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| **Review Sheet** | |
| Last Reviewed Last Amended Next Planned Review in 12 months, or  10 Sep '19 10 Sep '19 sooner as required. | |
| Business impact | Changes are important, but urgent implementation is not required, incorporate into your existing workflow.  **MEDIUM IMPACT** |
| Reason for this review | Scheduled review |
| Were changes made? | Yes |
| Summary: | The policy has been reviewed to ensure policy and procedure, references and terminology reflect up-to-date theory and thinking about behaviour that challenges. This policy is now inclusive of the de-escalation policy and procedure as it is recognised that this is a fundamental strategy for supporting behaviours that may challenge. New resources added to support staff working with people that may present with behaviours that may challenge. |
| Relevant legislation: | * The Care Act 2014 * Health and Safety at Work etc. Act 1974 * Human Rights Act 1998 * Mental Capacity Act 2005 * Mental Capacity Act Code of Practice * Mental Health Act 1983 |
| Underpinning knowledge - What have we used to ensure that the policy is current: | * Author: Department of Health, (2015), *Mental Health Act 1983 Code of Practice*. [Online] Available from: [Accessed: ] * Author: Department for Constitutional Affairs, (2007), *Mental Capacity Act 2005 Code of Practice*. [Online] Available from: [Accessed: ] * Author: Emerson E, (2001), *Challenging Behaviour: Analysis and intervention in people with learning disabilities*. [Online] Available from: [Accessed: ] * Author: Harris J, (1996), *Physical restraint procedures for managing challenging behaviours presented by mentally retarded adults and children.*. [Online] Available from: <http://www.ncbi.nlm.nih.gov/pubmed/8778938>[Accessed: 10/9/2019] * Author: National Institute for Health and Care Excellence, (2015), *NG10, Violence and aggression: short-term management in mental health, health and community settings*. [Online] Available from: <https://www.nice.org.uk/guidance/ng10>[Accessed: 10/9/2019] * Author: Royal College of Emergency Medicine, (2016), *Guideline for the Management of Excited Delirium / Acute Behavioural Disturbance*. [Online] Available from: [https://www.rcem.ac.uk/docs/College%20Guidelines/5p.%20RCEM%20guidelines% 20for%20management%20of%20Acute%20Behavioural%20Disturbance%20(May% 202016).pdf](https://www.rcem.ac.uk/docs/College%20Guidelines/5p.%20RCEM%20guidelines%20for%20management%20of%20Acute%20Behavioural%20Disturbance%20(May%202016).pdf) [Accessed: 10/9/2019] * Author: Department of Health, (2014), *Positive and Proactive Care: reducing the need for restrictive interventions*. [Online] Available from:   [https://www.gov.uk/government/uploads/system/uploads/attachment\_data/file/300293/JRA\_](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/300293/JRA_DoH_Guidance_on_RP_web_accessible.pdf) [Accessed: 10/9/2019]   * Author: Department of Health, (2002), *Guidance for Restrictive Physical Interventions for people with learning disability and autistic spectrum disorder, in health, education and social care settings*. [Online] Available from:   [http://webarchive.nationalarchives.gov.uk/20130107105354/http:/www.dh.gov.uk/prod\_cons](http://www.dh.gov.uk/prod_cons) [Accessed: 10/9/2019]   * Author: National Institute for Health and Care Excellence, (2015), *Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges*. [Online] Available from: <https://www.nice.org.uk/guidance/ng11>[Accessed: 10/9/2019] |

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| Suggested action: | * Encourage sharing the policy through the use of the QCS App |
| Equality impact Assessment: | QCS have undertaken an equality analysis during the review of this policy. This statement is a written record that demonstrates that we have shown due regard to the need to eliminate unlawful discrimination, advance equality of opportunity and foster good relations with respect to the characteristics protected by equality law. |



**1. Purpose**

* 1. To provide all staff with the core principles that promote Service User and staff safety, by understanding why behaviours that may challenge can occur and that the use of de-escalation can enable the respect and dignity of Service Users at all times and the use of the least restrictive option. Staff should read this policy with the Restraint Policy and Procedure of Holbeach Hospital & Nursing Home.
  2. To support Holbeach Hospital & Nursing Home in meeting the following Key Lines of Enquiry:

