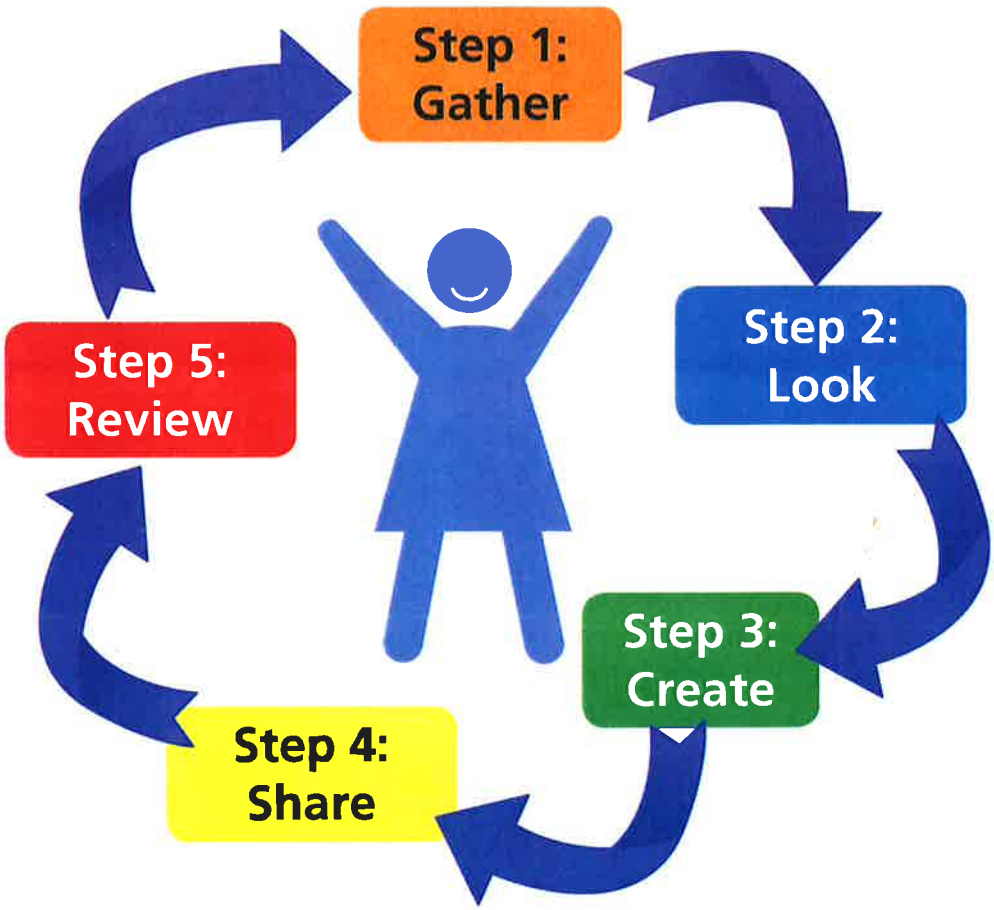
One Gloucestershire
Transforming Care, Transforming Communities

The Gloucestershire 5 Step Approach:

Personalised Care Planning for Behaviours that Challenge in Dementia



Step 1 – Gather information

Check for physical causes for example, PINCH ME (Ref: Portsmouth hospital NHST, 2011)

Gather ABC charts & life stories, for example 'This is me' (Ref: Alzheimer's Society, 2017)

Step 2 – Look at the information;

Explore & consider findings with staff and relatives/friends.

Think about: 'what is the person communicating?

