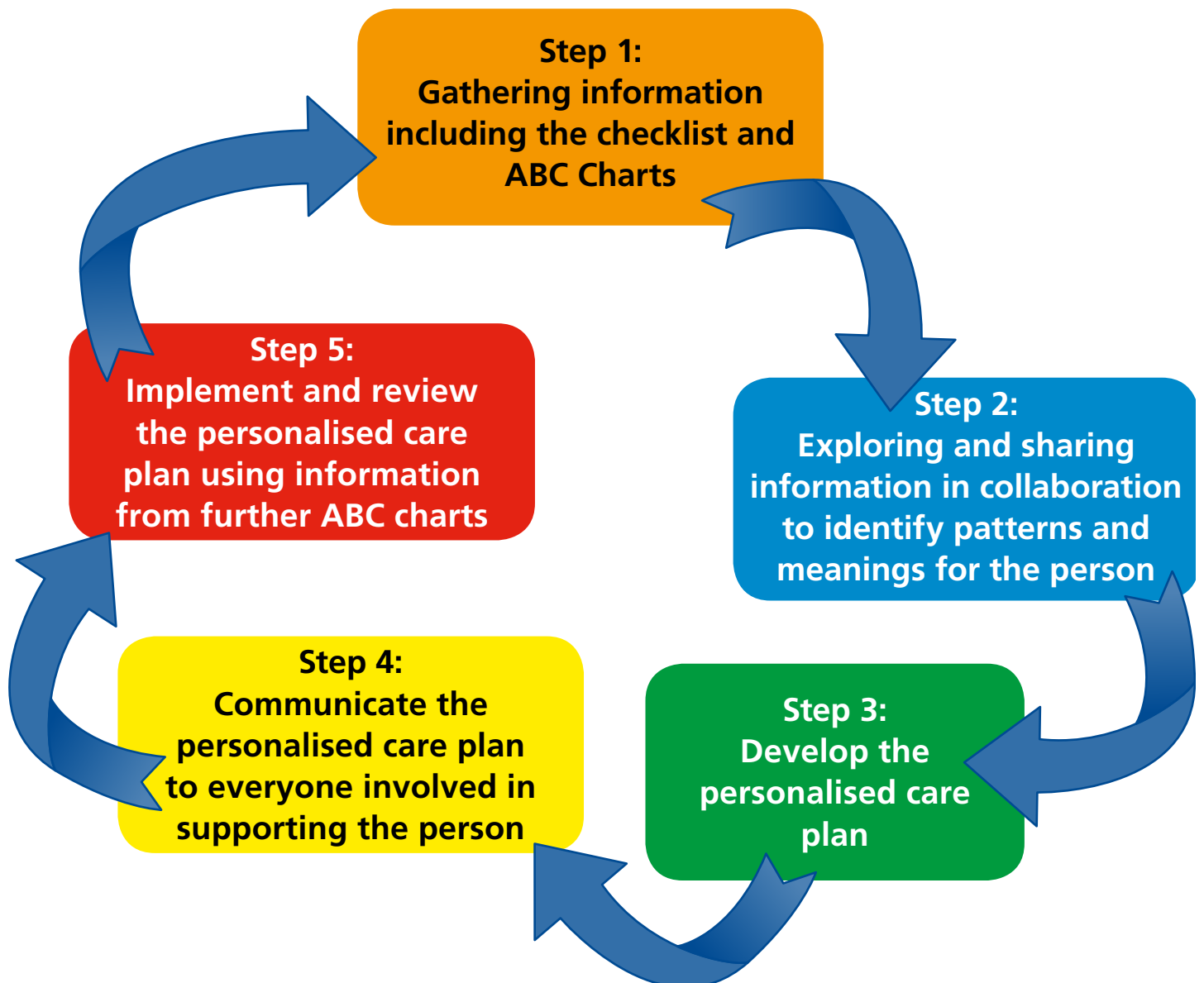


*The **Dementia Training & Education Strategy for Gloucestershire***

The Gloucestershire 5 Step Approach: Personalised Care Planning for Behaviours that Challenge in Dementia

*A guidance and resource pack for Health and Social Care staff
and informal carers*



Acknowledgements:

Rose McDowall, Team Manager, Managing Memory 2gether

Helen Vaughan, Joint Commissioning Manager for Dementia, NHS Gloucestershire Clinical Commissioning Group

