieces, conveying it to the mouth and chewing and swallowing. Spilling food, motivation to eat and risk of choking should be explored.

## Activity 3: Managing therapy and monitoring a health condition

They may have difficulties remembering to take medication or understanding the importance of taking it, impacting on compliance. Also, co-ordination issues may impact their ability to get medication out of packets. Any therapy in the home may require support or prompting due to processing difficulties.

### Remember in PIP...

Therapy input in a domestic setting, which covers majorities of weeks and where they require supervision, assistance or prompting to complete should be explored and considered. Ensure to explore how any medication is managed including compensation strategies like alarms to combat restrictions.

# Functional Impact

*A brief summary of the functional impact those living with this condition may experience*

## Activity 4: Washing and Bathing

A person with dementia may require prompting to commence the task of washing and bathing due to difficulties with memory or cognition. They may also suffer coordination problems which impact their ability to safely access a bath and wash themselves in a timely manner.

### Remember in PIP...

Do they require prompting to wash? Can they wash safely? Have they had any falls? Do they require assistance to get in and out of a bath? Are they washing in a timely manner?

## Activity 5: Managing toileting needs and incontinence

They may lack the awareness to manage their hygiene needs due to their condition and may require prompting. They may also experience incontinence. Also, due to coordination issues they may have difficulties sitting and standing from the toilet and cleaning themselves.

### Remember in PIP...

If the claimant is incontinent, how frequent is it and is this of bladder and bowel? Can this be managed with pads independently or do they need assistance to maintain hygiene? How do they transfer on/off the toilet?

## Activity 6: Dressing and undressing

Dressing may be impacted by the person's difficulties with sequencing thoughts. For example, ability to recognise trousers go on their legs. They may also have difficulties with coordination impacting on their ability to manage fastenings or dress in a timely manner. Cognitive difficulties may also impact ability to recognise clothes require changing or are dirty/ not appropriate for the environment.

### Remember in PIP...

Can they select their own clothing? Are they dressing appropriately? Can they physically dress their own body in a timely manner? Do they need prompting to change clothes?

# Functional Impact

*A brief summary of the functional impact those living with this condition may experience*

## Activity 7: Communicating Verbally

Whilst someone with dementia may be able to speak, their ability to express their needs and fully process what is being asked of them may be impaired. They may give irrelevant information that is off topic. This may be worse with fatigue and be influenced by auditory hallucinations.

### Remember in PIP...

The claimant needs to be able to both **express** and **understand** verbal information. Are there responses contextually appropriate? Do they have to have information broken down to understand it? Do they need assistance from someone to express or understand information?

## Activity 8: Reading and understanding signs and symbols

They may have lost the ability to process visual information and understand what this means. They may just see a page of jumbled words with no rational meaning or read from memory as a way of masking their difficulty. They may also be impacted by visual hallucinations.

### Remember in PIP...

Although retaining information is not considered within the scope of the activity, we need to establish the claimant's ability to process and understand what has been read. Can they manage their own post? Can they read a newspaper? Do they understand the context of what they have read? Could they read and understand a road sign?

## Activity 9: Engaging with others face to face

Some people with dementia can display disinhibited and insensitive behaviour and show a lack of awareness of their vulnerability and consequently require the presence of a family member or friend constantly due to misinterpretation of body language. There may be a history of violence due to frustration/irritability, which puts them or others at risk. They may be withdrawn from social interaction and become isolated. They may also experience auditory/visual hallucinations which affect their ability to interact and feel too anxious or emotionally labile.

### Remember in PIP...

Who can they engage with? Are they vulnerable? If they are anxious, who can support them



# Functional Impact

*A brief summary of the functional impact those living with this condition may experience*

## Activity 10: Budgeting

Their understanding of monetary value, planning for budgets and their concepts of transactions may be impaired. They may not be orientated or understand the requirement of this any longer and need support from a power of attorney. There may be signs of irrational overspending or making purchases out of character.

### Remember in PIP...

Can they reliably manage their own finances and plan for future purchases? How would they cope with a new bill? Would they remember to pay the bills? Could they understand change in a shop?

## Activity 11: Planning and following a journey

Consider that someone with Dementia may experience reduced orientation which may lead to them not knowing the time or place they are in, even if somewhere familiar. This can make it easy to get lost or distressed. They may also experience hallucinations or delusions which impact on their safety. They may have an inability to deal with change or follow directions. They may also be disinhibited and have no awareness of safety concerns, which may lead to them walking out into roads without looking for example.

### Remember in PIP...

The claimant needs to be able to complete this activity safely. If they report ability to manage a familiar journey, how would they cope with a minor diversion? How would they plan for a new route or cope getting to a new place? Are they vulnerable or impulsive? Do they lack safety awareness? Also consider their symptoms may equate to OPD secondary to their dementia, and such MOD must be explored.

## Activity 12: Moving Around

People can have reduced visuospatial perception, hence problems judging distances or objects (e.g. stairs) in 3D and poor control and coordination of their limbs. They can have issues with balance and need to use aids but be unable to due to poor memory, understanding and processing restrictions.

### Remember in PIP...

Consider that although stairs themselves are not considered within the scope of the activity, do they have regular falls? Do they have an altered gait? Do they have poor co-ordination?



## Additional reading or other resources

### EXTERNAL

- <https://www.dementiauuk.org/>
- <https://www.nhs.uk/conditions/dementia/about/>
- <https://www.alz.org/alzheimers-dementia/what-is-dementia>

### INTERNAL

- Desktop Aid – CSE
- Dementia Factsheet found in knowledge bank

## Version control