Use the 'at a glance' / enriched model or equivalent

Step 3 – Create a traffic light personalised plan (RAG plan)

Identify behaviours and patterns from the information gathered

Link to existing care plans

Step 4 – Share the traffic light personalised plan (RAG plan)

Make this visible for all workers and relatives /informal carers

Step 5 – Review and update the traffic light personalised plan (RAG plan)

Use any new ABC charts and other feedback from staff/relatives

The **Dementia Training** *& Education Strategy for Gloucestershire*

Record of Activity:

Traffic Light (RAG) plan

Date: Completed or Reviewed	Signature	Print Name

Abbey pain scores:

Date of Abbey score	Signature:	Print Name:

Think Psychological Needs

Think Delirium

If you are thinking it may be delirium check out possible cause with **PINCH ME**:

Pain
Infection
Nutrition
Constipation
Hydration
Medication
Environment

For fuller assessment and on-going review use CAM assessment
(refer to Page 18)

Example: At A Glance / Enriched Model

Name: .....

Type of Dementia:

Alzheimer's Disease

Lewy Body Disease

Vascular Dementia

Areas of the brain which may be compromised, difficulties with:

Parietal lobe *(doing, making sense of the world):*

Frontal lobe *(organising / decision making / controlling):*

Temporal lobe *(Memory / language / rhythm / storage):*

Occipital lobe *(vision):*

Life Story:

- Work / Children / Marriage
- Childhood anxiety / trauma or separation
- The person's passions and traumatic/
- Significant events
- What was / is the person's view of the above?
- What was / is important to the person?

Personality:

- Quiet and shy or outgoing and confident
- Competitive and organised or laid back and easy going
- Disorganised and chaotic or organised
- Curious or cautious

Behaviour causing distress

Relationships:

- Who were the person's significant friends and are they still around
- What were family / friends relationships like: good / bad / indifferent
- Are there any spiritual relationships?

Physical health and Mental Well-Being:

- Chronic or acute pain
- Any long standing physical disabilities
- Any mental health issues
- Other long term conditions
- Any sight or sensory impairments
- Any addiction issues
- Did the person have an interest in alternative therapies?

Environment:

- What are the routines?
- What is it like living where the person is living?
- Where does the person prefer to spend their day?
- Opportunities for engagement?
- Is it noisy? Is it quiet? Is it warm? Is it cold?
- Does it make sense for the person?
- Can the person move about if they want?
- Can the person have a cup of tea when they wish?

At A Glance / Enriched Model

Name: .....

Type of Dementia:

Areas of the brain which may be compromised, difficulties with:

Personality:

Physical health and Mental Well-Being:

Behaviour causing distress

Environment:

Life Story:

Relationships:

Traffic Light Plan (RAG Plan) My support plan for my well-being

The following page give ideas about things to document when pulling together the traffic light plan. Put in detail about the person that you know from life history information, talking with the person and /or the person's friends and family, other people supporting the person, and general observation.

Green (preventative) : things that keep me well and feeling Ok

- Things I enjoy having in my environment eg music /comfort items .....
- Things that might help you to communicate with me on my dominant side (eg right/left)
- Using open and friendly body language and environment
- My sensory likes and dislikes (eg tastes /sounds / sights)
- What period of my life do I tend to think and talk about eg when at work
- What kind of things do I like doing eg watching TV (which programme) .....
- When is it best to support me with my personal care eg late mornings .....
- What things help me to keep myself calm and content eg in the garden...

Amber (Proactive):things to try to meet my needs if I start to get distressed

- These are the warning signs that show I am becoming unsettled or distressed, eg looking more anxious, walking around more.....
- This typically happens when....
- Support me at these times by... approach calmly/low tone of voice/stand alongside me /saying 'sorry' or 'this is hard'?
- Use of VERA : validate /empathise/ reassure / activity
- The kind of things that might be a distraction for me at these times are...
- The kind of things that I might find reassuring at these times are .....
- The things that could be causing me distress in the environment are....

Red (Reactive): things to try when I'm distressed

- Keep me and others safe by..../help me feel better by...
- Avoid confrontation, only intervene if there is any immediate risk to me or others eg step away and allow the person a time out on their own
- Ensure my environment is safe and discretely remove risks
- Allow me to space and observe me to keep things safe from a distance
- Allow sufficient time (at least ....mins) for my anxiety to reduce after I am upset/don't ask me to reflect on what has happened.