**Key Question Key Lines of Enquiry**

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| --- | --- |
| EFFECTIVE | E1: Are people’s needs and choices assessed and care, treatment and support delivered in line with current legislation, standards and evidence- based guidance to achieve effective outcomes? |
| EFFECTIVE | E2: How does the service make sure that staff have the skills, knowledge and experience to deliver effective care and support? |
| SAFE | S1: How do systems, processes and practices keep people safe and safeguarded from abuse? |
| WELL-LED | W1: Is there a clear vision and credible strategy to deliver high-quality care and support, and promote a positive culture that is person-centred, open, inclusive and empowering, which achieves good outcomes for people? |

* 1. To meet the legal requirements of the regulated activities that Holbeach Hospital & Nursing Home is registered to provide:
     + The Care Act 2014
     + Health and Safety at Work etc. Act 1974
     + Human Rights Act 1998
     + Mental Capacity Act 2005
     + Mental Capacity Act Code of Practice
     + Mental Health Act 1983



**2. Scope**

* 1. The following roles may be affected by this policy:
     + All staff
  2. The following Service Users may be affected by this policy:
     + Service Users
  3. The following stakeholders may be affected by this policy:
     + Family
     + Commissioners
     + External health professionals
     + Local Authority
     + NHS



**3. Objectives**

* 1. To allow staff to develop an understanding of the needs of Service Users who may display behaviour that may challenge. With greater understanding, staff are able to monitor for triggers in behaviour and minimise the risk of escalation and further distress for the Service User.
  2. Staff are clear on the requirements within relevant codes of practice and associated policies and procedures, to support correct de-escalation balanced with the respect of human rights.



**4. Policy**

**4.1** Holbeach Hospital & Nursing Home will have knowledgeable, competent staff available and resources to respond appropriately to behaviours that may challenge as they present. This includes being aware of

the environment and how it can minimise triggers that may escalate those behaviours, whilst complying with Health and Safety and other policies associated with safeguarding Service Users, staff and visitors.

Staff will maintain an open and honest approach towards all Service Users at all times, and will deliver care in a consistent and non-judgmental manner.



**5. Procedure**

* 1. Holbeach Hospital & Nursing Home acknowledges that no policy or procedure can eliminate behaviours that challenge and there is no “one size fits all” approach to its management. However, the following procedures are based fully on evidenced-based practice, underpinned by person-centred care planning and the recognition that everyone is unique and individual.

Skilled management can often divert or distract from behaviours that may challenge. Staff should refer to the Stop and Pause document (in the Forms section of this policy) to understand why a Service User may present with behaviours that challenge, and to understand techniques for supporting effective person- centred care planning.

* 1. **Assessment**

Assessment should begin before admission. At the enquiry stage, sufficient information should be gathered to alert Managers of the types of needs the Service User has. At the pre-assessment stage Managers or senior member of staff must establish any conditions or previous history of behaviours that could present. It should also be established if the Service User has an advance statement in place.

Methods of dealing with the behaviour should be discussed with the Service User and/or their nominated person.

Managers must determine:

* That the service can meet the needs of the Service User
* That staff are competent to meet their needs whilst promoting independence
* The current Service User community and how dynamics may change

Where there is any doubt, Mrs Maxine Winch must not accept the care of the Service User and should discuss their concerns with Holbeach & East Elloe Hospital Trust whilst supporting to offer alternative providers.

Upon commencement of the service, a full assessment must be completed. Triggers for behaviour and methods of dealing with it must be documented in the Care Plan and explained to all staff involved in their care.

Service Users presenting with behaviour that challenges should have a symptom and behaviour record in place, until strategies become successful or the behaviour resolves, or on the advice of a suitable specialist health care professional. A template symptom and behaviour record can be located in the Forms section of this policy.

The Service User and family/significant other must be involved in the Care Planning and risk assessment and an agreement should be reached on what risks will be acceptable. This includes:

* What risk the Service User is prepared to take against the wishes of the staff
* What actions will be taken if the Service User exhibits behaviour that challenges which does not respond to the usual therapeutic interventions
  1. **Care and Treatment**

Holbeach Hospital & Nursing Home care staff must:

* + - Develop individualised Care Plans with Service Users that include an assessment of risk and any other health care professionals that may be involved in their care
    - Monitor and record behaviours using the symptom and behaviour record
    - Provide structured and planned activities following assessment of the Service User's needs. Which may include:
      * Reality orientation
      * Validation approach
      * Multisensory Environments
      * Music therapy
      * Relaxation and complementary therapies

Staff should refer to the Further Reading section of this policy for details in relation to the above therapeutic interventions.

