Dementia toolkit
Information for staff

Collaborative Project
Working together to improve care for older people

With all of us in mind
The Dementia Toolkit 2008 for South West Yorkshire Mental Health NHS Trust staff

With all of us in mind
Introduction to the Dementia Toolkit

What is the dementia toolkit?

This toolkit has been developed for staff working with people who have dementia and their carers within South West Yorkshire Mental Health NHS Trust (SWYMHT).

The dementia toolkit is designed to:

- Stimulate ideas about how to best care for people with dementia and their carers
- Identify skill or knowledge areas you want to develop and find out what training is available
- Become aware of what the research evidence suggests about a particular care approach

Within the sections you will find useful tools and case examples to show clearly how research has been used in practice.

The section on training shows what is available for staff to improve their skills and is a useful tool in developing a personal development plan as part of the annual Knowledge and Skills Framework (KSF) process (see appendix 2).
How was the toolkit developed?

The SWYMHT business group commissioned this project to improve evidence based practice in dementia care services within the Trust. To scope the project, a multidisciplinary focus group was held to understand the key issues surrounding evidence based practice, how research and guidance is accessed and used by staff and ways in which a dementia toolkit project might be beneficial. The focus group was audio recorded, transcribed and analysed in terms of emergent themes and topics areas. From this analysis a list of key topics were devised, and staff who attended the focus group were asked to rate the priority of each area (see appendix 1).

From this exercise the four topic areas were determined as follows:

1. Managing challenging behaviours in dementia
2. Evidence based interventions in dementia care
3. Managing communication difficulties in dementia
4. Training and support for staff within dementia care

From these general topic areas a list of relevant questions were developed through a literature search of existing guidelines and discussions with relevant staff i.e. old age psychiatrist, speech and language therapist, practice effectiveness managers and training managers within the Trust.

Search strategy for intervention research

Some of the clinical questions on interventions were similar to a recent guideline review conducted by Scottish Intercollegiate Guidelines Network (SIGN, 2006) in the management of patients with dementia guideline. Where this was the case the evidence and findings from this guideline were used as a starting point and updated. Evidence for the SIGN review was searched from 1997 - 2004, therefore the literature search was for studies from 2004 to present on the topic area using keywords.
The search strategy began with the national library for health search for evidence based reviews and systematic reviews on each particular topic. This included the Cochrane Library Database of Systematic Reviews. Dialog Datastar was then used to search databases such as Medline, PsycINFO, Embase and CINAHL, using keywords relevant to each clinical question.

**Course and training search**
The SWYMHT draft training plan for older people’s services provided information about priority training areas identified within the older people’s service delivery group. From this list of priority training areas a directory of all the internal and external training available locally was developed through networking with practice effectiveness managers, staff running internal training, education centre staff and local universities.

**Methodological quality of the research**
For each clinical question, evidence was identified that ranked highest according to the levels of evidence table on page 5. Studies were then scrutinised and graded using methodology checklists for the type of study being assessed (NICE, 2007).

**Project review and approval**
This project was led by Rebecca Spencer, research fellow. Each stage of the project was developed within the consensus group. Membership of the consensus group included Virginia Minogue head of West Yorkshire Mental Health Research and Development Consortium, Professor Stephen Curran old age psychiatrist, Ken Gledhill lead clinical psychologist, Jackie Davis learning and development manager, Ben Boyd general manager for older people’s services.

The scoping phase of the project was signed off by the consensus group and the Practice Effectiveness Subgroup of the Older Peoples Service Delivery Group (PESOPSDG). The project lead worked within the collaborative project group in developing the evidence reviews, pilot, revisions and dissemination plan.

The draft document has been reviewed by the contributors, service users and carers, collaborative project members and PESOPSDG members. The draft was piloted with staff from a range of grades and disciplines across the Trust to develop the report in terms of content, structure and ease of use.
References
Accessed December 2007

Accessed December 2007

Using the dementia toolkit
This toolkit can assist staff with planning care, reflecting on practice and decision making within clinical supervision or multidisciplinary team meetings. This toolkit draws attention to the evidence of effectiveness but this is intended to be used in conjunction with existing skills. By stimulating new ideas and using a healthy combination of best practice and inventiveness, this toolkit can help staff to address the range of issues and challenges that patients with dementia and their carers experience.

