

**‘Challenging Behaviour’ and dementia in Gateshead:
a guide to understanding, coping and responding**



Gateshead

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Experience from looking after people with dementia suggests that we can usually improve their care – even when their behaviour makes this difficult. This booklet aims to help you understand and improve the care that you provide. This approach might look like hard work, but we find that it is usually makes things easier in the long run

We guide you through the areas that it will be helpful to think about. For each area, we highlight possible causes of problems in dealing with challenging behaviours – **Warning Signs** – and suggest ways of improving the care you provide – **Signposts**. We give examples from our own experience in the blue boxes as we go along. There is space in each section for your own comments. This is important as every person with dementia is different.

The principles

There are some principles that we will come back to again and again. We think that they make it easier to care for people with challenging behaviours. The principles are:

- Challenging behaviour is not meaningless or unpredictable
- A better understanding of someone leads to more potential solutions for their problems
- Better understanding often results in more effective coping with the things that you may be unable to change
- The behaviour of staff has a large effect on the nature and extent of challenging behaviour shown by the patient
- Caring teams work better when everyone is trying to deal with situations in similar ways
- Where and how someone lives has a big effect on how they behave.
- Everyone gets stuck at some point and needs advice and support

The areas that we will cover are:

The person with dementia

Understanding the person helps you understand why they behave the way they do

What you expect people to do in your residence

If you can understand what you or other members of staff are asking of people, it makes it easier to see why their behaviour can be challenging to us

Describing what is happening

- **What it is**
 - If you know what the challenge is, it helps you know what needs to change
- **When it happens**
 - If you can see a pattern to the behaviour, you can try to prevent it happening in the first place or stop it before it gets too bad.
- **Who is affected**
 - An understanding of who is affected may help you understand what needs to change. Is it your resident, or is it you?
- **How other people react**
 - Other people encourage or discourage different behaviours; sometimes settling, sometimes unsettling

Identify possible reasons for the behaviour

Unmet needs are common in challenging behaviour, for example lack of social contact or activity; unfamiliar surroundings and routines; and poor physical or mental health.

Decide what to do about it – getting a plan

How to improve the care and quality of life of someone with a challenging behaviour. The importance of setting reasonable targets.

Seeing if it works

The value of good recording and rating scales

Involving other professionals

How to get help from other people

We also give you pointers for further reading, names of people to contact for help, and explanations of the words that we use.

But first - What do we mean by challenging behaviour?'

We have designed this workbook to help you understand and care for a person with a challenging behaviour. The first question seems to be '*What do we mean by challenging behaviour?*'

Challenging behaviours are things that people do that we find hard to deal with – we find them a challenge. Challenging behaviours may include:

- **Aggression:** such as shouting, screaming, hitting, biting, scratching, throwing things or appearing threatening
- **Demanding and repetitive actions:** such as asking the same question repeatedly or being noisy and demanding
- **Lack of ability or motivation:** opting out of activities or withdrawing from people, difficulties in meeting basic needs or accepting help.

The term 'challenging behaviour' can cover any behaviour that is hard to care for or that puts someone at risk

Warning Signs

Problems will occur if:

- You can not agree with other people whether someone is showing challenging behaviours
- You see the person as the problem rather than what he is doing (the behaviour) as the problem
- You can not describe the problem to other people

Thomas punches people who try to undress him. He hits out hard most mornings and evenings when he is being changed. Several staff members have been slightly injured and most now try to avoid him. His hygiene is poor and he has developed a skin rash. Other residents stay away from him and he is lonely

Signposts

Take one behaviour at a time

Try to describe why the behaviour is challenging

- What problems does it cause for the person?
- What problems does it cause for the other residents?
- What problems does it cause for the staff?
- What problems does it cause for visitors?

Your description of the challenging behaviour

Stage 1 The person with dementia

We put this stage first because if you can understand the person, you have a better chance of understanding why they behave as they do. Every person with dementia is different. As dementia gets worse, old habits may come back. How people behave is not only down to their situation, but also to what kind of person they are.

