Understanding the Experience of Distressed Behaviour in Dementia

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Look after yourself.
A note about ‘self care’

• We may have friends, colleagues or relatives affected by dementia
• Some of the material may feel distressing
• **Take care of yourselves**
  – Do you need us to be aware of anything?
  – Is there someone here who can support you?
  – Leave if/when you need to
Darkness in the Afternoon

For use in training health, social services and voluntary organisation staff and family carers

This film may be upsetting for some viewers
Darkness in the Afternoon

• There *may* be some distressing elements for you in this short film.

• Questions to think about:
  – Consider the lady’s perspective
  – Consider the man’s perspective
  – Consider who handled things well & what did they do?
Small Group Discussion

- Work on tables

  1. **Person with dementia** – what thoughts/feeling & behaviour did you notice?
  2. **Carer/husband** – what thoughts/feeling & behaviour did you notice?
  3. **What was handled well?** & how could you tell/what’s your evidence?
Feedback

• Only **One** brief point from each group
• What you struck you &/or what have you learnt?
Policy Context

2009

Living well with dementia: A National Dementia Strategy
Accessible Summary

Putting People First

2011

Common Core Principles for Supporting People with Dementia
A guide to training the social care and health workforce
Common Core Principles

• Every Person with Dementia should have the support of people who are confident in adapting their interaction to reduce the stress & anxiety that dementia can bring.

• It is essential that support is tailored to the person & their personal interests & specific needs, encouraging independence & choice in the decisions they make.
8 Common Core Principles

1. Know the early signs of dementia
2. Early diagnosis of dementia helps people receive information, support & treatment at the earliest possible stage.
3. Communicate sensitively to support meaningful interaction.
4. Promote independence & encourage activity.
5. Recognise the signs of distress resulting from confusion & respond by diffusing a person’s anxiety & supporting their understanding of the events they experience.
6. Family members & other carers are valued, respected & supported just like those they care for & are helped to gain access to dementia care advice.
7. Managers need to take responsibility to ensure members of their team are trained & well supported to meet the needs of people with dementia.
8. Work as part of a multi-agency team to support the person with dementia.
COMMUNICATION
3. Communicate sensitively to support meaningful interaction.

- Dementia may affect a person’s ability to understand & use language accurately & appropriately. This is often seen as difficulty in remembering words or using them accurately, repetition of thoughts & lack of coherence. As the condition progresses communication can be increasingly difficult.

- This is likely to vary from day to day and required the health & social care workforce, family & friends to respond & adapt their communication with the person.

- It is important to remember that other conditions and disabilities may also affect people’s ability to communicate (e.g. learning disability)
3. Communicate sensitively to support meaningful interaction.

- **Indicative behaviours demonstrated by the workforce:**
  1. Always **make time** for people with dementia & remain patient in every situation.
  2. You should **make use of the person’s past experiences** & life story to support communicating with them.
  3. You should take into account a person’s **usual communication skills** & background culture.
  4. Try to **keep the environment calm** & as quiet as possible when communicating, allowing plenty of time to have conversations.
  5. Always **face the person** in conversation and **be reassuring** in your expressions, tone of voice & words, to reduce frustration.
3. Communicate sensitively to support meaningful interaction.

- **When speaking:**
  - Speak clearly using **short sentences** – don’t give too much information or ask too many questions.
  - Use **simple vocabulary & avoid jargon**
  - Remember that **it takes time** for people with dementia to take in a question, find the right words & frame a reply; don’t use more explanations as this will cause more confusion – **just wait**
  - **Try not to finish a person's sentence** unless you are asked to do so
  - **Try to avoid negative statements** such as “don’t …”, instead try to reinforce positive behaviour
  - Remember to **monitor your tone of voice** carefully
  - **Enjoy interacting together & use humour** to communicate this pleasure
3. Communicate sensitively to support meaningful interaction

- Repetitive questions from people with dementia can be challenging – **try to respond as though it is the first time** you have heard the question.
- Whatever is said to you, it is best to **accept this & not argue**.
- You may need to **frame any questions so the person can answer ‘yes’ or ‘no’** in specific situations, but avoid using this technique too extensively.
- **Listen carefully** to grasp the meaning & tone of the person’s communication.
- You should use **non-verbal communication** such as gesture, facial expression & [possibly] written communication.
- Take account of any **visual, hearing or 2nd language** difficulties.
- You can use **images, pictures, symbols or music** to enhance communication & facilitate understanding.
- If the person is already receiving other services, communication should be undertaken according to any **communication guidelines** that have already been developed to support the person (e.g. their care plan).
3. Communicate sensitively to support meaningful interaction

• Bill & Pat Wilson

• [https://www.youtube.com/watch?v=_OD0z0u93sw](https://www.youtube.com/watch?v=_OD0z0u93sw)

• Think about how you would communicate with Bill
5. Recognise the signs of distress resulting from confusion & respond by diffusing a person’s anxiety & supporting their understanding of the events they experience.

- People with dementia can find that unfamiliar situations become very confusing & often they struggle with changes to their environment & routines.
- They may not perceive the environment or other people’s actions in the same way we do.
- This can lead to uncharacteristic behaviour that is difficult to understand & manage.
- Person-centred care is the key to supporting people with dementia & any challenging behaviour. This approach recognises that behaviours have underlying causes.
- To support this, health & social care staff should try to understand the personal history of the person & their life story in order to address the causes of challenging behaviour.
5. Recognise the signs of distress resulting from confusion & respond by diffusing a person’s anxiety & supporting their understanding of the events they experience.

• Be aware that challenging behaviour can be managed & supported in a variety of different ways, not just through the use of anti-psychotic drugs.

• You should be able to support people with dementia in a person-centred way which should help you identify any triggers that cause challenging behaviour. Always consider whether there is an unmet need that is causing the challenging behaviour.

• You should try to identify the cause of confusion or any unmet need that may be causing the challenging behaviour.

• Try to remember that all behaviour is a reaction to a feeling – try to understand why someone may feel the way they do.
5. Recognise the signs of distress resulting from confusion & respond by diffusing a person’s anxiety & supporting their understanding of the events they experience.

- The following can cause challenging behaviour:
  - Misunderstanding the environment
  - Feeling frustrated at being unable to understand others or make themselves understood
  - Feeling frightened
  - Loss of inhibitions, self-control & decreased awareness or rules about appropriate behaviour.
  - Responding to what they feel to be over-controlling care
  - Past history & experiences
  - Pain
  - Your responses or those of others to their actions
5. Recognise the signs of distress resulting from confusion & respond by diffusing a person’s anxiety & supporting their understanding of the events they experience.

- You can support a person with challenging behaviour by following the approach suggested by the Alzheimer’s Society
  - Find ways to **react calmly** if challenging behaviour has occurred
  - **Work out the triggers** to the aggressive behaviour
  - **Tackle the triggers** [not always possible]
  - Take time to **manage your own feelings**
  - **Be creative** in finding alternative activities to help an individual move on from feelings of anxiety
Questions?