Angela Willis, Strategic Lead for Gloucestershire Dementia Training and Education Strategy, Gloucestershire County Council

Keith Springthorpe, Community Mental Health Nurse, Care Home Support Team 2gether NHS Foundation Trust

Ann O'Reilly, Team Manager, Care Home Support Team/Reablement Mental Health Nurses, 2gether NHS Foundation Trust

Rachel Peak, Dementia Education Nurse, 2gether NHS Foundation Trust

Kathy Holmes, Engagement and Involvement Lead, Managing Memory 2gether

Liz Delahaie, Community Mental Health Nurse, 2gether NHS Foundation Trust

Louise Dickenson Knight, Community Mental Health Nurse, 2gether NHS Foundation Trust

Sam Harris, Community Dementia Nurse, 2gether NHS Foundation Trust

Tina Kukstas, Lead Nurse Practitioner (Organic Services), 2gether NHS Foundation Trust

Rob Jefferies, Positive Behaviour Management Training Manager/LDISS lead PBM Practitioner, 2gether NHS Foundation Trust

Martin Ansell, Older Age Psychiatrist 2gether NHS Foundation Trust

The Gloucestershire 5 Step Approach:

Personalised Care Planning for Behaviours that Challenge in Dementia

Introduction

A person with dementia will sometimes behave in a way that others find difficult or challenging to manage.

Behaviour changes can be a result of the progression of dementia but it may also be a response to emotional stress; physical illness; or environmental changes.

These behaviours may cause distress to both the person with dementia and to others including carers, who will need help and support to relieve the distress and develop a plan to improve quality of life.

Aim of this pack.

The aim of this pack is to describe a process approach to developing a personalised care plan for the person with dementia and their carers.

It proposes that all those involved in supporting people with dementia and their carers in responding to behaviour that challenges in Gloucestershire will use this process to ensure a consistent approach across all care settings.

Why is it needed?

NICE guidelines: Dementia Supporting people with dementia and their carers in health and social care says this about behaviour that challenges:

People with dementia who develop non-cognitive symptoms that cause them significant distress or who develop behaviour that challenges should be offered an assessment at an early opportunity to establish likely factors that may generate, aggravate or improve such behaviour.

The assessment should be comprehensive and include;

- the person's physical health
- depression
- possible undetected pain or discomfort
- side effects of medication
- individual biography, including religious beliefs and spiritual and cultural identity
- psychosocial factors
- physical environmental factors
- behavioural and functional analysis conducted by professionals with specific skills, in conjunction with carers and care workers.
- Individually tailored care plans that help carers and staff address the behaviour that challenges should be developed, recorded in the notes and reviewed regularly.