Activities will be reviewed and adapted according to the changing needs and preferences of Service Users. The GP and/or community mental health team should be sourced to support ruling out of medical conditions and to identify specific plans and strategies for dealing with new or repeated episodes of challenging behaviour from the Service User.

* 1. **Dealing with an Incident**

The following steps should be taken when supporting a Service User with behaviours that challenge:

1. Try to stay calm and don't enter into an argument. Reassure the person and try to distract their attention.
2. Ensure that there is only one staff member taking the lead with discussions with the Service User.
3. If the person is physically violent, give them plenty of space. Unless it is absolutely necessary, avoid closing in or trying to restrain someone, as this can make matters worse.
4. Ask yourself if whatever you are trying to do for the person really needs to be done at that moment. If you are able to give them a little space, come back in five or ten minutes and try again gently − you may be able to avoid a confrontation.
5. Watch out for warning signs, such as anxious or agitated behaviour or restlessness, and take action immediately to help the person feel calmer and reassured.
6. Try to work out what triggers any aggressive behaviour by communicating with other care staff and with those that know the Service User best. It may be something that can easily be addressed, such as changing a battery in a hearing aid so that they can hear you properly.
7. Talk to the Service User about what is upsetting them and involve their loved ones where possible, while being patient and reassuring.
8. Be aware and support other Service Users that may be within the vicinity of the challenging behaviour and distract accordingly. If necessary, encourage and support the other Service Users to move away from the vicinity.
9. In the event where lives are at immediate risk from the behaviour of the Service User, call 999 to access the police.
   1. **Restraint**

Holbeach Hospital does not advocate restraint.

* 1. **Post Incident Action**
* Notify GP and other members of the multidisciplinary team as appropriate
* Involve fellow care staff in discussions about the cause, learning and future management for the Service User
* Inform their relative/significant other
* Complete the appropriate Incident/Accident Forms
* If other Service Users were involved in the incident, a safeguarding alert and regulatory notification should be completed
* If the police were involved, complete a regulatory notification
* Update associated risk assessments and Care Plans
* Introduce a behaviour assessment form, if this is the first episode, or update accordingly
* Ensure that handover communications include the incident to inform all relevant Nurses that support the Service User
* Debrief and support any staff involved who may be emotionally affected by the incident
  1. **Training and Development**

New care staff will be required to complete the Care Certificate (refer to the Induction and Onboarding Policy and Procedure at Holbeach Hospital & Nursing Home for further details). The following completed standards will support a greater understanding of how to support Service Users with behaviours that may

challenge:

* Work in a person-centred way
* Communication
* Privacy and dignity
* Awareness of mental health, dementia and learning disabilities
* Safeguarding adults

Staff should be taught how to de-escalate using the different therapies identified within this policy, and should access the resources available within the Further Reading section of this policy.

* 1. Managers or designated other will source additional training, on an as and when required basis, dependent on the Service User group within the home. By use of resources and current

practice (refer to the Further Reading section of this policy associated forms), staff are encouraged to gain knowledge in the areas of:

* + - De-escalation techniques
    - Trigger awareness
    - Risk assessment and care planning
    - Conditions that can cause behaviours that challenge

Reflection around behaviours that challenges should be discussed as appropriate within supervisions sessions and via group team meetings.

Managers or designated other will ensure that there is access and key contact details available of local multidisciplinary professionals in the area who can offer support and advice.