The training section of this toolkit in particular can be used to assist staff in their Knowledge and Skills Framework (KSF) appraisal processes (see appendix 2). The KSF developmental review process is about ongoing development of all staff and the application of learning and development acquired. Staff using the dementia toolkit should be able to find opportunities to learn and develop their skills and become more effective in their roles.

Disclaimer:
The views and recommendations of this report are a result of a review of existing research at the time of publication and are not necessarily reflecting all the views of South West Yorkshire Mental Health NHS Trust, nor does it indicate its endorsement of a particular approach.
Key to the toolkit and table of contents

With all of us in mind
### Key to grading the evidence

#### Levels of evidence

<table>
<thead>
<tr>
<th>Level</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1++</td>
<td>High quality meta-analyses, systematic reviews of randomised controlled trials (RCTs) or RCT with very low risk of bias</td>
</tr>
<tr>
<td>1+</td>
<td>Well conducted meta-analyses, systematic reviews of RCTs or RCTs with a low risk of bias</td>
</tr>
<tr>
<td>1-</td>
<td>Meta-analyses, systematic reviews of RCTs or RCTs with a high risk of bias</td>
</tr>
<tr>
<td>2++</td>
<td>High quality systematic reviews of case-control or cohort studies. High quality case control studies or cohort studies with a very low risk of confounding or bias and a high probability that the relationship is causal</td>
</tr>
<tr>
<td>2+</td>
<td>Well conducted case control or cohort studies with a low risk of confounding or bias and a significant risk that the relationship is not causal</td>
</tr>
<tr>
<td>2-</td>
<td>Case control or cohort studies with a high risk of confounding or bias and a significant risk that the relationship is not causal</td>
</tr>
<tr>
<td>3</td>
<td>Non-analytic studies, eg. case reports, case series</td>
</tr>
<tr>
<td>4</td>
<td>Expert opinion</td>
</tr>
</tbody>
</table>

#### Strength of evidence

<table>
<thead>
<tr>
<th>Grade</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>At least one meta-analysis, systematic review of RCTs, or RCT rated as 1++ and directly applicable to the target population or a body of evidence consisting principally of 1+, directly applicable to the target population, and demonstrating overall consistency of results.</td>
</tr>
<tr>
<td>B</td>
<td>A body of evidence including studies rated as 2++, directly applicable to the target population, and demonstrating overall consistency of results; or extrapolated evidence from studies rated as 1++ or 1+</td>
</tr>
<tr>
<td>C</td>
<td>A body of evidence including studies rated at 2+, directly applicable to the target population and demonstrating overall consistency of results; or extrapolated evidence from studies rated as 2++</td>
</tr>
<tr>
<td>D</td>
<td>Evidence level 3 or 4; or extrapolated evidence from studies rated as 2+</td>
</tr>
</tbody>
</table>

#### Good practice points

- Recommended best practice based on the clinical experience.
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Appendix 4 Memory service information pack for service users
Appendix 5 Memory service information pack for carers
Challenging behaviour and improving communication

With all of us in mind
1. What is the evidence that supporting service users with challenging behaviour can reduce the distress and agitation associated with dementia?

**Challenging behaviours**

Service users with dementia may become distressed or anxious and often, staff and carers will not know why this happens or how to prevent and alleviate this distress. Challenging behaviours could be shouting, screaming, verbally aggressive comments or physical aggression. These types of behaviours can often be an attempt by the service user to communicate their distress over something.

**Behaviour management**

The term “behaviour management”, is used in research papers to reflect structured and normally time-limited interventions usually carried out by carers or care staff with the support of a professional with expertise in this area. Rather than behaviour management, a better term would be ‘supporting service users with challenging behaviour’ as this reflects the more person centred care approach the Trust actively promotes.

Examples of supporting service users with challenging behaviour (behaviour management)

- Carers being taught ways in which they can increase pleasant events for the person with dementia (Gormley, Lyons and Howard, 2001).