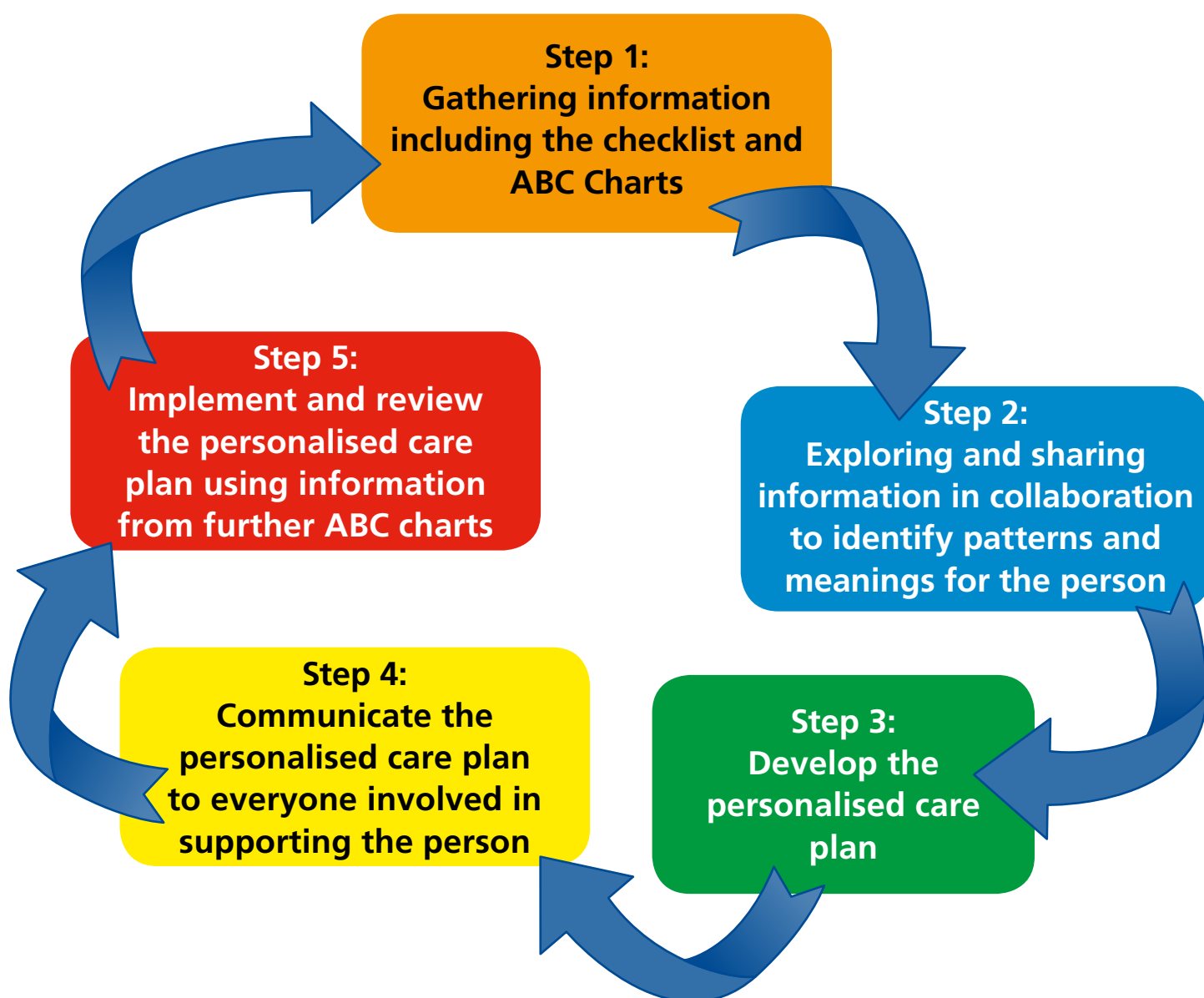
In addition to NICE guidance an assessment should also consider communication style and potential barriers. The frequency of the review should be agreed by the carers and staff involved and written in the notes.

A consistent approach is identified as being essential to the success of personalised care plans in reducing the distress associated with challenging behaviour. (James, I 2007)

What is in this pack?

- Explanation of the Gloucestershire 5 step process and of each step.
- Suggestion of tools with examples
- Resources to use in practice. (see **Appendices** which are in the 'Appendices Booklet' within the folder to photocopy as required).

The diagram below identifies the 5 steps in the process:



Step 1: Gathering Information

Gathering information including the checklist and ABC Charts (Appendices 1, 2, 3a and 3b)

It is increasingly recognised that knowing the personality and history of the person with dementia can help us understand their behaviour which is often due to unmet needs, either physical or psychological. It is therefore important to gather as much information as you are able to about both the person and the behaviour.

You will need to ask what is the behaviour that is causing concern and who is the behaviour a problem for?

It is suggested that you can use a checklist (Appendix 1) and below for examples of information to be explored. A further example of gathering brief information is to use a personal profile (Appendix 2). These help bring together information about the person.

All of this information will help in putting together the personalised care plan.

Checklist	
	Examples of areas to explore.
Type of dementia	How does this affect memory ,communication and everyday tasks
Life story	This is not just a list of dates. Ask about the person's life, work, marriage, and children. What were their interests and what were the things they were passionate about or important to them. Also consider any past traumatic events.
Personality	Consider, quiet, and shy, confident and outgoing. A bit of a 'joker' or someone who is more serious and angry.
Physical wellbeing	Does the person experience pain chronic or acute? Any long term conditions they are living with? Sensory impairments or disabilities? Current medication. Use of substances such as drugs and alcohol. Does the person have an interest in alternative therapy
Mental wellbeing	Any depression anxiety. What and / or who makes the person happy or sad? Think about spiritual beliefs
Relationships	Who are the family members who have contact with the person? Are relationships good / bad / indifferent?
Environment	Where is the person living? Do they like it? How do they spend their day? Does the person have freedom to make choices and engage with people outside of their home/the care home?