**6. Definitions**

* 1. **Advance Statements**
     + Advance statements are non-legally binding documents, but give an opportunity to identify a Service User's preferences about interventions and care
  2. **Behaviour that Challenges**
     + "Culturally abnormal behaviour(s) of such an intensity, frequency or duration, that the physical safety of the person or others is likely to be placed in jeopardy, or behaviour which is likely to seriously limit use of or result in the person being denied access to ordinary community facilities." (Emerson, 1995)
     + Behaviours that could be described as challenging include physical or verbal aggression, self-injury, property destruction, non-compliance and anti-social nuisance behaviour. The definition of any given behaviour as challenging is subjective and relative. Therefore, it is always necessary to precisely describe the behaviour that is being labelled as challenging in terms of its effects on the person, on their lifestyle, and on other people
  3. **De-escalation**
     + To reduce the level or intensity of a crisis etc, by use of a range of interventions and therapeutic techniques
  4. **Consent**
     + "Consent" is a Service User's agreement for a care or health professional to provide care
     + Service Users may indicate implied consent non-verbally (e.g. by presenting their arm for their pulse to be taken), orally, or in writing
     + For the consent to be valid, the Service User must be competent to take the particular decision, have received sufficient information to take it, and must not be acting under duress
  5. **Mental Capacity**
     + Having mental capacity means that a person is able to make their own decisions
     + The Mental Capacity Act 2005 is designed to cover situations whereby someone is unable to make decisions because of an impairment of, or a disturbance in the functioning of their mind or brain. The Act says that a person is unable to make a particular decision if, due to an impairment of, or a disturbance in the functioning of their mind or brain, they cannot understand information about the decision to be made (the relevant information), or retain the information in their mind, or use or weigh that information as part of the decision-making process or communicate their decision
  6. **Interventions**
     + A proactive recovery-focused approach aimed at preventing the likelihood of challenging behaviour occurring. The gathering of information from Service Users, their carers and families, colleagues and other agencies will lead to a formulation of the risk issues. That assessment will identify preventative strategies, both to promote a positive environment and to minimise the risks. Specific management guidelines will be based on individual planning of care. Interventions may include the promotion of alternative coping skills and activities, environmental change, de-escalation, physical control and restraint, and seclusion
     + Minimum level of interventions must be used, and Service Users supported in developing their own positive coping and risk management skills. Exceptions to these principles may be requested through an individual’s advance request



**Key Facts - Professionals**

Professionals providing this service should be aware of the following:

* + - Behaviour that challenges is not a diagnosis
    - Staff need to understand the theory of behaviour that challenges and support Service Users in a positive manner
    - Service Users should be involved as much as possible in understanding their own behaviour and identifying support methods
    - Assessment and Care Planning are central to the development of ways of supporting people with behaviour that challenges
    - The principles of the Mental Capacity Act 2005 must be followed at all times when supporting people through episodes of behaviour that may challenge
    - Staff will receive effective training on prevention, intervention and management of behaviour that may challenge, and only staff that have received training will be directly involved in the management of behaviour that may challenge
    - All incidents should be recorded and debrief sessions held following the event
    - To describe behaviour as challenging can be subjective and defined by culture and other factors
    - Behaviours that could be described as challenging include physical aggression, verbal aggression, self-injury, property destruction, non-compliance and anti-social nuisance behaviour



**Key Facts - People affected by the service**

People affected by this service should be aware of the following:

* + - You will be encouraged to describe in advance what interventions you wish to be used and in what circumstances, when behaviour that may challenge could occur



**Further Reading**

As well as the information in the 'underpinning knowledge' section of the review sheet we recommend that you add to your understanding in this policy area by considering the following materials:

**Deprivation of Liberty Safeguards Policy and Procedure Restraint Policy and Procedure**

**Social Care Institute for Excellence - Challenging behaviour:** A guide for family carers on getting the right support for adults 2011:

<http://www.scie.org.uk/publications/ataglance/ataglance37.asp>



**Outstanding Practice**

To be ‘ outstanding ’ in this policy area you could provide evidence that:

* + - The wide understanding of the policy is enabled by proactive use of the QCS App
    - Incidents of behaviour that challenges reduce over time due to innovative, creative and person-centred approaches
    - Stakeholders report extreme satisfaction with the way in which Holbeach Hospital & Nursing Home manages behaviour that challenges
    - Holbeach Hospital & Nursing Home is seen as a centre of excellence and trains others in behaviour that challenges
    - Service Users express satisfaction with how Holbeach Hospital & Nursing Home supports them, and understands their behaviours
    - Care Plans will include advance statements of Service User wishes regarding interventions in the event of an incident where behaviour may challenge
    - A guide will be available to all staff which describes the support methods available to staff affected by incidents of behaviour that challenges



**Forms**

The following forms are included as part of this policy:

|  |  |  |
| --- | --- | --- |
| **Title of form** | **When would the form be used?** | **Created by** |
| Assessment of behaviours - CP05 | Following any event of a behaviour that may challenge, used to assess and identify themes and trends that can aid strategies to reduce occurence in the future. | QCS |
| Example assessment of behaviours form - CP05 | To guide staff as to how to complete the form. | QCS |
| Risk Factors of Disturbed or Violent Behaviour - A Guide For Staff - CP05 | Guide to support staff on the key risk factors for disturbed or violent behaviour. | QCS |
| STOP and PAUSE - CP05 | This guide is for carers of those supporting people living with dementia and provides valuable prompts and considerations to support people. | QCS |

