Purpose

To provide person centred and safe Care to those living with dementia.

Scope

All workers.
All processes within the service.

Definition

Dementia is a loss of mental ability severe enough to interfere with normal activities of daily living, lasting more than six months, not present since birth, and not associated with a loss or alteration of consciousness.

Description

Dementia is a group of symptoms caused by gradual death of brain cells. The loss of cognitive abilities that occurs with dementia leads to impairments in memory, reasoning, planning and behaviour. While the overwhelming number of people with dementia are elderly, dementia is not an inevitable part of ageing; instead, dementia is caused by specific brain diseases. Alzheimer’s disease (AD) is the most common cause, followed by vascular or multi-infarct dementia.

The prevalence of dementia is difficult to determine, partly because of differences in definition among different studies and partly because there is some normal decline in functional ability with age. The prevalence of dementia roughly doubles for every five years of age beginning at age 60. Dementia affects about 1% of people between ages 60 and 64, 5-8% of all people between ages 65 and 74, up to 20% of those between 75 and 84, and between 30% and 50% of those age 85 and older. About 60% of nursing home patients have dementia.

The cost of dementia can be considerable. While most people with dementia are retired and are not affected by income losses from their disease, the cost of Care is often enormous. Financial burdens include lost wages for family caregivers, medical supplies and drugs, and home modifications to ensure safety. The psychological cost is not as easily quantifiable but can be even more profound. The person with dementia loses control of many of the essential features of his/her life and personality, and loved ones lose a family member even as they continue to cope with the burdens of increasing dependence and unpredictability.

Policy

The service will adhere to the following principles while providing Care for people with dementia:

- Care Planning and delivery will be person centred.
- Care delivery will be by staff who have specialist training in dementia care, and who have access to specialist support.
- Care delivery will focus on meeting needs and aspirations.
- The Agency will promote dignity and respect and maintaining human rights.
- Closely coordinated between different professionals and services across health, social Care and housing.

Procedure

Techniques and environmental changes supporting good quality dementia care:

Risk Assessment

Tools are available throughout the QCS system for personal and environmental risk assessment, and these
CC41 - Dementia Policy and Procedure

should be used comprehensively and assiduously when providing dementia Care.

Within Care Planning, very detailed risk assessment should be carried out in relation to the Service User with dementia and their physical environment. In addition, risk assessment of the potential conflicts between Service Users consequent on their individual behavioural characteristics. For example, a Service User whose walking causes them to invade the personal space, or even the belongings, of other Service Users.

In general, Service Users with dementia are at raised risk of:

- Abuse;
- Violent behaviour;
- Disruptive behaviour;
- Isolation;
- Falls;
- Malnutrition;
- Security;
- Tissue viability;
- Fast changing condition;
- Inability to give informed consent;
- Inability to participate in Care Planning;
- Inability to express wishes;
- Communication difficulties;
- Depression;
- Accidents.

Life History

The use of life history (LH) research and recording is especially important in the Care of persons with dementia. A full LH record, made available to all staff providing support to the Service User, enables the carer to more fully understand behaviours of the Service User, and suggest strategies for their management.

The life history can be obtained from the Service User and their family. It doesn’t have to be taken all at once. After you have the initial conversation, they are likely to think of more details to add. It’s particularly helpful to provide a form to the family members to take away and complete, that way they can provide thoughtful responses. The information sought after should assist in conversation with the Service User in the months and years to come as well as assist in facilitating activities.

- Friends and Family - It is important to record the names and details of the Service Users grandparents, parents, brothers and sisters, cousins, children, grandchildren, great grandchildren, nieces and nephews, etc. Focus on details of each that will bring back happy memories for the Service User. Record the ages of children and grandchildren.
- School and Education.
- Religious activities.
CC41 - Dementia Policy and Procedure

- Hobbies.

- Working Life.

The QCS Care Plan has a Life History section.