ABC Charts

In addition to this it is important to gather as much information as possible about the behaviour causing concern. This can be collected using ABC charts (Appendix 3a and 3b)

Why collect and analyse data from ABC Charts?

- To accurately describe the behaviours of concern.
- To understand what may be the triggers for an individual's behaviour
- Identify when and under what conditions a behaviour is more or less likely to occur
- To establish possible function of the person's behaviour i.e. what are they feeling
- To enable a testing of theories of why a behaviour may occur
- To inform the development of personalised care plan.



What are ABC charts?

These are charts that allow the collection of information and observations of behaviours.

Antecedent: is the term used when describing a condition or action that occurs immediately before a behaviour. Identifying the antecedents can help to understand why the behaviour may occur, and give clues to what might be triggering the behaviour

Behaviour: provide an accurate description of the behaviour as it occurs. What is happening, what is seen and what is heard by those observing or involved. The description should be factual and concise. Avoid descriptions such as manipulative or deliberate as they are not helpful in understanding the actual behaviour. It is best to avoid judgements.

Consequence: What happens after the event? What does the person say or do? What do others say or do?

For an example of how to complete an ABC chart, go to [Appendix 3a](#)

It is important to note that people often follow patterns of behaviour so that what happens following an incident may have an impact on future similar situations.

Even when a person is unable to recall the incident, the person may often recall the emotional flavour of an event and this may link back to triggers from the past.

Step 2: Exploring and Sharing Information

Exploring and sharing information in collaboration to identify patterns and meanings for the person

Exploring and sharing information in collaboration to identify patterns and meanings for the person

This is an essential step in the process in which the information gathered is shared with all those involved in contributing to the support and care; it enables the analysis and formulation of the personalised care plan by identifying any patterns and meaning of the behaviour to the person.

At this stage there is a need to:

- Talk to everyone involved, this does not always mean that everyone needs to be in the same place but it is helpful for this to happen.
- Talk to any informal carers/friends/relatives of the person. This 'Triangle of Care' approach will allow for expert information from relatives/friends to be included.
- Identify a time and place when most people are able to attend to discuss the plan and set aside time to discuss the information collected fully.
- Identify what is important, what needs to happen first.

A way to collate the information about the person in readiness for care planning is to use the enriched model of care planning (**Appendix 4 and 5**) in conjunction with any ABC charts that have been completed. This model allows for all the various key elements to consider to be visible to allow for a holistic approach.

Elements of the enriched model:

Life Story

Type of
Dementia

Personality

Relationships

Physical
Health

Environment

NB: if the person with dementia does not have capacity to understand the relevant information in the care plan then the person's relatives/carers have a legal right to be consulted on the content of the care plan. (Ref: Mental Capacity Act 2005; Best Interest Checklist)

See **Appendices 6a, 6b, 6c**: MCA1 forms for:

Health & Treatment (MCA1 6a) / Safety (MCA1 6b) / Personal Care MCA1 6c)

Step 3: Develop the personalised care plan; for example a 'traffic light' red/amber/green (RAG) plan.

Develop the personalised care plan

What is a personalised care plan?

A personalised care plan can take many forms and provides a format to highlight ways to respond to the person dependant on the person's assessed needs.

A RAG plan is one form of personalised care planning (**Appendix 7**)

This is a plan that provides a description of interventions for the person with dementia and their carers at all levels of arousal or presentation of challenging behaviour.

It is based on the traffic light system: **Red Amber Green**.

Green: staff remain proactive to meet the person's needs to support 'well-being' and engage positively to meet physical/ psychological needs

DEVELOPING THE GREEN PLAN

Use the information from the check list and ABC charts to identify:

- Likes / dislikes.
- Normal routines and activities the person enjoys.
- What situations trigger confrontation, what approaches are helpful.
- What environmental factors might be adapted to promote well-being.

GREEN PRINCIPLES OF CARE PLANNING. Be sensible and realistic with approaches.

- The person is engaged and relaxed.
- Avoid putting the person in situations that may cause distress
- Try to reflect the person's point of view and avoid confrontation / arguments.
- Use encouragement and praise.