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| **Behaviour Chart (The ABC of Behaviour)** | | |
| **Service User's Name:** | **Room Number:** | **Date Chart Started:** |

# care staff should refer to the Service User's care plan in place to support how potential behaviours can be managed.

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Time** | **Behaviour** | **What happened before (Antecedent)** | **What happened during (Behaviour**  **observed)** | **What happened after (Consequences)** | **Interventions Necessary** | **Staff Initials** |
|  |  |  |  |  |  |  |

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| --- | --- | --- |
| **Behaviour Chart (The ABC of Behaviour)** | | |
| **Service User's Name:** Jane Smith | **Room Number:** | **Date Chart Started:** |

**care staff should refer to the Service User's care plan in place to support how potential behaviours can be managed.**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Time** | **Behaviour** | **What happened before (Antecedent)** | **What happened during (Behaviour**  **observed)** | **What happened after (Consequences)** | **Interventions Necessary** | **Staff Initials** |
| 16/1/15  11:05 | Jane observed in the corridor ‘air punching’ people as they walked past. | Jane really struggled to cut up her lunch today and needed support, she appeared to be frustrated by this. | Jane's voice escalated, so she appeared angry at others nearby. | Jane went on her own to her bedroom and was later seen smiling at staff. | Other Service Users were encouraged to remove themselves from around Jane.*Try offering support to Jane with dining to reduce frustration.* | LC |
| 25/1/16  08:45 | Jane was offered medication which was accepted but she promptly spat them out. | Jane had been asleep. | Jane appeared to be surprised to be woken to take her medication. | Jane returned to sleep. | MAR recorded as refused, returned after an hour and Jane accepted her medication. NB: *need to ensure that Jane has plenty of time to wake up before offering medication next time.* | MM |

**The following lists are not intended to be exhaustive and these risk factors should be considered on an individual basis. Those factors will include factors linked with demographic or personal history and should be taken into account when assessing the risk of disturbed/violent behaviour, including the following features:**

* History of disturbed/violent behaviour
* History of misuse of substances or alcohol
* care worker reporting the Service User’s previous anger or violent feelings
* Previous expression of intent to harm others
* Evidence of rootlessness or ‘social restlessness’
* Previous use of weapons
* Previous dangerous impulsive acts
* Denial of previous established dangerous acts
* Severity of previous acts
* Known personal trigger factors
* Verbal threat of violence

# Evidence of recent severe stress, particularly a loss event or the threat of loss. These factors should be considered in combination with any of the following:

* Cruelty to animals
* Reckless driving
* History of bed-wetting
* Loss of a parent before the age of eight years

# In addition to these factors, clinical variables should be taken into account when assessing the risk of disturbed/violent behaviour, including the following features:

* Misuse of substances and/or alcohol
* Drug effects (disinhibition, akathisia)
* Active symptoms of schizophrenia or mania, in particular:
  + Delusions or hallucinations focused on a particular person
  + Command hallucinations
  + Preoccupation with violent fantasy
  + Delusions of control (especially with a violent theme)
  + Agitation, excitement, overt hostility or suspiciousness
  + Poor collaboration with suggested treatments
  + Antisocial, explosive or impulsive personality traits or disorder
  + Organic dysfunction

# In addition to these factors, situational variables should be taken into account when assessing the risk of disturbed/violent behaviour, including the following features:

* Extent of social support
* Immediate availability of a potential weapon
* Relationship to the potential victim (for example, difficulties in relationship are known)
* Access to the potential victim
* Limit setting (for example, staff members setting parameters for activities, choices, etc.)
* Staff attitudes

# Helping someone with dementia who is distressed or behaving unusually

There are often good reasons why someone with dementia is distressed or behaving unusually. As you know, the person’s brain is working differently and can affect their normal character and many things on a daily basis. This may include forgetting things, repeating things over and over and misunderstanding what others say. The person might not always be able to tell you what’s troubling them. Sometimes we react to unusual behaviour without knowing how the brain changes have affected the person’s abilities or what they might need or be saying through their behaviour. It can be difficult to work out what the likely cause is and what you can do to help, for the benefit of both of you.