Memory Box

Accompanying the life history it is useful to ask the family to put together a personal memory box for the individual. The box could contain photos, newspaper cuttings, books, ornaments. If the person was a gardener they could include favourite tools (if not a safety risk). If they were a chef or cooking fanatic they could include cooking utensils, etc. Memories relating to brothers and sisters are also very important. It is often the unexpected that brings pleasure and peace to people who’s memories are fading.
ABC Charting

This is a technique that is widely used. The approach can be defined as:

- **“A”** - What are the antecedents or triggers of the challenging behaviour? The idea is that all behaviours are triggered by something; they are not random. The trigger could be an environmental issue (too hot, too cold, too noisy?), an unmet need (want the WC, hungry, thirsty?) or a disease (pain, headache, not-well feeling?)

- **“B”** - Is the challenging behaviour which is causing the problem.

- **“C”** - Is the consequence of the behaviour, or the reaction of those affected by the behaviour. The way that we react to challenging behaviours can have a large impact on whether that behaviour is more or less likely to re-occur.

- **“D”** - For De-escalate and Decide. Once the situation has been diffused and calmed down, decide what you can do to prevent a similar situation in the future.
CC41 - Dementia Policy and Procedure

Antecedent
What are the antecedents or triggers of the challenging behaviour?

Behaviour
What is the challenging behaviour that is causing issue?

Consequence
What is the consequence of the behaviour, or the reaction of those affected by the behaviour?

De-escalate and Decide
Let the individuals involved have some time to calm down, then decide what best to do to avoid similar instances in the future
<table>
<thead>
<tr>
<th>Date, Time and Reporters Name:</th>
<th>Antecedent: What triggered or came before the behaviour?</th>
<th>Behaviour: Describe the behaviour including location and environment, for instance noise levels, lighting issues.</th>
<th>Consequence: What did you do or what happened to the behaviour?</th>
<th>Final outcome: What did the observed person do when the incident was over?</th>
</tr>
</thead>
<tbody>
<tr>
<td>25/03/17, 8 am Jane Doe</td>
<td>I was going to put his dentures in.</td>
<td>He was sitting up in bed; the bedroom was sunny and bright. He punched me in the chest as I offered the dentures.</td>
<td>I pulled away and cried out in pain, told him not to hit me and left the room.</td>
<td>I returned a few minutes later to find him asleep so I left him like that.</td>
</tr>
</tbody>
</table>
Communication techniques are important to the successful outcome of the process. Some tips on effective (and non-effective) communication techniques follow.

Communication Do’s:

- Position yourself to maintain eye contact and be at the person’s eye level or lower;
- Look at the person directly and make sure that you have their attention before you speak. Always identify yourself first and tell them what you are intending to do;
- Ensure that the tone of voice used is one which conveys respect and dignity. Think about how you communicate, don’t just react;
- Use visual clues wherever possible;
- Make sure your expectations of them are realistic. For instance, ask for only one action at a time;
- Watch the person’s body language and non-verbal communication and try to interpret it;
- Use a calm and reassuring tone of voice and wherever possible, paraphrase what you just said;
- Always speak slowly, but not patronisingly so, and enunciate your words clearly. If the person is hearing-impaired, manage your communication to overcome or alleviate that;
- Talk about things which are familiar to the person;
- Use touch if that is appropriate.

Communication Don’ts:

- Don’t talk to the person as if they were a child or use baby talk;
- Don’t use complex words or phrases or long sentences;
- Don’t glare at the person you are speaking to or otherwise visually challenge them;
- Don’t try to compete with a distracting environment; change the environment or move;
- Don’t start to speak without having first said who you are;
- Don’t break eye contact while speaking, for instance by going off and doing something in the room while carrying on speaking;
- Don’t cause more confusion and confrontation by asking for unrealistic things, such as asking the person to do more than one thing;
- Don’t ignore your own body language – be aware of it and manage it positively;
- Don’t ramble – keep to the point;
- Don’t interrupt the person unless it is absolutely necessary;
- Don’t attempt to touch the person, or invade their personal space if they are showing any fear or aggression.
CC41 - Dementia Policy and Procedure

