



# Family/Carers Awareness Session

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# Who are we?



Inspected and rated

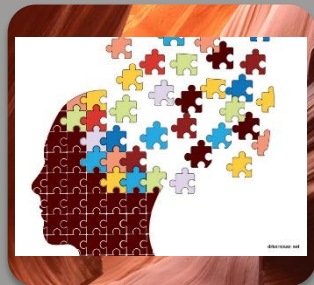
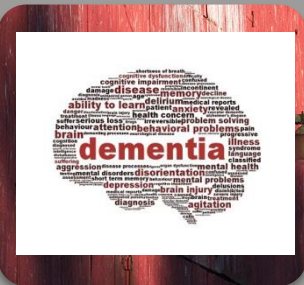
Outstanding ☆



**Fee based service to individuals and organisations providing comprehensive nursing assessments, signposting and contingency planning, as well as on-going monitoring and specific 1-1 and group training. FREE TO OUR SWEETTREE CLIENTS IN LONDON, CHELTENHAM AND SEVENOAKS**



Today I am here to support  
Dementia Friendly Charlbury



What is  
Dementia?

How does  
Dementia  
present?

How do we  
support and care  
for a person with  
dementia?

How important is  
understanding  
pain and  
infections?

How do we  
support the family  
and professional  
carer?

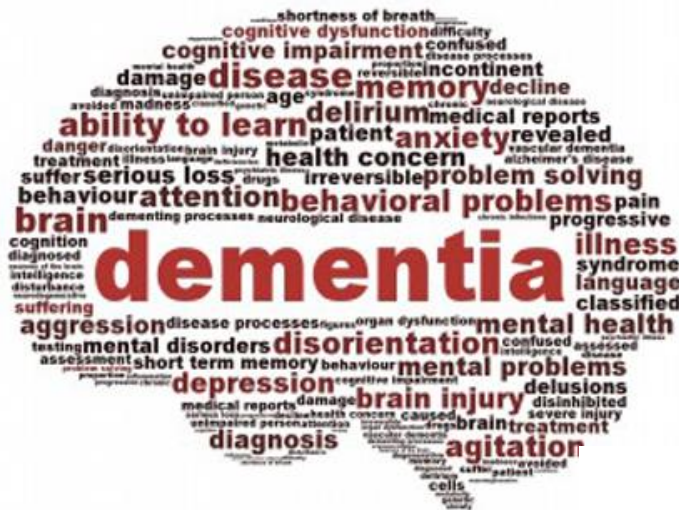
# What is Dementia?

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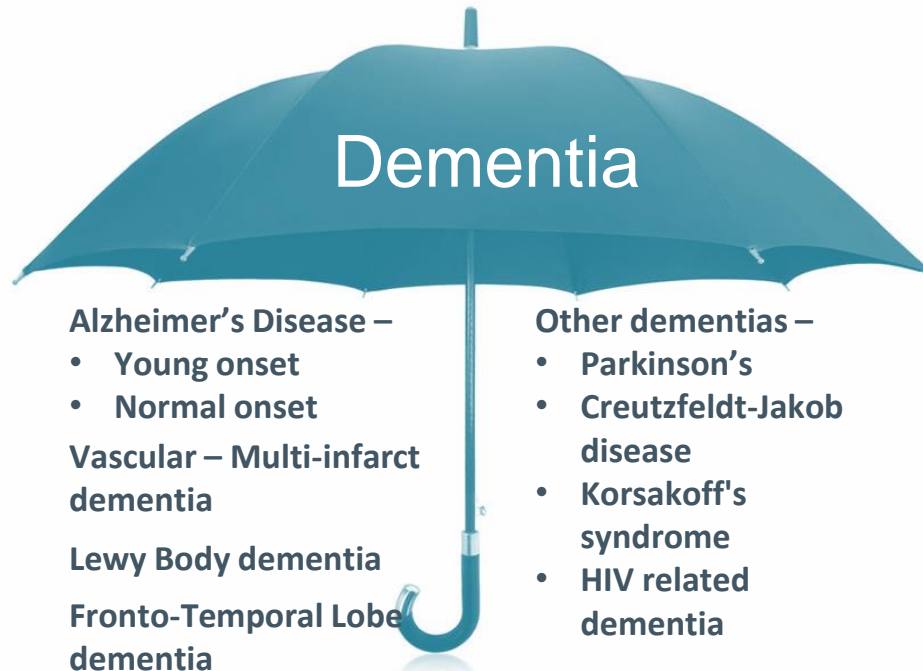
What is Dementia?

Dementia is the loss of everything you know.