Warning Signs

Problems will come if:

You do not know anything about your resident's background

He has been given a label (i.e. an inappropriate name like *troublemaker*) and people do not look beyond that

You do not know what he likes and dislikes

You do not know how he deals with upsets and stress

Signposts

Talk to your resident, their family and friends to get an understanding of what they are like as a person

Use reminders and prompts e.g. from possessions or old photographs

Find out how to make a Life Book or follow the Path of Life – we give details at the end

It is important to understand the person's background and culture. It can help us understand what is important to that person

Find out what he was good at and not so good at

Jane Summersby has been called attention seeking because she calls for help from her room but does not seem to need anything when people go in. Finding out about her background showed that she was one of 13 children. She married at 17 and had seven children of her own, all of whom now live away. She was landlady of a pub for most of her life. People who knew her then said she was the life and soul of the party. She always sought out company. This suggests that she is not used to being alone and that her cries for help come from her loneliness and fear when she is in her room alone. When someone else is there she feels comforted

What you think is important about your resident

Stage 2 What you expect people to do in your home

Sometimes we ask people to do things that they can not understand, or do not want to do. They then protest in whatever way they can. With some thought, you might be able to find a way around problems by changing your routines.

Warning Signs

Problems will come if:

You have routines that all of your residents have to fit into whether they want to or not. For example:

- People lack choice in when and what they eat
- People lack choice in when they get up and when they go to bed
- People lack choice in whether to be alone or in company
- People cannot choose how to spent their time
- There is nothing for people to do

Signposts

Make sure that you are able to be as flexible as possible in what you ask of people

Get everyone together, staff and residents, to discuss what you expect from each other. Try to get agreement on which routines would be a good idea

Try to get the right balance between keeping people safe and allowing them some freedom

Identify a range of personal or group activities for people to get involved in

Ask if you are behaving towards your residents as you would like to be treated yourself

Stan Robbington likes to stay up late watching television. Some of the staff feel that this is fine and let him go to bed when he wants. Other staff think that he gets too tired and is upset the next day, so they try to persuade him to go to bed early. The morning staff do not know when he had gone to bed the night before so they wake him up at different times depending on who is on duty. Mr Jones is getting confused about when he can go to bed and is starting to protest loudly when this is suggested. This disturbs the other residents who are trying to get to sleep.

What effect do your routines have on your resident?

Stage 3: What about risk?

For most people risk is inevitable and an accepted part of life. People with mental health problems are, however, often discouraged from taking risks. This is often because of perceived limitations or fear that they or others might be harmed, resulting in criticism of services.

If avoiding risk means stifling or restricting people unnecessarily then this will only increase the likelihood of an increase in challenging behaviour. What is vital is that a balance is found between promoting and tolerating risk and protecting people from harm.

Warning Signs

Problems will come if:

There is no guidance (e.g. policy and training) for staff about positive risk taking

People think they can avoid risk

Families and carers do not agree with each other on their approach to risk

There are no processes in place to identify and assess risk and evaluate measures that can reduce the chances of harmful events

Emotional wellbeing is secondary to physical safety

Signposts

Risk taking can be improved if your service can ensure that:

Your service has a clear and agreed position regarding risk – ideally this should influence policy, supervision, training and practice.

Some risks can be taken if these improve emotional wellbeing

Others, such as family and other carers understand your views on risk.

Your resident is checked for health risks and any illnesses are treated

Your resident's medication is reviewed regularly, especially for side effects.

You know what your resident likes to do and how you can promote meaningful activity

Risk should be addressed in terms of activity. For instance if there is an increased risk of aggression when a resident is approached as a consequence of him being unsteady on his feet then the risk, and the staff approach to it should be written within a mobility plan.

Norm Greatheart is rather unsteady on his feet and has some vision problems. He likes to get about and becomes frustrated when he can't pass through a locked door. He can get irritated when approached by staff and has lashed out at several staff. A plan was established to approach Norm from directly in front as his vision was better when he was looking straight ahead and to use his name clearly and repeatedly on approach. This seemed to take the element of surprise out of interactions and appeared less threatening to Norm. The plan also included taking opportunities to go out with Norm when possible. The potential falls risk was discussed with his wife who agreed it was a risk worth taking to give Norm some freedom and activity.

It is important that any risk-taking assessment should be used as an aid to decision making and, where appropriate, support planning. Risk assessment should be used when it:

- Is necessary to clearly highlight the risk.
- Clarifies who or what is at risk
- Is a useful teaching resource (for service users and staff).
- Will improve the quality of the service given.