Traffic Light Plan (RAG Plan) My support plan for my well-being

My Name is……Date:……

I like to be called……

Green (preventative) : things that keep me well and feeling Ok
Amber (Proactive):things to try to meet my needs if I start to get distressed
Red (Reactive): things to try when I'm distressed

Example 1: Joe

Green (preventative): things that keep me well and feeling OK

Example: I always have tea (3 sugars) **before** getting up. I like a beer with my evening meal: (alcohol free beers in fridge). I like to get up late (just before lunch) and go to bed late (around 11.30pm). I sleep with the window and door open. I prefer a strip wash rather than shower/bath.

I like anything active due to my past job as a builder. I enjoy listening to radio 2 or country music. I like to go in the garden after lunch even if it's raining/cold. (coat and boots in room). Once in the garden I can potter around safely alone.

Regular walking in the garden helps me with lifelong back pain. Please give me paracetamol if I'm wincing on movement.

Amber (Proactive): things to try to meet my needs if I start to become distressed

Example: I walk around faster when I am becoming distressed usually in the evenings when I feel that I should be going out. Reminding me that *'things are taken care of'* can help me feel secure. Finding me tasks to do such as packing items (use boxes /papers to shift through) can help me feel I have a purpose. Walking along with me to my room and supporting me to put on my Don Williams CDs can help me keep occupied at these times.

Check pain relief (use pain assessment such as Abbey Pain Scale)

Red (Reactive): things to try when I'm distressed

Example: In the evenings sometimes I start to pace about when I'm very distressed shouting to *'get me out'*. Leaving me to walk about for around 15 minutes can sometimes help me to express my frustration. Saying; *'you're looking for work Joe'* will recognise how I'm feeling. Offering me a hot chocolate (saying *'hot chocolate time now Joe, work's all done'* may support me to feel comforted and will remind me that it is evening and time to settle.

I like digestive biscuits with any evening drinks.

Do not confront me at these times by saying that I don't need to work.

Example 1: Joe

Green (preventative) : things that keep me well and feeling Ok

- I always have tea (3 sugars) **before** getting up. I like a beer with my evening meal: (alcohol free beers in fridge). I like digestive biscuits with evening drinks.
- I like to get up late (just before lunch) and go to bed late (around 11.30pm).
- I sleep with the window and door open. I prefer a strip wash rather than shower/bath.
- I like anything active due to my past job as a builder. I enjoy listening to radio 2 or country music.
- I like to go in the garden after lunch even if it's raining/cold. (coat and boots in my room under my bed). Once in the garden I can potter around safely alone.
- Regular walking in the garden helps me with lifelong back pain. Please give me paracetamol if I'm wincing on movement.

Amber (Proactive):things to try to meet my needs if I start to get distressed

- I walk around faster when I am becoming distressed usually in the evenings when I feel that I should be going out.
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- Check pain relief (use pain assessment such as Abbey Pain Scale)

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- Do not confront me at these times by saying that I don't need to work.

Example: ABC chart plus examples (positive (in green) and negative (in yellow))