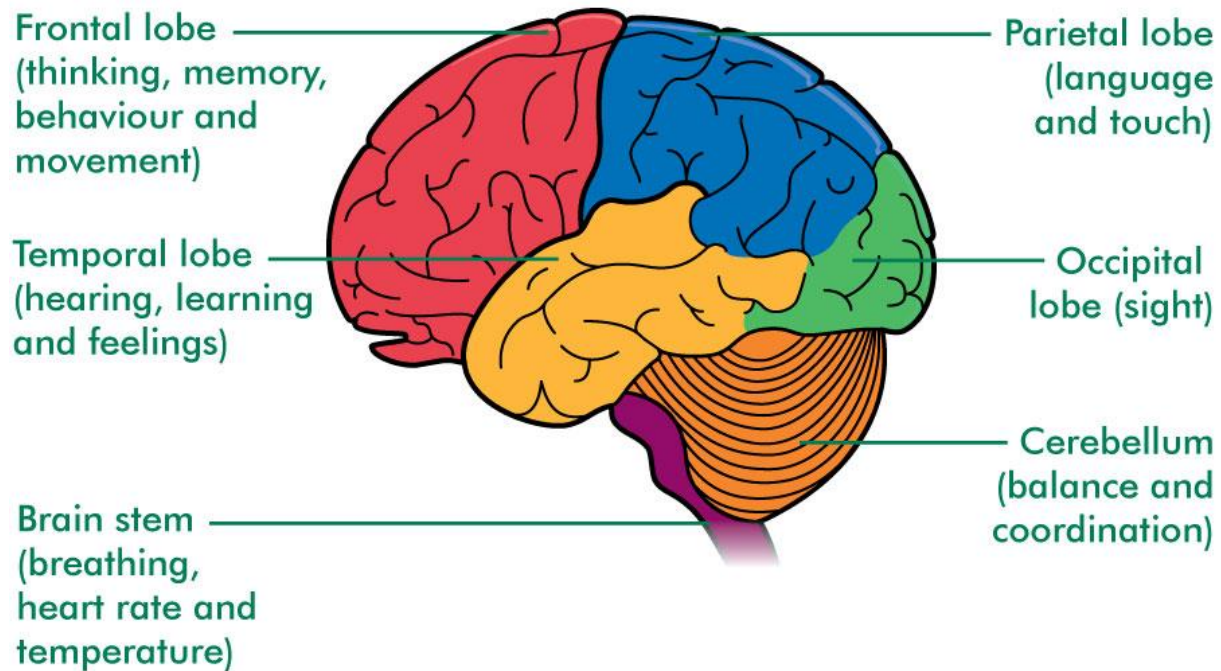


# Types of dementia

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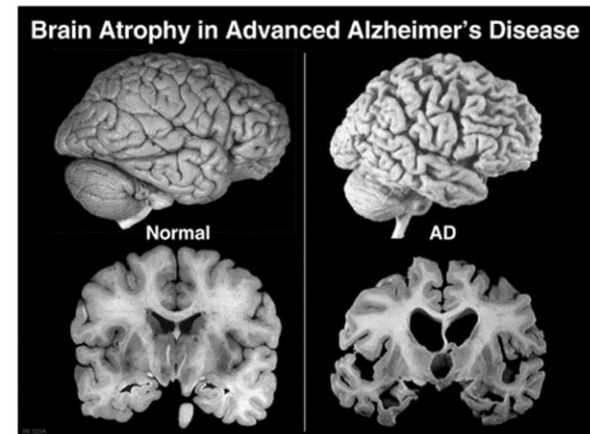
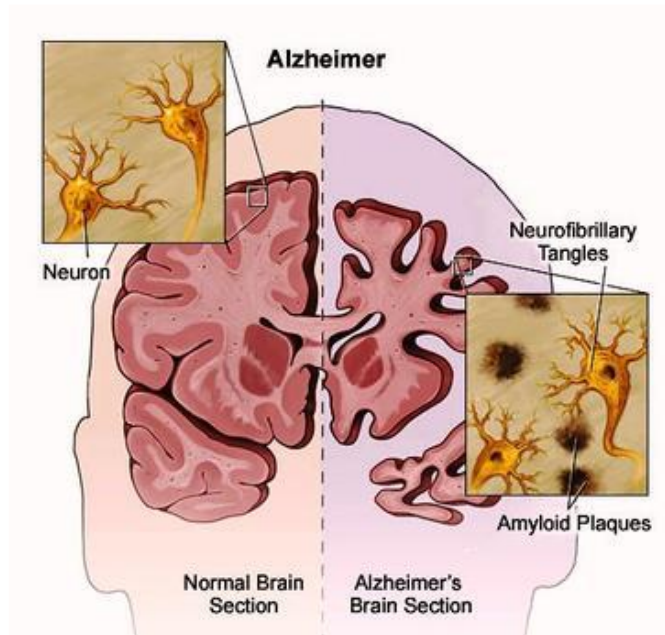


# Here is your computer.....





# What causes Alzheimer's disease?



# Anatomy & physiology

## Hippocampus

- Date stamps and logs our memories - a bit like a librarian.

## Memory loss

## Amygdala

- Processes emotions and it records our reactions
- It keeps us safe and alerts us of danger
- Triggering fight, flight or freeze responses

## Emotional instability

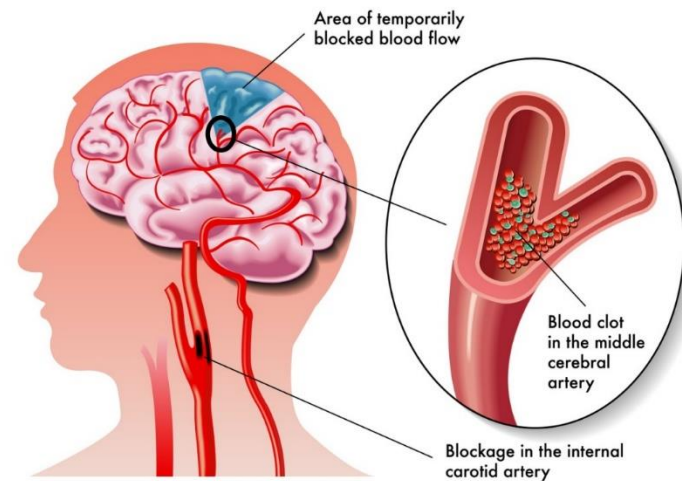


# What causes Vascular dementia?

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## Causes:

- A single large stroke
- Lots of mini-strokes (transient ischemic attacks)
- Narrowing and blockage of the small blood vessels deep inside the brain

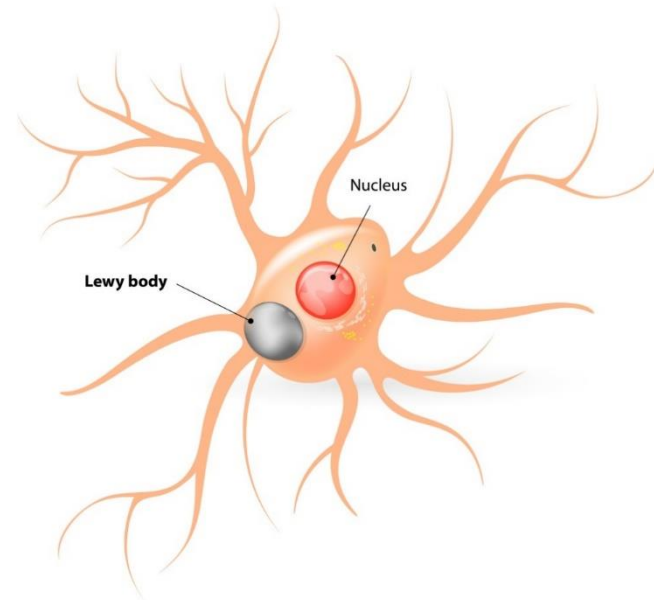


# What causes dementia with Lewy bodies?

## Cause:

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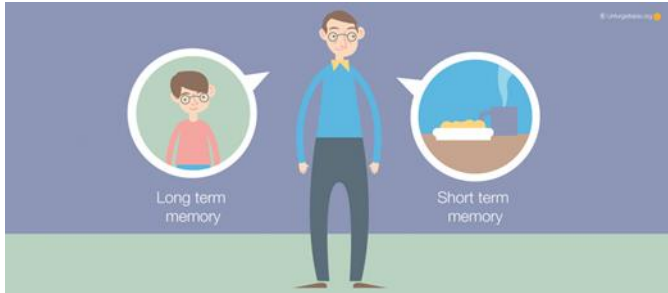
- Tiny round deposits called Lewy bodies
- Found in the nerve cells which disrupt the brains normal functioning



How does dementia present?

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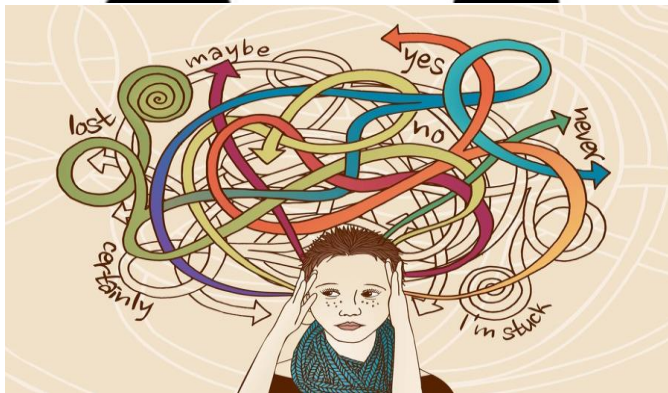
# What do you see?



- Short Term Memory Loss (with an intact long term memory at the initial stage)



- Language problems



- Confusion



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Home Care Services



**SweetTree**  
Dementia Nurse Consultancy

# What do you see?

- Depression



- Lack of problem solving skills



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# What do you see?