A risk-taking assessment could describe:

- The activity to be undertaken.
- The past experience of the activity for staff, service user or significant others.
- The past ability or inability to participate in the activity.
- The skills, knowledge, equipment required to undertake the activity
- The skills, knowledge and equipment possessed by those involved in the activity that could maximise benefits and minimise risks.
- The possible desirable outcomes.
- The possible undesirable outcomes.
- The possible alternative activities.

It is important to note that under the **Mental Capacity Act** every service user should be considered as having the capacity to make decisions, including risky ones, unless they have been assessed as lacking capacity. Staff need to be clear that decisions made on behalf of a service user can be clearly identified as a 'best interest' decision. This involves making sure that the decision has been discussed with others with a knowledge of or interest in the person.

If restrictions to choice and decision making are applied these must be reviewed regularly and considered under '**Deprivation of Liberty Safeguards**'.

If a service user is lacking in capacity and is being deprived of their liberty an application for authority to do so must be made by the service to the local supervisory body (local authority for care homes and PCTs for hospitals)

Stage 4 Describe what is happening

Agreeing on what needs to change makes it easier to do something about it. To do this people need to agree on how they describe what is happening. Having a good idea of the details makes it easier to work out why someone is doing something

Warning Signs

Problems will come if:

Staff members disagree about what the problem is

You do not know when and where the behaviour happens.

You do not know who else is involved

Elsie Jones has the reputation of being violent. Looking at her behaviour in greater detail showed that she tries to hit any male member of staff who is attempting to help her with intimate care

People's behaviour is described in ways that mean different things to different people. For example, aggression, bad, naughty, attention seeking

Signposts

Try to work out the details of your resident's behaviour

You can use the checklist below to give you some ideas

See when the behaviour first started. Did anything change around then?

Write down what you think the problem is in as much detail as you can

What does your resident do?

How often does it happen?

When does it happen?

Where does it happen?

What sets it off?

How do other people react?

What is your resident doing?

- Hitting, nipping, slapping, or similar
- Threats, hurtful comments
- Shouting or screaming
- Asking the same question despite being answered
- Wandering
- Pacing up and down, not sitting still
- Refusing medication
- Refusing food or drink
- Taking off clothes in the wrong place
- Going to the toilet in the wrong place
- Something else

Who is affected by this behaviour Resident, Other residents, staff, relatives

What things make it worse? When are the behaviours worse? What are the contributions of staff, other residents, or visitors?

What things make it better? When are the behaviours better?

Where does it happen?

When does it happen

Always Sometimes Hardly ever

- Own bedroom
- Other person's bedroom
- Bathroom
- Toilet
- Dining room
- Lounge
- Corridor
- Other room (please give details)



When does it happen	Likely to Trigger		Unlikely to Trigger
	Always	sometimes	
Being woken up / asked to get out of bed			
Being dressed / asked to dress			
Being asked to go to bed			
Being undressed / asked to undress			
Being helped to / from the toilet			
Being helped during bathing			
During breakfast			
During lunch			
During tea			
Being washed			
When given medication			
During visits from relatives			
After visits from relatives			
When this person requests something they can't have			
When there is a delay in this person receiving what they want / want to do			
When no one is with this person			
When the resident is with other people			

If you can predict where and when the behaviours may be displayed, then they are usually easier to prevent in the first place. Patterns often appear and limited resources may be targeted at these times.

Stage 5 Identify possible reasons for the behaviour

If you can appreciate why someone is behaving in a particular way, you may find it easier to accept. You also have a better chance of finding a way to help them change

Warning Signs

Problems will come if:

Staff members disagree why someone is behaving that way

You think that the problem is the person rather than what they do.

You cannot think why someone is behaving in the way that they do

You say that they do it just because they have dementia

Signposts

Try to work out the details of your resident's behaviour

Put yourself in their situation. How would you feel and what would you do?

You can use the checklist below to give you some ideas. Often your resident is trying to tell you something. What might it be?

If people do not have words, they will try to tell you how they are feeling through their actions

What are they trying to cope with by behaving the way that they do?

Are they unwell? Common causes of a change in behaviour are what seem to be minor illnesses such as infections or constipation

We give some examples below. There are literally hundreds of approaches that you could try to tackle any number of challenging behaviours. Thinking about a challenging behaviour in an organised and agreed way will improve your chances of responding successfully to it.