Date/ time	Where did the incident occur?	Which staff were involved?	What was the person doing just before the incident? **A=Antecedent**	What did you see happen? **B=Behaviour**	What did the person say at the time of the incident?	How did the person appear at the time?	How was the situation resolved? **C=Consequence**
01/06/18	Asleep. Became aggressive. Shouted. **Negative example: not enough detail provided. Use of labelling language. Judgemental.**					**Angry**	Left alone.
01/06/18 8:30am	Incident occurred in the Ethel's bedroom. Vicki and Lisa were supporting Ethel. A = Ethel was encouraged out of bed as she was incontinent of urine and needed support with personal care. Ethel had not slept very well during the night. B = Ethel attempted to grab at Vicki and pinch her and shouted "leave me alone" and "it's cold cold cold, away away ". **Positive example: plenty of detail Use of quotes to describe what happened**					**Anxious, Frightened, Irritable, Tired**	Staff moved away from Ethel to give her some space. Vicki approached Ethel with a cup of tea and talked about what she liked for breakfast (porridge) and reassured her that she was there to help her. Vicki wrapped Ethel in the towel for comfort and warmth. Ethel became more relaxed and allowed both staff to support her with personal care.
01/06/18	Dining room. Nurse and Carer walked resident into dining room but they would not sit down. She got very angry and grabbed knife and shouted at everyone. **Negative example: not enough detail provided. Use of labelling language. Judgemental**					Angry	Got knife off resident. Moved resident away from the area.
01/06/18 17:00	Incident happened in dining room. Tony and Steve were supporting Ethel to sit at the dining room table next to Marjory. Dining room was busy, staff and residents moving around and taking their seats. Radio was also playing, loudly. Sun glaring in through garden window and dining room very warm. Ethel banged knife on the table and put her hands on the table and did not want to sit down and tried to push staff away, saying "go away" and "I want to go home". **Positive example: plenty of detail Great description of environmental factors Use of quotes to describe what happened**					**Angry, Anxious, Frightened, Frustrated**	Tony offered a spoon and said 'you need the quiet'. Led Ethel to a quieter area of the dining room near the open window – she likes nature. Tina found a small table for Ethel to eat her lunch whilst looking at the garden.

5 step approach: ABC chart plus examples (positive (in green) and negative (in yellow)

Date/ time	Where did the incident occur?	Which staff were involved?	What was the person doing just before the incident? **A=Antecedent**	What did you see happen? **B=Behaviour**	What did the person say at the time of the incident?	How did the person appear at the time?	How was the situation resolved? **C=Consequence**
						Angry, Anxious, Worried, Bored, Content, Depressed, Despairing, Frightened, Happy, Frustrated, Irritable, Physically unwell, Restless, Sad	
						Angry, Anxious, Worried, Bored, Content, Depressed, Despairing, Frightened, Happy, Frustrated, Irritable, Physically unwell, Restless, Sad	
						Angry, Anxious, Worried, Bored, Content, Depressed, Despairing, Frightened, Happy, Frustrated, Irritable, Physically unwell, Restless, Sad	