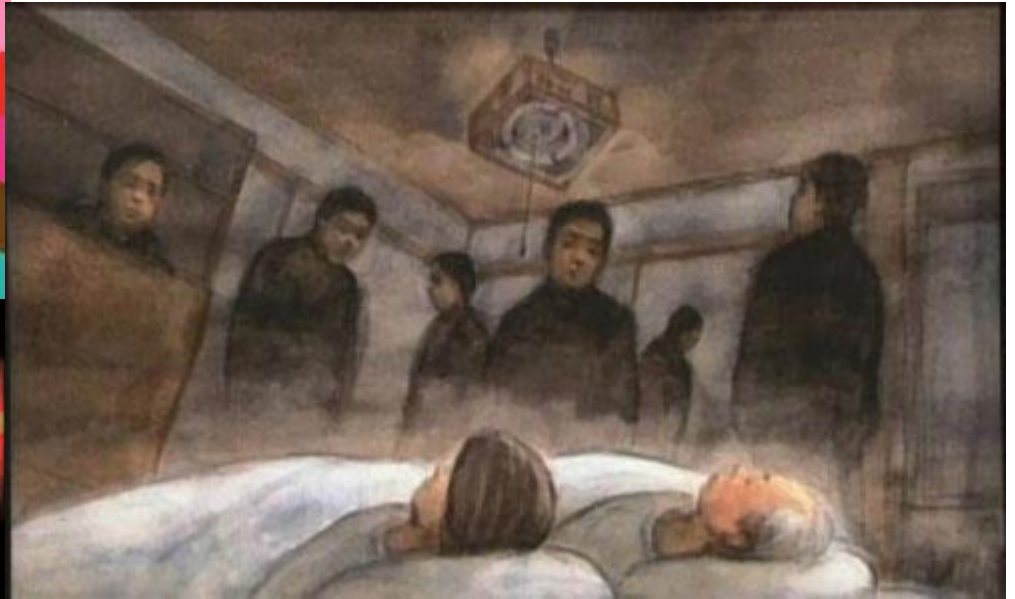
Sensory Deficits



Emotional changes



# What do you see?

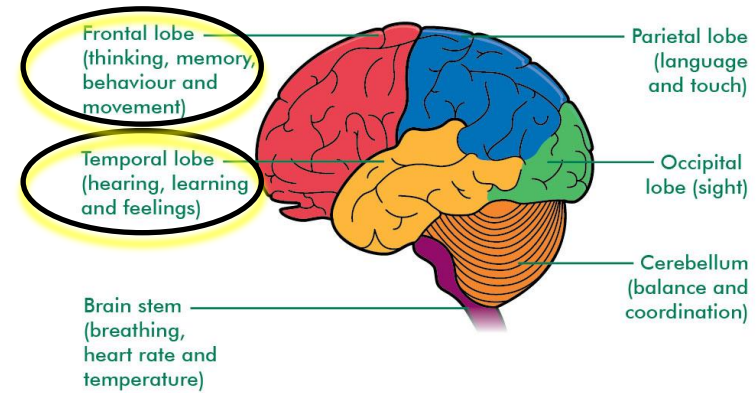
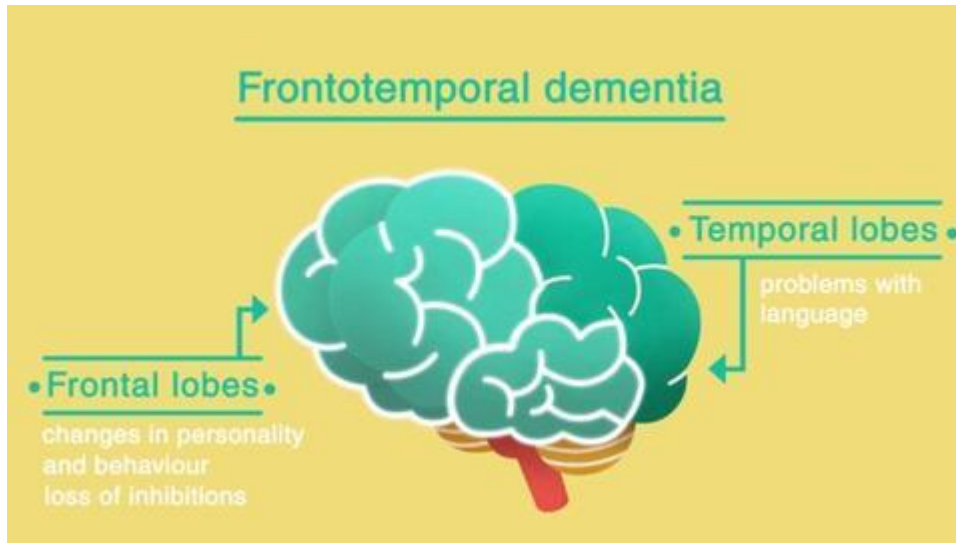


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# Lets talk frontal temporal



# Lewy Body

**MOST COMMON  
LEWY BODY DEMENTIA  
SYMPTOMS**

 <b>Dementia</b>	 <b>Hallucinations</b>	 <b>Cognitive Fluctuations</b>
 <b>Movement Disorders</b>	 <b>Poor Regulation of Bodily Functions</b>	 <b>Sleep Problems</b>
 <b>Depression</b>	 <b>Anxiety</b>	 <b>Apathy</b>
 <b>Agitation</b>	 <b>Paranoia</b>	 <b>Delusions</b>

**Dr. Axe**  
FOOD IS MEDICINE

How do we support and care for a person with dementia?

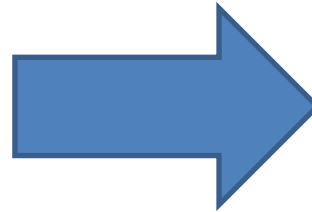


Communication is KEY

Our Approach

Intervention as “therapy”

Living in the “persons world”



Assessment

Intervention

# Behaviours that challenge



Slides from Dr Aimee Spector

Training Session available –  
Use of ABC

# Let us think about the behaviour that “challenges us” (ABC approach)

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What are the CAUSES of behaviours? Is it an unmet needs?

How do we RESPOND to the behaviours? (immediate)

How do we respond to the unmet needs? (more long term planning)

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# What is the problem?

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The first step is to understand what the problem is..

- 1. What exactly is the person doing?*
- 2. Who is around?*
- 3. Where is this happening?*
- 4. When is it happening?*

Concentrate on behaviour that you can see and describe the behaviour in as much detail as you can

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# What might be causing the problem?