Mrs Smith stays up late watching television. Her family think that this makes her too tired during the day and want her to go to bed earlier. The staff think that she should be allowed to choose when she goes to bed. She herself does not seem able to say why she wants to stay up Mrs Smith is confused by different people telling her different things. She actually likes to go to bed at different times depending on how she feels.

<p>Aggression: Is the person in pain? Do they feel threatened? Are they able to tell you how they feel or what they want? Does the way in which staff members react to the resident provoke a certain response, antagonize the person or make the situation worse?</p>	<p>For example: When a staff member is helping John care for himself, he felt embarrassed and abused</p>
<p>Stripping off clothing: Is the person hot? Are they tired? Do they want attention or do they want to shock/ invoke a response. Is the clothing too tight or uncomfortable? Does the person want to go to the toilet?</p>	<p>For example: Dave used to walk around inside his house naked from the waist up.</p>
<p>Shouting or screaming: Is the person in pain? Do they feel isolated or what to talk to someone? Are they distressed, feeling helpless or frustrated? Are they unable to tell you their needs or wishes?</p>	<p>For example: Joan feels bored and ignored- frustrated because you can not understand her.</p>
<p>Wandering: Does the person have too much surplus energy? Have they failed to find a balance between rest and activity? Are they walking with purpose- are they looking for someone or something? Do they feel frustrated at being 'confined' to the same environment? Do they want some fresh air? Are they bored?</p>	<p>For example: Bill used to walk miles across fields each day with his dog.</p>
<p>Refusing to eat or take tablets: Is the person suspicious/ paranoid/ depressed? Do they dislike the food offered to them? Are they used to eating at different times of the day. Have we explained what it is we want to give them and why. Are they given enough prompting and encouragement</p>	<p>For example: Leonora used to snack during the day and eat her main meal later in the evening.</p>
<p>Using the floor as a toilet Is the person disorientated or confused? Is there an underlying physical problem- infection or enlarged prostate? Has the person any awareness of their behaviour? Have you completed a continence assessment? Look at the medication they are prescribed.</p>	<p>For example: Stan has an undiagnosed enlarged prostate that means he can not wait to go to the toilet. He can not find his way around so gets caught short.</p>

Write down why you think your resident is behaving this way.

Are they trying to tell you something?

Are they unwell? What would you want to investigate /rule out?

Stage 6 Decide what to do about it – get a plan

Having a plan helps everyone feel more positive, and improves your chances of making changes for the better

Warning Signs

Problems will come if:

No one can agree what to do

You try lots of different things at once

You put all your eggs in one basket, medication for example

You give up too quickly or, on the other hand, do not change a plan that is not working

Your plan depends on isolating or punishing your resident

You get into a battle of wills which no one can win

No one takes a lead or everyone tries to take a lead

Eliza Smith shouts for her mother for hours on end. She is only quiet when someone is with her. She has been hit by another resident who was fed up with the noise that she made. The staff looked at when her shouting was the worst problem and arranged for her family, visitors from her church, and volunteers from Age Concern to sit with her at those times.

Signposts

Keep the behaviour in proportion. No one is entirely good or entirely bad.

Make sure that your resident is checked for physical ill health. Treat any illnesses

Make sure that your resident's medication is reviewed. Do they need any changes? Is everything working as it should? Are there any side effects?

Make sure that your resident is in good mental health

Who gets on best with this person? How does he or she behave? What could you copy from them?

Consider what your resident would like to do and how you could help. Can you plan meaningful activity, Diversion, One to one, quiet environment, Music, Simulated Presence, Reminiscence, Reality Orientation, Multi-sensory, Validation Therapy?

Try to get a plan that is:

Clear – everyone knows what to do.

Consistent – everyone does the same thing

Contingent – how people respond depends upon how your resident behaves

Compliant – respectful of people’s dignity and human rights

Make sure you know who needs to change – is it you, other staff, other residents, or visitors. Is the behaviour a problem for the person, or do other people need to be more tolerant?

Keep medication for challenging behaviour as a last resort. It often has limited benefits and side effects can be severe

Write down your plan:

Describe the problem:

What can you do to prevent the problem happening?

What can you do to stop the behaviour once it starts?

After it happens, what can you do to make it less likely to happen again?

Even if the behaviour does not change at all, what can you do to improve your resident’s life?