Some techniques for communicating with a person with dementia:

- Ensure that you communicate only in a quiet place that is free from distraction;
- Be aware of the person’s language and culture (a consequence of good Care Planning and Life History recording) and take these into account in your communication behaviour;
- Be aware of the person’s perception capability, attention span, intellectual level and degree of understanding (again a consequence of good Care Planning), and take that into account when communicating. Stay within the person’s perception and understanding boundaries;
- Ensure that the communication is open and conveys respect and trust. Patronising speech or talking to the person with dementia in a child-like way may either foster a sense of helplessness and dependency or trigger an angry and defensive response;
- Pause often, making sure that the person has an opportunity to respond;
- Make sure that sensory aids (hearing aids, spectacles) are appropriately utilised and sensory impairments (wax, cataracts) are treated.

How to make sure you are heard and seen:

- Check that their hearing aid is on and working (if applicable);
- Stand in front of the person where they can see you;
- Face the person directly so they can see your facial expression and mouth;
- Place yourself at eye level or lower when talking or listening;
- Identify yourself by name;
- Use the person’s name.

How to make contact with the person:

- Keep yourself and those around you calm and relaxed;
- Touch the person gently, if they like to be touched (Care Planning again);
- Smile and use humour.

How to make communication easy to understand:

- Wherever you can use gestures, pictures and/or signs to explain or express things;
- Always avoid talking over/ across/about the person;
- Always speak gently and clearly at an even pace - avoid shouting;
- Always ask just one question at a time;
- Always use specific names of people and places instead of pronouns: e.g.; Jim, our neighbour, or Sally, our dog, not “him” or “it”;
- Wherever you can, use a statement rather than ask a question;
Always wait for a response after you speak;
Always explain what you are going to do and what you are doing;
Always repeat or rephrase your message if there is no response.

Some other ideas:
Always allow for the time a damaged brain takes to process messages;
Always show your concern with reassurance and acceptance;
Always give praise when it’s appropriate;
Always respond to the feelings expressed by the person;
When talking in a group, place the person so that the conversation is around them and they won’t feel ‘left out’;
Make it easy to join in conversation by asking questions that only need a ‘yes’ or ‘no’ answer;
Always avoid arguments over mistaken ideas: e.g.; If the person insists they have seen a TV program a million times before even though it is a first run say: “Oh well, I don’t think I’ve seen it before. It’s interesting isn’t it?”;
Remember that touching enhances feeling of security, especially if the person is upset. Unless they respond aggressively.

Specialist Support
The Care Planning process should pay particular attention to the identification and involvement of external specialists, such as the CPN, in the process in order to incorporate their specialist knowledge into the service delivery.

Challenging Behaviour or Distressed Reaction
Ensure that challenging behaviour or distressed reaction is recorded, and reviewed as a part of the Care Planning cycle. Use the recording chart in the QCS Challenging Behaviour Policy and Procedure.
A checklist can be useful in helping you step through the process of changing challenging behaviour.
Challenging behaviour Checklist

Tick off the following steps as you complete them:

Step 1: Identifying the problem

- Who finds the behaviour challenging?
- What is the behaviour you are interested in changing?
  - Does the behaviour occur:
    - Too much;
    - Too little;
    - In the wrong place;
    - At the wrong time;
  - What behaviour will you prioritise?

Step 2: Setting goals

- What can you realistically expect to achieve?
- What behaviour will you prioritise?

Step 3: Monitoring the behaviour

- How frequently does the behaviour occur?
- Are there any times of the day when the behaviour is most likely to occur?
- What are the ABC's of the behaviour?

Step 4: Generate Ideas

- Have you brainstormed with others to develop ideas about possible interventions?
- Have you prioritised the ideas so you know what to work on first?