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- Lack of stimulation?
  - Lack of meaningful activity?
  - Lack of control?
  - Lack of meaningful relationships?
  - Problems with communication?
  - Problems with memory?
-

# Our approach could be the issue (social psychology)

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(Kitwood 1997) suggested factors the “might exacerbate the symptoms of dementia”

- **Disempowerment** – “wrapping up in cotton wool”
- **Infantilisation** – treating an individual as a child
- **Outpacing** – acting at a pace that is too fast for the individual to understand

# Social- Impact of the environment

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Considering the impact of the environment and noise (Powell 2007)

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# Is there an unmet need?

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These might include client's need for:

- A degree of autonomy / independence
  - Relationships / sense of community
  - Stimulation
  - Sense of purpose
-

# Is this a problem?

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- Is the behaviour really a problem which needs to be worked on?
  - Does the behaviour put the person at risk?
  - Does it decrease their quality of life?
  - Does it influence the quality of life of other people?
-

# What happens after?

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**Consequences:** what happens after a behaviour, causing the behaviour to get better or worse.

Can also include your reaction to the behaviour.





**Recognize what you're up against.**

Recognise how the dementia is affecting communication and adapt.



**Avoid distractions.**

Quiet environment that allows the person to focus

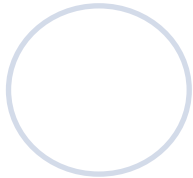


**Speak clearly and naturally in a warm and calm voice.**

Refrain from treating the person as an infant



**Refer to people by their names.**



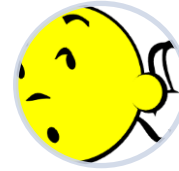
**Talk about one thing at a time.**

Avoid a scatter gun approach  
Avoid multiple threads



**Use nonverbal cues.**

Smile and good eye contact, at the severe end of the spectrum non-verbal and visual clues



**Listen actively.**

If you are struggling check out what is being said.



**Don't quibble.**

Avoid correcting, and take a step back to reduce frustration and confrontation



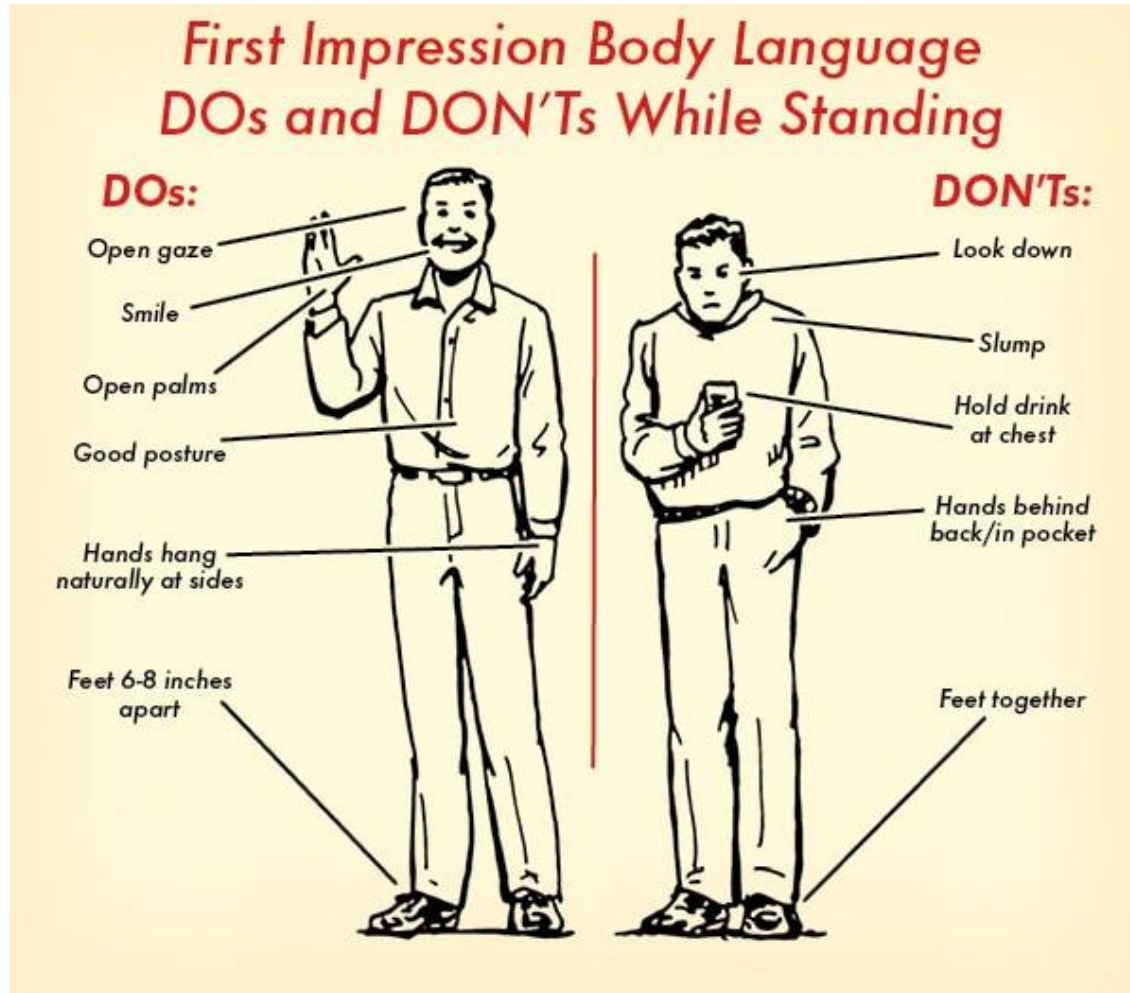
**Have patience.**

Allow time for a response,, give choice, allow for contribution and use visual if struggling