The Alzheimer’s Society has more advice and information for people with different types of dementia, not just Alzheimer’s dementia. You can go to the website [www.alzheimers.org.uk](http://www.alzheimers.org.uk/) or call them on their helpline (Freephone) on 0300 222 11 22. We have listed useful factsheets on particular behaviours at the end of this leaflet.

If you would like further help, please don’t struggle on your own as there are many ways in which people in your situation can be helped. Please contact your local Alzheimer’s Society or your doctor for advice. If you want information on how services can help you, see *How Health and Social Care Professionals Can Help*. <http://alzheimers.org.uk/factsheet/454> We know that you have probably tried many things and there is often no ‘right way’ or magic solution. Some approaches work better for some people and situations than others. Also, they may work at one time and not another. It can help to see yourself as exploring what are the most helpful approaches. We have used the ideas of “STOP” and “PAUSE” to describe the key ways to help you listen and watch, to improve your understanding of distress and unusual behaviour.

**You may need to try some things for several weeks before you see improvement.** If distress or behaviours do not resolve with the advice given below, consult your doctor or ask for a referral to your local specialist mental health services, which works with people with dementia and their families.

# You respond… ‘STOP’ and ‘PAUSE’ STOP

1. **– See** things from the point of view of person with dementia
2. **– Think** about your own thoughts and feelings

**O – Observe** and ask what the person is trying to communicate and what is going on

**PAUSE**

**P – Patience** and persistence

**P is for PHYSICAL**

**Are they in pain?**

Pain can be a common cause of changes in behaviour and can result from many problems such as joint pain, dental problems or discomfort from skin problems or constipation.

**What to do:** Ask the person if they are in pain. Watch out for signs of them being in pain. Change their position if they have been sitting in one place for a long time. If you think they are in pain, get advice from their doctor. Note the activity they’re doing when they are distressed or seem uncomfortable so you can give information to their doctor. Please seek advice from their doctor if the person is taking any medication for pain, either prescribed or purchased. It may be that prescribed painkillers need adjusting or that those being self-medicated are unsuitable.

See the factsheet ‘*Pain in dementia’* from the North West Dementia Centre: [https://www.pssru.ac.uk/pub/MCpdfs/Pain\_factsheet.pdf](http://www.pssru.ac.uk/pub/MCpdfs/Pain_factsheet.pdf)

# Has their medication been reviewed or changed recently? Are they taking all their medication correctly?

New medicines might be causing side-effects. Older medicines may no longer be needed or may need adjusting. Incorrect use of medication may result in extra side-effects or result in limited or no expected benefits.

# Do they have an infection?

They might have an infection such as urinary tract or chest infection or cellulitis. This can lead to changes in behaviour, such as confusion.

**What to do?** Look out for things like smelly or cloudy urine (wee) or an unusually wheezy chest or redness, itchiness or

soreness of the vagina (women) or penis (men), or red and hot patches of skin and report these to their GP.

# Are they hungry or thirsty?

Dementia can cause changes in taste and appetite. People may have difficulty managing or recognising food or cutlery. Dehydration (lack of liquid) can happen with changes between hot and cold weather. People may avoid drinking in order to avoid going to the toilet. Being dehydrated can lead to further problems.

**What to do:** Note any problems with eating or drinking. People may need prompting to use cutlery, such as putting a fork in their hand and guiding their hand to the food. Meals may need to be small and often to ensure that blood sugar is maintained. Look for very yellow urine, which is a sign that they ought to be drinking more. Encourage drinking and provide support for going to the toilet if needed (see advice in Self-esteem below). Look for problems with denture pain or mouth ulcers. Let their GP know if you are concerned about how much they are eating or drinking.

*See* factsheet *Eating and drinking* on the website: <http://alzheimers.org.uk/factsheet/511>

# Are they getting enough sleep at night?

Dementia can cause changes in people’s sleep schedule so that they wake up more often and stay awake for longer at night. Confusion about time can lead them to think it is daytime at 4am and want to get dressed.

**What to do:** Note any signs of pain or discomfort upon waking. Keep bedtime routines and provide nightlights and comfort objects. Avoid watching TV in the bedroom or the person spending long periods of time in bed while awake; use bed for sleep and sex. Encourage outdoor exercise or activities to keep them alert during the day. Try to stop or reduce daytime napping. Avoid alcohol and caffeine before bedtime. See their GP if problems persist.