Step 5: The medical review

- Do infections or metabolic changes cause the behaviour?
- Do medication side-effects contribute to the behaviour?
- Is pain or physical illness an issue?
- Do eyes, ears or teeth need to be checked?

Step 6: Putting ideas into practice

- Have you tried strategies for preventing the behaviour?
- Have you correctly identified signs that behaviour will occur and acted upon them?
- Have you tried rewarding a behaviour you would like to see more of?
Is everyone being consistent?

Have you developed a good training plan if required?

Have you tried a combination of behavioural and medical treatment interventions if required?

Step 7: Evaluating what you’ve done

What is the frequency of the behaviour now?

Was everyone consistent?

Was there a change in the behaviour?

Have you congratulated yourself for your hard work?

What is the next area to focus on?

Environmental issues particular to Dementia Care; Some suggestions:

- Impervious floors.
- Enhanced cleaning capability.
- Enhanced environmental risk analysis.
- Adaptations:
  - Always – keep everything lower than the norm, as already disturbed visual acuity is further disrupted by looking up:
    - Except of course electrical equipment which may be grabbed, or have liquids tipped into it.
  - Do not have chairs too high.
  - Have a mixture of chair designs and colours, so as to readily identify them the particular Service Users and promote “ownership”.
  - Plain chairs, with cushions to break them up.
  - Consider a small kitchen area, e.g. sink, to allow for remembered diversional activities such as washing cups etc.
  - Critically review all utensils for use by Service Users; non-standard items, such as special feeding cups, may not be recognised for what they are and reduce the Service User’s independence.
  - Avoid reflection and glare.
  - Make surfaces, such as grab rails, tactile and vary the finish, so that people can identify where they are by feel and become familiar with their “home” area.
  - Grab rails – make sure they can be held onto – i.e. the brush handle type, not the dado rail type.
  - Signs, e.g. menu, black lettering on white board/paper.
  - Large clock in public area, not high, numbers not Roman numerals.
  - Full size picture at the end of a corridor to reduce feeling of confinement.
CC41 - Dementia Policy and Procedure

- Door handles create anxiety – try and avoid.

- Irrespective of individual key-holding (to be promoted), lock bedroom doors when vacated by use so that others cannot “rummage”.

- Mirrors in rooms at Service User height.

- Large unbreakable mirror on the back of bedroom door, acts as a barrier to wandering. Can be used elsewhere.

- Lighting – good, and no sudden changes, or shadows.

- Plain curtains.

- Consider curtains fixed on Velcro, ditto nets, to avoid damage.

- Flooring should not be polished and reflect light – seen as a puddle.

- Consider dimmer switches, as they are more controllable.

- Consider pressure pads to trigger nurse call, located by the bed under a rug.

- Consider voice intercom to rooms to supplement nurse call.

- Avoid patterns and reflections.

- Name, number and maybe photo on bedroom doors, not too high.

- No steps.

- No sudden flooring colour changes.

- Door openers.

- Sound external doors, locked, or distractions.

- No sharp edges.

- Door jamb gaps closed.

- Pictograms.

- Familiarity/Reminiscence.

- Sensory garden.

- Loop system.

- Large graphics and signage.

- Dining room design.

- Robust window restraints.

Staff issues particular to dementia care
CC41 - Dementia Policy and Procedure

- Increased risk identification and management awareness.
- Increased abuse awareness training.
- Increased human rights training/awareness.
- Increased attention to life history and behaviour context.
- Additional communication training.
- Life skills support training.
- Nutrition training.
- Continence training.
- Tissue viability training.
- De-escalation training.
- Enhanced medications handling training.
- Cognitive impairment training.
- Dealing with family guilt and bereavement training.
- Specialist dementia training.
- Revised induction training.
- Improved family communication and support.
- Enhanced key worker working.
- Links with external advocacy.
- Links with external professionals.
- Need for staff stress relief – “time out”.
- Greater attention to staff retention.
Reminiscence Workbook

This workbook is to be completed by family members and loved ones of the Service User. Please fill in this form as completely as possible. If there is an area you cannot complete, write ‘unknown’ or ‘not applicable’.