Amber: If the person demonstrates behaviours suggestive of increasing distress then staff respond by guidance in the plan to implement strategies to respond to the distress

DEVELOPING THE AMBER PLAN

- Use information from checklist and ABC charts to identify when the person is becoming distressed
- Describe the behaviour changes the person shows
- Think about what needs might not be met for example is the person in pain, hungry, needing the bathroom.
- Think about what approaches may be helpful and describe them in the plan.
- What can be done to improve the environment for the person

AMBER PRINCIPLES OF CARE PLANNING be sensible and realistic with approaches

- **Slow down** your interactions and communication, give the person time
- Keep communication straight forward and concrete ie. 'Doris, I can see you are worried /upset angry/ distressed'
- Don't insist on finishing task if it is causing increased distress, reduce the demands on the person
- Acknowledge the persons feelings; give time to watching and listening.
- Reduce environmental 'noise'; remove triggers if possible
- Consider distraction and what might work for the person based on their life history
- ALL STAFF BE CONSISTENT IN APPROACH

Red: As the person's behaviour becomes challenging, staff respond using precise guidance in the plan aiming to maintain the person's safety and move situation back to amber/green.

DEVELOPING THE RED PLAN

Keep the person safe and the people around them safe

Aim to reduce high levels of distress

Know what the crisis plan is – who will be called for support, what you do.

RED PRINCIPLES OF CARE PLANNING – be sensible and realistic with approaches

- Keep the person safe and the people around them safe. **Be aware** of escape routes
- Can you safely leave the person alone to settle
- **Allow time**
- **Allow space** maintain a distance
- **Stay calm** and approach in non-threatening way. Be aware of personal space and non-verbal behaviour.
- **Speak clearly and calmly** – use the person's name and engage the person with eye contact.
- Do not argue with the person.
- **Be respectful** and reassuring
- Use Positive Behaviour Management techniques if hands on is essential for safety. Seek training in this if unsure of the techniques.

Green:

carers remain proactive to meet the person's needs to support 'well-being' and engage positively to meet physical/psychological needs

Amber: If the person demonstrates behaviours suggestive of increasing distress then staff respond by guidance in the plan to implement strategies to respond to the distress

Red: As the person's behaviour becomes challenging, staff respond using precise guidance in the plan aiming to maintain the person's safety and move situation back to amber/green.

Example of a Personalised care plan is below for Peter

(Appendix 8: Peter's Personalised Care Plan)

Green Behaviours	Why?	How We Respond
<ul style="list-style-type: none">• Peter responds positively to requests and prompts when being supported with care.• Peter engages with his food and drink when he is supported with this. He prefers traditional food such as;<ul style="list-style-type: none">• <i>porridge</i>• <i>'sausage and mash'</i>• <i>Fish and chips</i>• <i>Enjoys gravy with most meals</i>• Peter enjoys music, especially Dolly Parton.• Peter likes to reminisce.• Peter enjoys his armchair and a newspaper.	<p>Peter:</p> <ul style="list-style-type: none">• Feels safe• Feels comfortable• Feels in control• Is pain free• Feels respected <p>NB:</p> <ul style="list-style-type: none">• Peter's sentences may not always be easy to understand.	<ul style="list-style-type: none">• Where possible care to be provided by female carers. Continue to explain to Peter what is happening at all times when undertaking any care tasks• Be consistent and respectful in your approach. Peter is happy to be called by his first name.• Don't rush Peter – give Peter time to eat his meals and relax with a cup of tea.• Talk to Peter about his interests: farming, cows, music (Dolly Parton).

Amber Behaviours	Why?	How We Respond
<ul style="list-style-type: none"> • Peter is reluctant to get out of bed. • Peter raises his voice and tells carers to 'go away'. • Peter reluctant to receive personal care. <p>Peter finds it increasingly difficult to make himself understood.</p> <p>NB: Peter enjoys Dolly Parton. He also enjoys the radio. He has a radio and CD player in his room.</p>	<ul style="list-style-type: none"> • It's possible that Peter is in pain • Too many / difficult demands • Environment busy or noisy • Male carers • Overwhelmed at what is happening • Has been offended by perceived impoliteness <p>NB: Try pain relief as prescribed if Abbey Pain scale indicates possibility of pain or there are other indicators.</p>	<ul style="list-style-type: none"> • Gain eye contact and move to Peter's level • Be quiet and calm in your approach • Do not crowd Peter • Support to be provided by someone with whom Peter has a positive relationship. • Try use of favourite music to help Peter to relax • Use short sentences to explain what you are doing. Apologise if you feel you have inadvertently offended Peter. Remember manners... • Try pain relief as prescribed if Abbey Pain scale indicates possibility of pain or there are other indicators.