# Could they have hearing or eyesight problems?

People can become disinterested in a conversation or an activity just because they cannot see or hear easily.

**What to do:** Check how well they can see or hear things, even if they have glasses or a hearing aid. Improve the lighting. Make sure that you talk loudly and clearly into the good ear. Avoid competing noises or activities such as TV or radio. Try to move slowly and approach the person from the side where the eyesight and/or hearing are best. Get advice from an optician or hearing specialist if you think their sight or hearing could be improved.

# Could they be making ‘visual mistakes’?

People with dementia might still have good vision but have problems with making sense of things correctly in front of them (called visuospatial difficulties). This might make it difficult for them to watch TV, use objects correctly or walk confidently. Other examples include misinterpreting reflections in mirrors or avoiding stepping on shiny floor because it looks wet or slippery.

**What to do:** Improve the lighting. Make sure the rooms are free from clutter and there is space to move around with confidence. Cover-up or change busy patterns on walls and floors. Help the person recognise objects. Do this by showing them how to use the object, getting them to touch the object or using noise, e.g. flushing toilet. Use short simple statements rather than questions or gestures to indicate walking to the toilet, etc. For example, say “come to the toilet” rather than “would you like to go to the toilet”?

# Could they be experiencing hallucinations?

Hallucinations may occur with some types of dementia, especially dementia with Lewy bodies. Visual hallucinations are most common and involve seeing things that are not present, usually people and animals. This can be frightening and lead to changes in behaviour.

**What to do:** If they are not worried then don’t dwell on it. Listen carefully and acknowledge what the person is saying. Talk calmly and try not to argue with them. Consult their GP if the hallucinations persist or worsen or are frightening.

# Could the room temperature be too hot or too cold?

**What to do:** If it is very hot and the temperature cannot be reduced, consider giving them more drinks, use fans or sit them outside in the shade. If it is cold, try the use of blankets and extra clothing.

**A is for ACTIVITIES**

**Could they be bored or needing social contact?**

**What to do:** Use simple activities to prompt conversation, such as looking at a vase of flowers, a picture on the wall or looking out of the window. Involve them in everyday activities like laying the table. Try and do activities they used to enjoy doing, e.g. gardening or visiting the seaside. Give the person regular opportunities to talk to someone. If one is near, visit

your local dementia café where both of you can meet and chat with others in a similar situation (contact your local Alzheimer’s Society for more information). See factsheet on ‘Keeping active and involved’ at: [https://www.alzheimers.org.uk/get-support/publications-and-factsheets/living-with-dementia-active-and-involved](http://www.alzheimers.org.uk/get-support/publications-and-factsheets/living-with-dementia-active-and-involved)

# Is there too much going on or is the person in unfamiliar surroundings with people they don’t recognise?

**What to do:** Consider having more routine and structure in the day by doing the same things at the same time every day; have a quiet-time or use calming activity or music, especially at times they are tired, such as after lunch.

**U is for YOU**

**Are you looking after yourself?**

Your situation may be extremely difficult to cope with and you may feel helpless and frustrated. It is important that you look after yourself and your health and have support. You are not going to get it right all the time. It’s important that you do not take all the responsibility for managing very demanding situations.

**What to do:** Try to share the responsibilities with others and accept help from family, friends, neighbours or professionals.

Many people benefit from talking with people in a similar situation. You can find information and support from your local Alzheimer’s Society branch or carers support organisations (contact details at bottom). You can get ideas on how to solve problems or plan for future living arrangements.

See factsheet *‘Carers: Looking after yourself’* at: <http://alzheimers.org.uk/factsheet/523>

If you are providing support for someone who cannot manage without it, you are legally entitled to a Carer’s Assessment under the Care Act. This assessment is about your needs and what support you need in your caring role. To seek a Carer's Assessment you can call your local Social Care Services or ask someone from your local Carers Centre.

# How do you manage the effects on your relationship?

Dementia has probably had an enormous impact on your relationship, both in practical and emotional ways. It is normal to want to want to turn the clock back to how things used to be before the dementia. You may experience changes in your usual roles, talking and sharing together and closeness. You may find some social situations difficult and embarrassing. Some friends may also avoid you. All of these changes can be experienced as a painful loss.

Within your relationship, you may see things differently from each other. One of you is aware of the difficulties and the other may be unaware or does not seem concerned. Dementia can cause people to forget or be unaware of their difficulties as well as how their actions affect others. This is due to brain damage and is not done on purpose. You might have different ways of coping with the dementia. For example, one of you might downplay the difficulties and one of you might be more accepting and open in talking about dementia.