This information will help The Agency to build a life history for your loved one. Details and memories from the past will help the staff to build a person centred Care Plan and will also assist in conversation and facilitating enjoyable activities for your loved one.

The last page of this workbook will include some items that you may provide to include in a ‘Memory Box’.

<table>
<thead>
<tr>
<th>Service User’s Name:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Family Member’s Name:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Date Workbook Completed:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

Use additional pages if you run out of room.

Don’t be afraid to contact the service if you think of more details later on that you would like to add to this workbook.
## CC41 - Dementia Policy and Procedure

### Friends and Family

Use this section to give details of family, close friends and work mates. Helpful details to include are names, ages, where they live and any fond memories your loved one has with the individuals.

<table>
<thead>
<tr>
<th>Grandparents:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Parents:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Aunts and Uncles:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Brothers and Sisters:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>
### CC41 - Dementia Policy and Procedure

<table>
<thead>
<tr>
<th>Section</th>
<th>Content</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Children:</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Nieces and Nephews:</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Close Friends:</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Workmates:</strong></td>
<td></td>
</tr>
</tbody>
</table>
## School and Education

<table>
<thead>
<tr>
<th></th>
<th>Years Attended</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Primary School</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Secondary School</strong></td>
<td></td>
</tr>
<tr>
<td><strong>University</strong></td>
<td></td>
</tr>
</tbody>
</table>

### Favourite Subjects

### Degrees
# Working Life

Use this section to give details of past jobs or careers. What was their vocation? Where did they work? What did they enjoy about it?
### Religious Activities

List religious activities and memories.

### Hobbies

List hobbies or favourite activities. Gardening, painting, cooking, etc.
### CC41 - Dementia Policy and Procedure

<table>
<thead>
<tr>
<th>Section</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Holidays</strong></td>
<td>Does your loved one have any favourite holidays? Please list holidays along with any favourite holiday memories.</td>
</tr>
<tr>
<td><strong>Travels</strong></td>
<td>List any memories of favourite holidays or trips.</td>
</tr>
<tr>
<td><strong>Music</strong></td>
<td>Does your loved one have a favourite band or musical artist?</td>
</tr>
<tr>
<td><strong>Television and Films</strong></td>
<td>Does your loved one have a favourite television show or film?</td>
</tr>
</tbody>
</table>
Memory Box

Creating a Memory Box for your loved one is a great way for them to take a stroll down memory lane. It can also be a great comfort to have familiar items from home and items that remind them of happy days.

Below are some suggestions of items you could put in your loved one’s Memory Box.

- Photos.
- Newspaper Cuttings.
- Books.
- Ornaments.
- Keepsakes.
- Small Toys.
- Jewellery.
- Tickets/programmes from cinema/theatre/sport.
- Tools that were used for hobbies (examples: gardening gloves, paint brushes).
- Tools that were used for professional life.
- Items associated with family members (baby shoes, stuffed animals).
- Items associated with favourite pets.

You know your loved one best, what do you think would bring to mind happy memories for them?

Key Lines of Enquiry Table

<table>
<thead>
<tr>
<th>Key Line of Enquiry</th>
<th>Primary</th>
<th>Supporting</th>
<th>Mandatory</th>
</tr>
</thead>
<tbody>
<tr>
<td>C.E1 - How do people receive effective care, which is based on best practice, from staff who have the knowledge and skills they need to carry out their roles and responsibilities?</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>C.C2 - How does the service support people to express their views and be actively involved in making decisions about their care, treatment and support?</td>
<td>✓</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>C.C4 - How people are supported at the end of their life to have a comfortable, dignified and pain free death?</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td>C.R1 - How do people receive personalised care that is responsive to their needs?</td>
<td>✓</td>
<td></td>
<td>✓</td>
</tr>
</tbody>
</table>

Note: All QCS Policies are reviewed annually, more frequently, or as necessary.