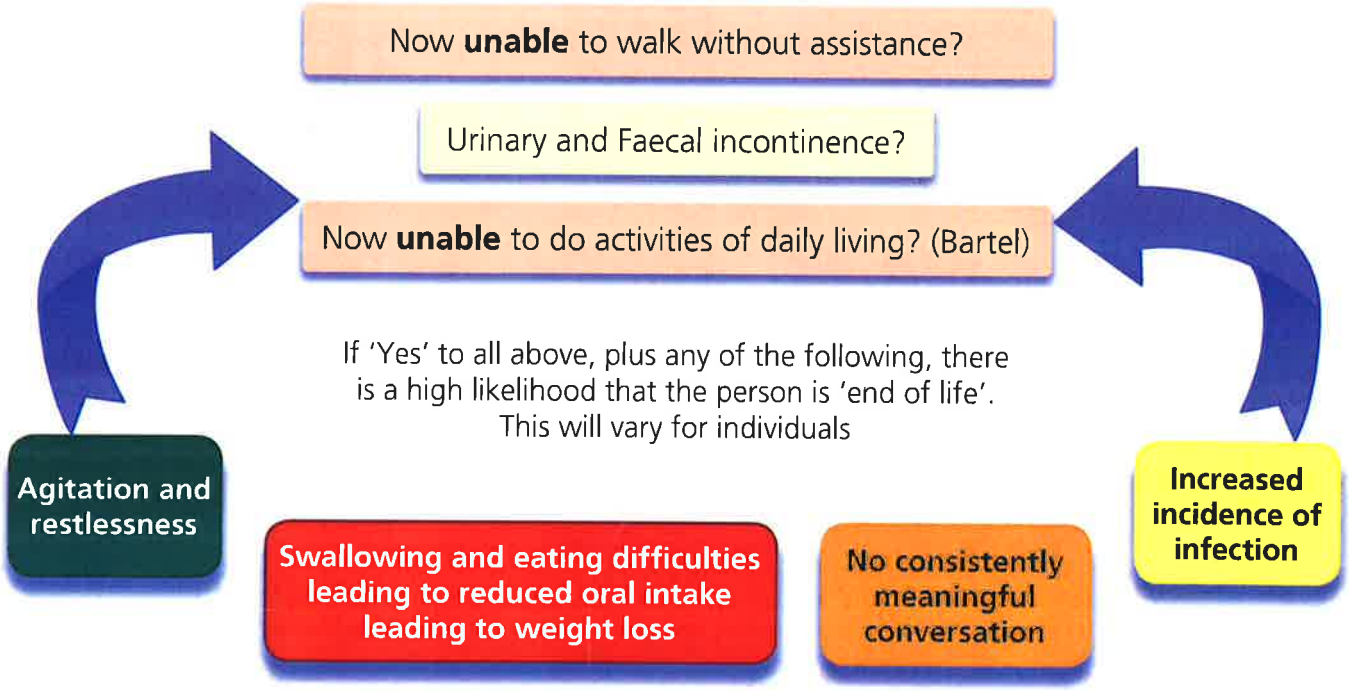
End of Life and Dementia Guidance

Dementia is a life limiting condition.

The following guidance is to support clinicians to identify whether the person with dementia is at the end of life phase.

First:

Check the 'Unable sandwich': is the answer 'Yes' to each layer?
Use the Rockwood Score; is the person 6 or above, and would you expect the frailty score to increase?



Ref: Thomas et al (2011) Prognostic Indicator Guidance(= (PIG) 4th Edition The Gold Standards Framework Centre in End of Life Care and Nathan Davies and Steve Lliffe (2016), After the Liverpool Care Pathway Study, Rules of Thumb for End of Life Care for people with dementia.

Second

If indicators above indicate high likelihood the person is end of life, discuss with MIC:
M - Medical Team (GP)
I - Informal carers (Family/significant others)
C - Care Team (other members of multi-disciplinary team)

Definitions:

'Palliative care': support people as they live and die with life limiting illness
'End of Life Care': person expected to die in the next 6 – 12 months (Ref: Gloucestershire EoL strategy)

Third: If the indicators and discussions suggest a likely transition to end of life, plan PEACE;

- **P** Palliative and Pain Management
- **E** Eating and Drinking
- **A** Advance Care Planning and Best interests
- **C** Comfort Care Planning
- **E** Engage with informal carers and, whenever possible, the person with dementia

Clinical Frailty Scale*

1 **Very Fit** – People who are robust, active, energetic and motivated. These people commonly exercise regularly. They are among the fittest for their age.

2 **Well** – People who have **no active disease syptoms** but are less fit than category 1. Often, they exercise or are very **active occasionally**, e.g. seasonally.

3 **Managing Well** – People whose **medical problems are well controlled,** but are **not regularly active** beyond routine walking.

4 **Vulnerable** – While **not dependant** on others for daily help, often **syptoms limit activities.** A common complaint is being "slowed up", and/or being tired during the day.

5 **Mildly Frail** – These people often have **more evident slowing,** and need help in **high order IADLs** (finances, transportation, heavy housework, medications). Typically, mild frailty progressively impairs shopping and walking outside alone, meal preparation and housework.

6 **Moderately Frail** – People need help with **all outside activities** and with **keeping house.** Inside, they often have problems with stairs and need **help with bathing** and might need minimal assistance (cuing, standby) with dressing.

7 **Severely Frail – Completely dependent for personal care**, from whatever cause (physical or cognitive). Even so, they seem stable and not at high risk of dying (within ~ 6 months).

8 **Very Severely Frail** – Completely dependent, approaching the end of life. Typically, they could not recover even from a minor illness.

9 **Terminally Ill** – Approaching the end of life. This category applies to people with a **life expectancy <6 months**, who are **not otherwise evidently frail.**

Scoring frailty in people with dementia

The degree of frailty corresponds to the degree of dementia.