**Understand there will be good days and bad days.**



Remember: Good body language and a positive approach can reduce the potential for confrontation and anxiety from the person. Positive body language goes a long way to “building up the relationship” with the person.





# What can we do?

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## Managing behaviour that challenges

- ABC approach
  - Understand the person
  - Validation therapy
  - Non-confrontational approaches
  - Meeting their needs
  - *Therapeutic lying*

## Stimulation and Engagement

- Creative arts therapies
  - Multi-sensory
  - Meaning activities
  - iCST
  - Reminiscence therapy
-

# Living in the person's reality

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Therapeutic lying examples:

'I want to go home'

'Where is my mum?'

'I need to pick the kids up from school'

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**“... if the function of truth in a situation is to bring nothing but pain and distress to a confused, demented fellow human being, then its utilisation in that instance is at best futile, at worst cruel. When we have exhausted all other possible therapeutic options – including truth-telling – and only when it is likely to enhance the person's well- being, should a ‘best interests lie’ be trialled and then benefit reassessed”**

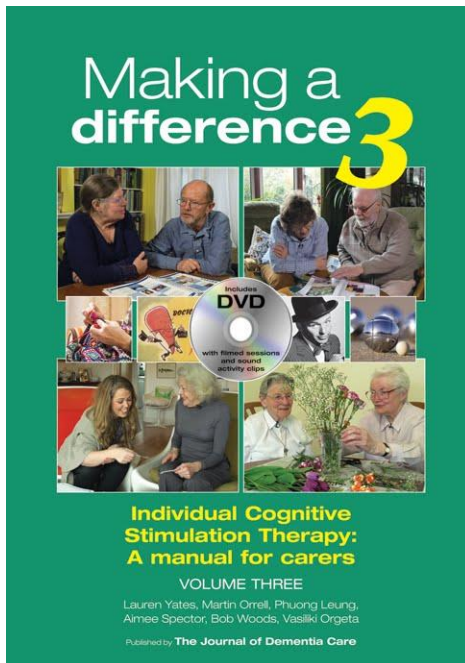
***Tony McElveen, ST5 Old Age Psychiatry, NHS Greater Glasgow and Clyde***

***Any violation of that basic trust must have strong justification, and it is important to follow a rigorous evaluation process when moving forward with deception. But it is important to remember that there are times when the best thing we can do for our patient is provide him with comfort –sometimes the truth is harsh and harmful. Sometimes the best thing we can do is not to tell him news that will make things worse. Sometimes the best way for us to show respect is to show **compassion**.***

***Matthew Allen Butkus, McNeese State University***



# iCST manual and key principles



1	<b>Mental stimulation</b>
2	<b>Developing new ideas, thoughts and associations</b>
3	<b>Using orientation in a sensitive manner</b>
4	<b>Focusing on opinions, rather than facts</b>
5	<b>Using reminiscence as an aid to the here-and-now</b>
6	<b>Providing triggers to support memory</b>
7	<b>Stimulating language and communication</b>
8	<b>Stimulating everyday planning ability</b>
9	<b>Using a person-centred approach</b>
10	<b>Offering a choice of activities</b>
11	<b>Enjoyment and fun</b>
12	<b>Maximising potential</b>
13	<b>Strengthening the relationship by spending quality time together</b>

Training Available: Using  
iCST



- **Mental stimulation**

- Getting people's minds active and engaged.
- trying to get them to exercise skills that may not be used so much and stimulate different parts of the brain.
- Aim: to pitch activities so that people have to make an effort, but not too high (avoid deskilling)

- **Developing new ideas, thoughts and associations.**

- we tend to talk about things from the past. Whilst this is enjoyable for people, it often involves recalling information which has been over-rehearsed.
- encourage new ideas, thoughts and associations, rather than just recall previously learned information.
- This can be more stimulating and interesting.



- **Focusing on opinions rather than facts**

- If we ask people for their opinions, then they may be amusing, sad, unusual, controversial or puzzling, but they cannot be *wrong*.
- DO NOT: ask ‘who is prime minister?’
- DO: ask which policies they like, who their favourite politicians have been and what they agree / disagree with.

- **Using reminiscence as an aid to the here-and-now**

- Using past memories is an excellent way of tapping into a strength that many people with dementia have, in terms of recalling experiences.
- Reminiscence can be a useful way of orientating people to the here-and-now. For example, comparing prices over time in the ‘money’ session, looking at how appearances have changed over time in ‘faces’.

- **Using a person-centred approach**

- Valuing people with dementia and their carers by treating them as they would want to be treated at all stages of the dementia.
- Treating people as individuals, e.g. through consideration of their histories, personality and coping mechanisms.
- Looking at the world from the perspective of the person with dementia, as the subjective experience of the individual is considered reality. E.g. through art or poetry.