Red Behaviours	Why?	How We Respond
<ul style="list-style-type: none"> • Peter has struck a male member of staff on the shoulder • Raised voice • Resistive to support with care tasks 	<ul style="list-style-type: none"> • Peter may be in pain/ discomfort • Peter may struggle with too much information • Feelings of frustration that he can't convey his meaning in words. • Anxiety and fear that care approaches will result in pain. • Peter may be overwhelmed and reacting to too many people talking to him / touching him at the same time. • Peter is offended by what he perceives as impolite behaviour. 	<ul style="list-style-type: none"> • Remain calm and polite in approach (be aware of body language and tone and pitch of voice). • Use minimal language & allow processing of information • One, preferably female, carer, with whom Peter has a good relationship to communicate with Peter. • Allow time for situation to calm and leave Peter alone if safe to do so. • Report and communicate situation for future review.

Step 4: Communicate the personalised care plan to everyone involved in supporting the person.

Communicate the personalised care plan to everyone involved in supporting the person

Consistency from everyone in delivering the care plan is essential and sharing the plan and having a shared understanding of the approaches outlined is a key step in the process.

If the plan has sensible and realistic interventions then it will be able to be successful. The need to share the information is essential to enable a consistent approach.

Share the plan, being mindful of confidentiality and consent of the person.

If the person with dementia does not have capacity to understand the relevant information within the plan, then the plan can be consulted on and shared in the Best Interest of the person. Mental Capacity Act (2005)

Think about who are the people who need to know the plan and how it will be communicated to them for example a family meeting, a staff handover meeting, a multi-disciplinary meeting. Consider whether it needs to be shared across all agencies.

CHECK: Does the care plan identify that the person is approaching end of life (EoL) and requires an end of life care plan?

Questions to consider? If 4 or more of these signs are positive, this is a strong indication the person may be approaching end of life.

- Onset of falls with no recent previous history
- Increased apathy and withdrawal. Perhaps a notable reduction in communication with long periods of vacantly staring.
- Increased or new anxiousness.
- Exacerbated levels of confusion (not in line with the progression of dementia)
- Recent chest infections or urinary tract infections (if 3 in 12 month period consider End of Life care plan)
- A change in sleep pattern and/or nutrition intake
- Onset of incontinence
- Development of additional physical ailments
- Starts talking about /asking for dead people / family members more frequently. (Calling for parents, looking for siblings, partners etc.)

If the person is approaching end of life then this will indicate a need for an end of life care plan.

There are several considerations relating to end of life for people with dementia which need consideration (**Appendix 9**)

Step 5: Implement & Review the Personalised Care Plan

Implement and review the personalised care plan using information from further ABC charts

It will always be necessary to review how the care plan is working, and to do this the ABC charts can be used to describe behaviours as described in step one. The whole process is then repeated; do not miss out any of the steps.

This information will enable modifications to the interventions to be made and test out if they are successful.

It is useful to look at which interventions are being used, frequent use of aversive reactive strategies and frequent use of the most restrictive strategies, would indicate a need to re-evaluate the care plan and everyone understands of same. It may be that the principles of positive risk taking need to be explored and agreed.

It is important to keep in mind the goal of the personalised plan which is to;

- Increase opportunities for well being
- Minimise distress for the person and others
- And help to reduce the stress for carers.

Note: The care plan will not necessarily eliminate the behaviour causing concern.

'Behaviour is a form of communication: often a person's attempt to communicate their physical or psychological unmet needs. The Gloucestershire approach will help carers both formal and informal, to respond positively to the person with dementia whose behaviour sometimes challenges others to understand the world as they experience it. If we remain curious, we will discover so much more about the lives of people with dementia.

Rose McDowall, Manager for the Gloucestershire Memory Services, ²gether NHSFT

Tina Kukstas, Lead Nurse for Organic Services, ²gether NHSFT

Use of Medication

Once non pharmacological measures have been exhausted then there is a role for medication in the management of behaviours that challenge.

Pain can be assessed using the Abbey Pain scale (**Appendix 10**) and can be addressed for a range of analgesics from regular paracetamol through to opiate patches. It is important to ensure compliance.