- Using assistance with activities of daily living in specific way which attempts to meet the patient's need for privacy, social contact, security and independence (Beck et al, 2002).

- Encouraging the person with dementia to express thoughts, recall memories, learn and have recreation time using all the 5 senses (Beck et al, 2002).

- Identifying and avoiding events which trigger aggression, using certain communication techniques, validation and distraction techniques (Gormley, Lyons and Howard, 2001).
Evidence (see page 5 for grading of evidence)

1+ Although mood related symptoms associated with dementia, including facial expression, contentment and interest can be improved by behaviour management (Beck et al, 2002; Teri et al 1997) there was no evidence for significant reduction in disruptive behaviour in nursing home residents or those in the community (Gormley, Lyons and Howard, 2001).

1+ There is evidence to support the use of behavioural management to reduce depression in people with dementia living in the community with a caregiver (Teri et al 1997). Depression in people with dementia receiving behavioural therapy either involving pleasant events or problem solving was compared to that in control groups. Patient depression was improved for up to six months after both interventions.

Strength of evidence (see page 5 for grading of evidence)

B Behaviour management may be used to reduce depression in people with dementia.

Some examples of supporting service users with challenging behaviour in practice

When a service user with dementia becomes agitated and presents with challenging behaviour it may help to use an ABC chart to record exactly what happens when these behaviours occur (please see appendix 3). The ABC chart is useful for objectively recording the environment, types of behaviour and what happened immediately before the person with dementia became agitated. This helps to identify causes of distress so that preventative action can be taken in the future. To prevent further agitation, staff can distract the service user by playing their favourite music, encourage them to talk about family members from their photographs or memory book, use magazines and talk about past interests. By recognising early signs of agitation, often staff can use non-verbal techniques, distractions and prompts to prevent further distress or aggression. This avoids upset for the service user and other residents/their carer or family members. Staff might also consider training the person with dementia's main carers in recognising these early signs of agitation and what steps they might take to reduce agitation.
Another way of finding out causes of distress is to use Dementia Care Mapping (DCM). DCM is an observation technique to look at care through the eyes of the service user and is based on person centred care principles. We have several qualified dementia care mappers within our Trust who you could make a referral to regarding a service user or you might want to consider doing the DCM course yourself (please see the training section for full details of DCM courses and contacts within the Trust).

Evaluation
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References


2. What factors should staff consider when assessing a patient's communication skills and what might improve communication?

We tend to think of communication as talking, but in fact it consists of much more than that. As much as 90% of our communication takes place through non-verbal communication such as gestures, facial expression and touch. Non-verbal communication is particularly important for a person with dementia that maybe losing their language skills. When a person with dementia behaves in ways that cause problems for their carer, they might be trying to communicate something (Alzheimer's Society, 2005). Always talk to the person with dementia rather than trying to communicate through a third party e.g. wife, husband or carer. Bear in mind that the view of a relative or friend, no matter how caring, can be subjective rather than objective (CSIP Older Peoples Mental Health Programme, 2007).

Common communication problems in dementia

Some of the communication difficulties that may arise in dementia are through:

Communication barriers: Dementia may not be the main barrier to communication. It is also important to assess physical illness, visual impairment, hearing impairment, distractions in the environment and cultural differences. For example, pain, discomfort, illness or the side-effects of medication, problems with sight, hearing or ill-fitting dentures. Make sure the person's glasses are the correct prescription, that their hearing aids are working properly, and that their dentures fit well and are comfortable.

Aphasia: This is an impairment of language that is usually used to describe speech impairment and other language problems including reading (dyslexia), writing (dysgraphia) and handling numbers (dyscalcula). UK connect is an organisation that does a lot of work with people with aphasia, using tools to develop communication and regain confidence, for more information visit: http://www.ukconnect.org/

Dysarthria: This is difficulty with speaking and makes speech unclear, perhaps as a result of a stroke. It is caused by weakness of the face muscles, tongue, larynx (voice box) and muscles used for breathing. It may cause a person to sound quick, slow, quiet and/or slurred which can make their speech difficult to understand.
Tools for staff

It is important for people with dementia and their carers that they are given access to information that may help them understand and come to terms with the diagnosis. A good example of this is the Wakefield memory service, service users and carers information packs (see appendix 4 and 5)

Communication with people with dementia in research has highlighted what communication can work and provided examples of these approaches (Allan, 2001).