**What to do:** Try to continue with the important things in your relationship, including contact with others. Accept that you might need to take responsibility for looking after both of you.

See the changes as the result of the dementia symptoms and the different ways in which people cope and notice the moments when you are sharing or enjoying things together. Talk about the impact of the loss and changes if you want to. If you need time on your own or with others, having time apart might improve your mood and relationship.

If you want to feel closer together, do things that you can both do, for example life story work. Develop a “life story” together to support reminiscing and conversations.

# Do you understand why they are distressed or behaving out of character for them?

You may struggle to understand someone’s changing behaviour. How you understand the behaviour is crucial to how you will react. If you blame yourself or the person, you are more likely to get angry or frustrated.

**What to do:** Try and find out as much as you can about dementia and what causes certain behaviours. Try to avoid taking things personally or having arguments over mistaken ideas or attempt to change their viewpoint. Your arguments will only end up frustrating you and probably upsetting them. Be mindful of your own tone and facial expressions and try to speak calmly.

**S is for SELF ESTEEM**

**Are they frustrated because they are unable to communicate their needs or they can no longer do the things they used to do?**

People with dementia can find it difficult to feel good about themselves. They may struggle to adjust to the effects of dementia because they cannot maintain the same skills and activities. This can often be expressed through mood changes

or unusual behaviours. You may be tempted to do things for the person to help them and to make life easier. This is understandable. However, your intention to make life easier could result in taking away the person’s confidence and independence in doing things themselves. The saying, ‘if you don’t use it, you lose it’, can be true.

**What to do:** The aims of the following ideas are to support the person with dementia to adjust to the effects of the dementia, to live life as independently as possible and to engage in social and meaningful activities. Include people in conversations and be aware of how they might be feeling. Let the person finish their sentences unless they ask for your help. Don’t point out their mistakes. Keep the flow of conversation going – move on if the person has trouble finding a word or appears anxious. Let them do jobs they are used to doing, e.g. putting some of the shopping away. Break the job down into smaller steps to help them. This will help them feel they are doing something useful. Explain what you plan to do or what you are doing. Ask them questions which require yes/no responses and give plenty of time to respond.

See factsheet: *Communicating at* [https://www.alzheimers.org.uk/sites/default/files/2020-03/communicating\_500.pdf](http://www.alzheimers.org.uk/sites/default/files/2020-03/communicating_500.pdf)

**E is for EMOTIONS**

**Are they sad, scared, depressed or anxious?**

People with dementia still experience feelings and emotions even though they may not be able to explain to you their feelings or remember what caused them to feel that way.

**What to do:** Note down what was going on to see if something triggers the change in feelings or mood. This might be due

to certain music, noises or a visit from someone. Encourage distracting activities such as walking. Touching or holding their hand may help calm them and show them you care. Try to pick out key words or phrases and repeat these back as it may help the person focus on a particular topic. Respond to the person’s feelings rather than correcting the accuracy of what they are saying. For example, if someone says they miss their mother, think about the meaning behind what they are saying. Are they sad or worried about something? You could encourage them to tell stories about their mother and what they miss about her to help them feel more secure. You might need to try out different ways of responding to see what works best.

If someone’s low or anxious feelings or mood persists, ask their doctor for a referral to specialist mental health services.

# Other useful factsheets from Alzheimer’s Society:

*Unusual behaviour -* <http://alzheimers.org.uk/factsheet/525> *Coping with incontinence -* <http://alzheimers.org.uk/factsheet/502> *Dressing -* <http://alzheimers.org.uk/factsheet/510>

*Sex and dementia -* <http://alzheimers.org.uk/factsheet/514> *Moving and walking about -* <http://alzheimers.org.uk/factsheet/501> *Washing and bathing -* <http://alzheimers.org.uk/factsheet/504> *Dealing with aggressive behaviour -* <http://alzheimers.org.uk/factsheet/509> *Visuoperceptual difficulties -* <http://www.alzheimers.org.uk/factsheet/527>

*Hallucinations -* [https://www.alzheimers.org.uk/about-dementia/symptoms-and-](http://www.alzheimers.org.uk/about-dementia/symptoms-and-) diagnosis/hallucinations

# Local Authorities

South Holland District Council