Stage 7 See if it works

You will need to find a way of seeing if your plan is working. Having a simple record or rating scale can be a help

Warning Signs

Problems will come if:

You just go on people's opinions – they often disagree

You set a target that is too ambitious, people rarely change entirely

You set no target at all – you will never know if you have succeeded

No one will take responsibility for writing things down

Ronnie Smith hits a lot of staff. A plan was put into place but he still hit people. Everyone was starting to loose heart, but the records showed that he was only hitting out half as often as before, so the plan was kept. After a while, he did not get any better, so the plan was changed with a further improvement

Signposts

Have a simple record that can be filled in at a regular meeting – handovers are good. Try and discuss with your team before completing the record. It helps people to agree

Set a target that is better than how things are right now, but does not depend on the problem disappearing entirely. That way you can feel that you have progressed even if you do not have complete success. You can always set another target if you need to.

Think about using a simple rating scale of 1-10 where e.g.

1 = no problem and 10 = extreme problem

1	2	3	4	5	6	7	8	9	10
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Records where people just need to put a tick or a number are more used than ones where people have to write a lot.

Write down how your plan went

Do you need to change things?

Stage 8 Get some help from someone else

Caring for and meeting the needs of someone with challenging behaviours can be difficult. Experience, help, and support are all useful.

Warning Signs

Problems may come if:

You try to change someone without seeking help, especially if your team does not have a lot of experience or training

Signposts

Try contacting someone from the list that follows

Working effectively with people with challenging behaviours needs a team approach. It is unlikely that any one person or profession has all of the answers. Often a number of different approaches need to be combined to have a real impact. Involving people with specialist expertise can be very useful

If further medical help is needed, for example if challenging behaviour is a response to hallucinations, seek help from a doctor

Mr Jones has a number of problems. He is very unhappy. He shouts, resists care, wanders, and disturbs other residents. Interventions to control his pain, improve his orientation, give him better occupation during the day, and allow him to self care as much as possible, all helped over time. Co-ordination with the GP, Psychiatrist, Nurses, and Activities Organiser was needed.

Write down who you want to contact. What was the outcome?

Name	What to contact for	How to contact them
Within your organisation	Advice about a specific resident Day to day support	Find out who is your clinical lead for challenging behaviours
GP/Social Worker/Community Nurse	Medical screening Advice and support Additional resources Treatment of straightforward illnesses	Contact your resident's GP or Social Worker in the first instance
Mental Health Services	Assessment of complex problems Prescribing for mental health problems Management of severe risk	Contact via your resident's GP
Challenging Behaviour Outreach Service	Teaching and training in managing challenging behaviours Advice and support in complex high risk cases	Contact via mental health services

Before you contact these organisations, make sure that you have followed this workbook – they will be pleased to look at what you have done already

Further information

- Consider training in managing challenging behaviour, de-escalation techniques, breakaway, and safe use of control and restraint
- Training packs are available from several different suppliers. For example, **Coping with Maggie - Caring for Margaret: communicating through behaviour** (2002) from Home first Community Trust, Antrim, Northern Ireland
- Useful fact sheets can be obtained from the **Alzheimer's Society** at www.alzheimers.org.uk
- Graham Stokes and Ian James have written a lot in this area. For example, **The Essential Dementia Care Handbook: A Good Practice Guide** by Fiona Goudie and Graham Stokes published by Speechmark Publishing Ltd (2002) and **Behaviour that challenges us: the Newcastle support model**. by Ian James and Malcolm Stephenson in the Journal of Dementia Care, September/October 2007
- Best practice guidelines can be found in **Dementia: Supporting people with dementia and their carers in health and social care** from the National Institute for Health and Clinical Excellence (2006)
- Nice Guideline 25 (2005)
- You can contact other organisations to learn from their experiences. For example, Mental Health Concern www.mentalhealthconcern.org produced **Challenging Behaviours: a position paper** in 2006
- Making Decisions. A guide for people who work in health and social care. (2009) Office of the Public Guardian
<http://www.publicguardian.gov.uk/docs/opg-603-0409.pdf>
- Deprivation of Liberty Safeguards. A guide for hospitals and care homes. 2009 DoH
- <http://www.scie-socialcareonline.org.uk/profile.asp?guid=f355e5a5-9439-40d3-9e8b-c6229c9adf03>

Version 4

August 2010

This is a working document which will be updated as it is used. Please send any comments and criticisms to Daniel Collerton at:

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