Common **symptoms in mild dementia** include forgetting the details of a recent event, though still remembering the event itself, repeating the same question/story and social withdrawal.

In **moderate dementia** recent memory is very impaired, even though they seemingly can remember their past life events well. They can do personal care with prompting.

In **severe dementia**, they cannot do personal care without help.

*1. Canadian Study on Health and Aging, Revised 2008.

2. K. Rockwood et al. A global clinical measure of fitness and frailty in elderly people. CMAJ 2005; 173: 489-495

DALHOUSIE UNIVERSITY

Abbey Pain Scale

For measurement of pain in people with dementia who cannot verbalise

How to use scale: while observing the resident, score questions 1 to 6.

Name of resident: .....

Name and designation of person completing the scale : .....

Date : ..... Time : .....

Latest pain relief given was ..... at ..... hrs.

Q1.	**Vocalisation** eg whimpering, groaning, crying	Absent 0	Mild 1	Moderate 2	Severe 3	**Q1**	
Q2.	**Facial expression** eg looking tense, frowning, grimacing, looking frightened	Absent 0	Mild 1	Moderate 2	Severe 3	**Q2**	
Q3.	**Change in body language** eg fidgeting, rocking, guarding part of body, withdrawn	Absent 0	Mild 1	Moderate 2	Severe 3	**Q3**	
Q4.	**Behavioural Change** eg increased confusion, refusing to eat, alteration in usual patterns	Absent 0	Mild 1	Moderate 2	Severe 3	**Q4**	
Q5.	**Physiological change** eg temperature, pulse or blood pressure outside normal limits, perspiring, flushing or pallor	Absent 0	Mild 1	Moderate 2	Severe 3	**Q5**	
Q6.	**Physical changes** eg skin tears, pressure areas, arthritis, contractures, previous injuries	Absent 0	Mild 1	Moderate 2	Severe 3	**Q6**	

Add scores for 1 - 6 and record here			**Total Pain Score**	
Now tick the box that matches the Total Pain Score	**0 - 2 No pain**	**3 - 7 Mild**	**8 - 13 Moderate**	**14 + Severe**
Finally, tick the box which matches the type of pain		**Chronic**	**Acute**	**Acute on Chronic**

Jennifer Abbey, Neil Piller, AnitaDe Bellis, Adrian Esterman, Deborah Parker, Lynne; Giles and Belinda Lowcay (2004) The Abbey pain scale: a 1-minute numerical indicator for people with end-stage dementia , International Journal of Palliative Nursing, Vol 10, No 1pp 6-13.

CONFUSION ASSESSMENT METHOD (CAM) SHORTENED VERSION

Name of Patient:	Name of Assessor:	Date:

I. ACUTE ONSET AND FLUCTUATING COURSE	
Is there evidence of an acute change in mental status from the patient's baseline?	Yes / No
Did the (abnormal) behaviour fluctuate during the day, that is tend to come and go or increase and decrease in severity?	Yes / No
II. INATTENTION	
Did the patient have difficulty focusing attention, for example, being easily distractible or having difficulty keeping track of what was being said?	Yes / No
III. DISORGANIZED THINKING	
Was'the patient's thinking disorganized or incoherent, such as rambling or irrelevant conversation, unclear or illogical flow of ideas, or unpredictable switching from subject to subject?	Yes / No
IV. ALTERED LEVEL OF CONSCIOUSNESS	
Overall, how would you rate the patient's level of consciousness?	
-- Alert (normal)	Yes / No
-- Vigilant (hyperalert)	Yes / No
-- Lethargic (drowsy, easily aroused)	Yes / No
-- Stupor (difficult to arouse)	Yes / No
-- Coma (unrousable) ·	Yes / No

If all items in section 1-111 are Yes and at least one item from section IV is Yes a diagnosis of delirium is suggested.

Adapted from Inouye SK et al, Clarifying Confusion: The Confusion Assessment Method. A New Method for Detection of Delirium. Ann Intern Med. 1990; 113:941-8.