- **Offering a choice of activities**

- People should always be offered choices, geared to levels of ability or interests.

How important is it to understand pain and infection?





# Under-Treatment of Pain in Dementia: Assessment is Key

Potential underuse of analgesics for recognized pain in nursing home residents with dementia: A cross-sectional study

Influence of dementia on multiple components of pain

**Dementia + pain + lack of communication and misperception of pain = frustration**



## It is important to identify past and current medical history

- Arthritis (pain and stiffness in joints, especially the hands knees and hips – this pain increases on movement)
- Lower back pain ( chronic pain which can worsen on movement or remaining in one position for a long time)
- Osteoporosis (with the potential for painful fractures often in the spine, wrist and hip)
- Coronary heart disease (potential for chest pain or angina)
- Diabetes (indirectly tingling and burning nerve pain and potential for ulcers)
- COPD – Chronic Obstructive Airways Disease ( muscle pain due to wheezing and coughing)
- Thyroid ( muscle aches and pains)
- Cerebrovascular disease (both small and large strokes can lead to post-stroke pain for example muscle spasticity and headaches)
- + outcomes of falls.

## An example paper tell us:

Pain affects the well-being of the person.

Deterioration in physical and cognitive abilities

Reduction in appetite and potential increase of falls

Worsening psychological symptoms.

**So what are these “worsening psychological Symptoms”?**

## The importance of pain management in older people with dementia FREE

Anne Corbett, Bettina S. Husebo, Wilco P. Achterberg, Dag Aarsland, Ane Erdal, Elisabeth Flo ✉

*British Medical Bulletin*, Volume 111, Issue 1, 1 September 2014, Pages 139–148, <https://doi.org/10.1093/bmb/ldu023>

**Published:** 01 September 2014    **Article history** ▼

# BPSD (Behavioural and Psychological Symptoms of Dementia)

Hitting

Screaming

Kicking

Grabbing things

Throwing things

Verbal aggression

Pacing

Restlessness

Repetitive mannerisms

Complaining

Repetitive questions

Negativism

Hoarding



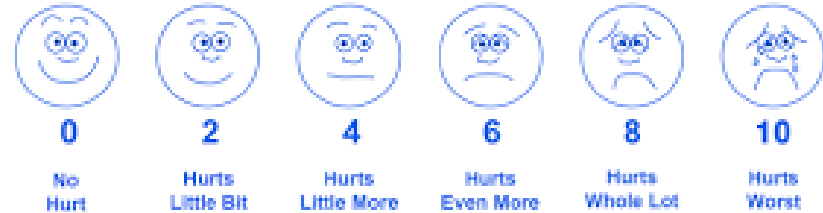
# How do we know if some-one is in pain and they can't self-report?

## Pain Assessment IN Advanced Dementia PAINAD

	0	1	2	Score
<b>Breathing Independent of vocalization</b>	Normal	Occasional labored breathing. Short period of hyperventilation	Noisy labored breathing. Long period of hyperventilation. Cheyne-stokes respirations	
<b>Negative Vocalization</b>	None	Occasional moan or groan. Low level speech with a negative or disapproving quality	Repeated troubled calling out. Loud moaning or groaning. Crying	
<b>Facial expression</b>	Smiling, or inexpressive	Sad. Frightened. Frown	Facial grimacing	
<b>Body Language</b>	Relaxed	Tense. Distressed pacing. Fidgeting	Rigid. Fists clenched, Knees pulled up. Pulling or pushing away. Striking out	
<b>Consolability</b>	No need to console	Distracted or reassured by voice or touch	Unable to console, distract or reassure	
				TOTAL

This material prepared by the Geriatric Research Education Clinical Center, is provided by the Iowa Foundation for Medical Care, the Medicare Quality Improvement Organization for Iowa, was prepared by MenuStar, under contract with the Centers for Medicare & Medicaid Services (CMS), an agency of the U.S. Department of Health and Human Services. The contents presented do not necessarily reflect CMS policy. 850W-IA-NH-4306-034

### Wong-Baker FACES® Pain Rating Scale



© 1981 Wong-Baker FACES Foundation. www.WongBakerFACES.org  
Used with permission.

#### Instructions for Usage

Explain to the person that each face represents a person who has no pain (hurt), or some, or a lot of pain.

Face 0 doesn't hurt at all. Face 2 hurts just a little bit. Face 4 hurts a little bit more. Face 6 hurts even more. Face 8 hurt a whole lot. Face 10 hurts as much as you can imagine, although you don't have to be crying to have this worst pain.

Ask the person to choose the face that best depicts the pain they are experiencing.

## So we can learn from this.....

Identification and assessment of potential pain is important (past and current medical history)

That there could be a link between pain and challenging behaviour and this should be explored and eliminated.

That randomised trials have concluded that first line treatment of pain “might” reduce symptoms of distress.

Another cause of pain?



Pain + Infection = delirium

Delirium = agitation + confusion + sensory deficits + misperception

10-20% in acute beds have delirium

10-50% have delirium post-surgery

In 2012/13 79,200 admissions to hospital

In long-term settings just under 20%

In a nursing home of 60 beds around 10-12 residents

Traditionally under-reported so maybe more



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# What can we do?