This includes:

✓ Work with pictures.

✓ Communication during other activities.

✓ Focusing on non-verbal communication (Allan, 2001). For detailed practice examples, please visit: http://www.jrf.org.uk/bookshop/eBooks/186134810X.pdf go to page 47 onwards

✓ ‘Talking mats’ are a visual framework that uses picture symbols to help people with communication difficulties understand and respond more effectively (Murphy, 1998). For examples see: http://www.speechmag.com/content/files/Microsoft_Word__Talking_Mats.pdf?PHPSESSID=41275e5a274c300293bda284f914647b

10 tips to improve communication

(CSIP older peoples mental health programme, 2007)

✓ Always believe communication is possible.

✓ Try to focus on the non-verbal signs as well as verbal.

✓ Avoid making assumptions, check things out with the person.

✓ Make your communication a two way process that engages the person.

✓ Avoid the use of jargon or complicated explanations. Keep your conversation as simple as possible without being patronising or sounding childish.

✓ Try to avoid questions that have ‘why’ in them. The reasoning involved in giving an answer may be too difficult. This in turn could make them annoyed or upset.

✓ Be a good listener. Give the person your full attention and resist the temptation to finish their sentences or talk for them.

✓ Talk at a slower pace so that the person has the opportunity to grasp what is being said.

✓ Maintain a calm and unhurried approach.

✓ Above all, don’t be afraid to say ‘I don’t understand’.
Some examples of improving communication in practice
To communicate using something the person is familiar with is sometimes the most rewarding way of communicating. Using family and past life pictures to generate responses and prompt recall can work with people even if they have severe dementia. The use of music that the person enjoyed can also provide positive results. When working with people who have severe dementia and who are unable to communicate verbally, the use of touch involving hand massage can provide them with a much needed contact.

A service user with dementia may be disorientated in the environment in which they live and placing pictorial signs to aid recognition of appropriate rooms such as the toilet can significantly impact on their ability to remain continent (for examples please see www.finddementiasigns.co.uk). The use of a red toilet seat in white bathrooms has also been shown to help people with dementia identify the toilet.

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References


Carer stress and validation therapy

With all of us in mind
3. What support interventions have demonstrated a reduction in carer stress associated with caring for someone with dementia? Can this support delay institutionalisation?

Carers may include a spouse, relative or friend and stress is common with approximately 30% having significant psychiatric problems (Donaldson, Tarrier and Burns, 1997). Carers may experience a range of problems for example; depression, stress, taking care of themselves, finding social support and managing behaviour problems in the person they care for.

Educational and skill building (15 studies)

An educational and skill building approach would provide carers with information (for example the carers information and support pack (in Appendix 5) and teach the skills required to manage behaviour, depression, anger, reduce stress or a combination of these. For example (Belle et al, 2006):

<table>
<thead>
<tr>
<th>Risk Area</th>
<th>An example tool or questions that would identify this risk</th>
<th>Objective</th>
<th>Some examples of the treatment techniques</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depression</td>
<td>Centre for Epidemiologic Studies Depression Scale CES-D (Radloff, 1977; Irwin, Artin and Oxman 1999).</td>
<td>Enhance carers’ emotional wellbeing and skills for mood management</td>
<td>1. Provide educational materials on safety, caregiving and stress.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>2. Teach and practice stress management techniques (e.g. breathing exercises, music and stretching exercises).</td>
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<td></td>
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<td></td>
<td>3. Teach and role-play strategies for mood management and the use of a thought record.</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>4. Plan and develop a schedule of pleasant events</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>2. Teach and practice stress management techniques (e.g. breathing exercises, music and stretching exercises).</td>
</tr>
</tbody>
</table>
Activities of Daily Living (ADL) skill training involves assessing people’s abilities and performance to understand the underlying factors. The intervention may involve an individual programme for enabling a person to perform as many of their ADL tasks as possible themselves. Programmes include graded assistance, which means the carer providing the least assistance needed at each step. Strategies could include verbal or visual cues, demonstration, physical guidance, partial physical assistance and problem solving. Professionals trained in assessments and care planning with ADLs can devise ADL skill training programmes for use by carers and/or care staff (NICE, 2006).
Psychotherapy and counselling (3 studies)
Evidence in this category has focused on Cognitive Behavioural Therapy (CBT), but that does not mean that other approaches are not helpful to carers. The procedure and content of the CBT approach can be adapted to the needs of older people to optimise the effectiveness (Evans, 2007).