Depression can be identified through biological symptoms (loss of appetite, tearfulness, early morning wakening and changes in mood during the day). Treatment would be an anti-depressant such as citalopram unless agitation or insomnia are problematic when mirtazapine is preferable.

Where behaviours are part of dementia, especially driven behaviours then memantine is a suitable option. The dose can be built up to 20mg per day unless the patient has severe kidney failure.

There is a role for anti-psychotic medication (for example haloperidol or risperidone). These are useful for treating psychotic symptoms (hallucinations and delusions). There is also a role in treating very distressed behaviour where people are hitting out at others with a high risk of harm to others and the person.

This type of medication is not without risks, there is an increased risk of falls and worsening cognition. There is also a small increased risk of stroke. If used they should be started at a low dose and then titrated upwards. They should be reviewed every 3 months and discontinued if the behaviour has settled.

Dr Martin Ansell, Consultant Psychiatrist for Older People, 2gether NHSFT

For further information go to CCG Live Dementia on the following link:

https://ccglive.glos.nhs.uk/intranet/index.php?option=com_k2&view=item&layout=item&id=409&Itemid=694

Frailty and Dementia

Changes in the symptoms and wellbeing of the person living with dementia also need to be considered in the context of frailty as a Long Term Condition. Frailty develops as a consequence of age-related decline in multiple body systems, which results in vulnerability to sudden health status changes triggered by minor stress or events such as an infection or a fall at home. People with frailty have a substantially increased risk of falls, disability, long-term care and death. Frailty is considered a graded abnormal health state that benefits from interventions such as case finding/case management, anticipatory care planning and end-of-life care.

(**Appendix 11**)

APPENDICES

Appendix 1: Checklist

Appendix 2: Personal Profile

Appendix 3a & 3b: ABC Charts

Appendix 4: Enriched care planning chart

Appendix 5: Peter example enriched care planning

Appendix 6: MCA1 Forms x 3 (Treatment/ Safety / Personal Care)

Appendix 7: Blank Personalised Care Plan

Appendix 8: Example Peter's Personalised Care Plan

Appendix 9: End of Life Information

Appendix 10: Abbey Pain Scale Assessment

Appendix 11: Rockwood Frailty Scale

Appendix 12: Feedback Form

REFERENCES and suggested reading

National Institute for Clinical Excellence (2006) Clinical Guidance 42 Dementia: Supporting people with dementia and their carers in health and social care.

James Ian Andrew. (2011) Understanding Behaviour in Dementia that Challenges. Jessica Kingsley Publishers

Kitwood Tom (1997) Dementia Reconsidered: The Person Comes First (Rethinking Ageing)

May Hazel; Edwards Paul; Brooker Dawn (2009) Enriched Care Planning for people with dementia. Bradford Dementia Group.

Powell Jennie. *Care to communicate. Helping the older Person with dementia* 2000. London: Hawker Publications

Sells Debbie, Shirley Louisa; Journal of Dementia Care: person Centred risk management: The Traffic light approach (2010)

James Ian, Stephenson Malcolm: Journal of Dementia Care: the Newcastle support model (2007)

Suggested reading for Gloucestershire case example:

Using the resources within this pack will enable the opportunity to consider the best care and support and encourage recording and sharing key information. Where this opportunity is missed it can result in a person struggling to have their behaviours recognised with associated risk of significant harm. The following is a link to the safeguarding page from Gloucestershire County Council where Peggy's story can be downloaded;

<http://www.gloucestershire.gov.uk/gsab/article/117699/Gloucestershire-Safeguarding-Adults---Adult-Case-Reviews>

Request for feedback on the Gloucestershire Approach

These resources have been developed to facilitate a consistent approach to caring for people living with dementia across local services and in response to needs articulated by colleagues working across the county.

In order to judge whether this tool meets those objectives, we invite and encourage comment and feedback. For example:

- Aspects that worked well?
- Areas that didn't work?
- Is there anything missing?
- Is there anything you would like to see changed?

Appendix 12 is a feedback form which allows for feedback about the 5 step approach and resources, as well as any anonymised stories to provide evidence of any outcomes that this approach has delivered in your workplace. This will also offer an opportunity to showcase the excellent work being delivered in Gloucestershire for people with dementia.

Thank you for your interest. Please share this approach.