## Prevention

- **Pain**
- **Infection**
- **Nutrition**
- **Constipation**
- **Hydration**
- **Sleep**
- **Medication**
- **Environment**

**Pain** – can provide a distraction and reduce anxiety

**Infection** – with associated pain, increased mobility, increase well being

**Nutrition** – changing environment, activity to stimulate hunger

**Constipation** – keeping active, promote stimulate hunger for a balanced diet

**Hydration** – keeping active,

**ENCOURAGE UP TO 2 L A DAY AND ACT IN HOT WEATHER.**

**Sleep** – active in day, reduce anxiety, calming environment, relaxation. **AVOID**

**CAFFEINE AT NIGHT, MAINTAIN STRUCTURE, REPLICATE DAYLIGHT TO AVOID SUNDOWNING**

**Medication** – helping reduce stress and anxiety

**Environment** – supportive healing environment active/calm

# See what you see..... (RCN 2017)

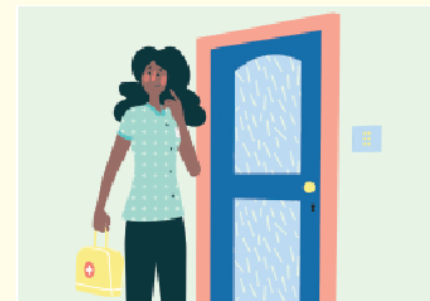
## Don't Discount Delirium

Supported by



Royal College  
of Nursing

Any person can get delirium, but it is more common when a person is older, has cognitive or sensory impairment or is very ill. You can make a difference if you recognise delirium early and escalate it.





Just look for a change in:

AROUSAL (AWAKENESS)	THINKING	PERCEPTION	FUNCTION	BEHAVIOUR
More sleepy than usual	Poor concentration	Seeing things	Less mobility	Refusing to co-operate
More alert or active than usual	Slow responses	Hearing things	Less movement	Withdrawn
Hard to wake up	More confused	Paranoid	Restless/agitated	Change in attitude
			Not eating	Change in communication
			Sleep problems	

**ACT IF YOU SUSPECT DELIRIUM - TELL SOMEONE IMMEDIATELY**

# What is a contingency?

**Don't Discount Delirium**

Supported by  

## Delirium Escalation Plan

This is not a strategy but a local escalation plan which provides you and your team with instructions regarding what to do if delirium is suspected. Remember to check if your organisation has an existing delirium strategy in place.

**Client group:**

**Circumstances:**

**What to do/who to contact:**

**ACT IF YOU SUSPECT DELIRIUM - TELL SOMEONE IMMEDIATELY**

September 2017 / Publication code: 006\_618

## Client Group

Mrs S has a diagnosis of Alzheimer's. She has also a history of falls and it has **been identified recurrent urine infections**. She also has a catheter in place

## Circumstances

Mrs S struggles to maintain a healthy fluid intake. **She forgets to drink and has a tendency to leave them and walk away. She is also prone to infections due to the catheter.**

Mrs S will present **with increased confusion and agitation and she may hallucinate (the difference being that this will be a rapid increase suggesting delirium rather than her dementia).**

## What to do/who to contact

On first sign of any "rapid" changes in behaviour as well as physical deterioration (fever) contact the GP. **Stress on "first signs" of "rapid deterioration"**

Encourage drinks and sit with Mrs S rather than allowing her to self administer fluids

# How do we support the family?



**MindEd**  
**for Families**



**Seek support and advice (don't go it alone)**

# I'm A Carer And I'm Stressed Out

[Easy Read PDF](#)[Professional Author Details](#)

Date published: 31 March 2018 Deadline for review: 31 March 2021

## Introduction

Many people don't really think about whether they are a carer.

You may be looking after your husband or wife, another relative or friend or neighbour. They may have problems with their physical health such as walking or chronic pain and need practical help or they may have mental health problems or dementia. If you are giving them support because they are struggling to cope and do not get paid for this, then you are a carer.

- **Recognize what you're up against.**
- Recognise how the dementia is affecting communication and adapt.

- **Avoid distractions.**
- Quiet environment that allows the person to focus

- **Speak clearly and naturally in a warm and calm voice.**
- Refrain from treating the person as an infant

- **Refer to people by their names.**

- **Talk about one thing at a time.**
- Avoid a scatter gun approach
- Avoid multiple threads

- **Use nonverbal cues.**
- Smile and good eye contact, at the severe end of the spectrum non-verbal and visual clues

- **Listen actively.**
- If you are struggling check out what is being said.

**Understand there will be good days and bad days.**

- **Have patience.**
- Allow time for a response,, give choice, allow for contribution and use visual if struggling



## Think about this....

### **Empathy**

How is the person feeling

### **Mirroring**

How is your anxiety and impatience affecting the person

### **Disempowerment**

How does it feel if the person is being done for rather than allowing them to do it for themselves.

### **Over-stimulation**

Can this cause anxiety and frustration?

### **Under-stimulation**

Is this good?



Impatient – WALK AWAY



Angry – WALK AWAY



## **Continue to learn**

Never be afraid to say I don't know and need some advice.  
Don't go into a situation unprepared