Other interventions (2 studies)
These approaches might include individual or family counselling combined with support groups or family therapy and telephone support groups. More high quality research is needed in this area.

Evidence (see page 5 for grading of evidence)

1+ Educational and skill building programmes can reduce carer distress (depression, anxiety and anger and frustration) and increase coping ability (Belle et al, 2006; Gallagher-Thompson and Coon, 2007).

1+ Individual or group cognitive behavioural therapy is effective in reducing depression symptoms for depressed carers (Gallagher-Thompson and Coon, 2007).

1+ A multiple education, support and skills training approach can lead to significant improvements in carers’ quality of life (measured in terms of depression, burden, social support, self-care and patient problem behaviours), although this was not a significant improvement for black or African-American caregivers (Belle et al, 2006).

1+ There is evidence to support the use of comprehensive carer support to prolong or sustain patients living in the community (Brodaty, Gresham, and Luscombe, 1997; Elonniemi-Sulkava et al, 2001).

Strength of evidence (see page 5 for grading of evidence)

B. Assessment of quality of life areas (e.g. depression, burden, social support, self-care and patient problem behaviours) and an individualised approach that combines education, skills training and support can offer most benefit to carers of patients with dementia (Belle et al, 2006; NICE, 2006).
B. Cognitive behavioural therapy can be beneficial to depressed carers (Gallagher-Thompson and Coon, 2007).

✓ Training the carer in the skills to improve activities of daily living can lead to less disruption and reduced carer stress (NICE, 2006).

✓ When developing a care plan for the carer consider involving the person with dementia and other family members as well as the primary carer (NICE, 2006) and/or care staff (NICE, 2006).

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References


4. What is the evidence to support the use of validation therapy to improve the quality of life of people with dementia?

Validation therapy
The originator of validation therapy, Naomi Feil (1993) suggested that repetition and retreating into the past may be an active strategy to avoid stress, boredom and loneliness and argues that people with dementia can retreat into an inner reality based on feelings rather than intellect as they find their present reality too painful (Douglas, James, and Ballard, 2004). Validation therapy is an approach used to communicate with disorientated elderly people that involves acknowledging and supporting their feelings in whatever time and place is real to them, even if this may not correspond to their “here and now” reality. Care needs to be taken not to become too focussed on confused communication and failing to identify simple explanations such as pain or hunger (Douglas, James, and Ballard, 2004). Benefits claimed for patients through the use of validation therapy include:

• restoration of self worth
• minimisation of the degree to which patients withdraw from the outside world
• promotion of communication and interaction with other people
• reduction of stress and anxiety
• stimulation of dormant potential
• help in resolving unfinished life tasks
• facilitation of independent living for as long as possible (Neal and Briggs, 2003).

Evidence (see page 5 for grading of evidence)
1+ A systematic review of two RCTs and a further RCT showed there is insufficient evidence from large scale trials to draw any reliable conclusions about the effectiveness of validation therapy for people with dementia (Neal and Barton Wright, 2003; Schrijnemaekers et al, 2002). The potential benefits that have been reported by proponents of the approach might simply reflect changes resulting from any structured group activity or from extra attention given to individuals.
Strength of evidence (see page 5 for grading of evidence)

B No suggestion can be made about validation therapy at this time.

Some examples of validation therapy in practice
When a patient with dementia is orientated to a different time and place (usually severe dementia) it can be beneficial to validate their feelings and thoughts about the issues they experiencing. An example of this was a service user who becomes agitated every day at 1pm believing that his mother is due to come and pick him up. When staff told him that his mother is no longer alive, he would become more agitated and distressed. Taking a different approach of validation therapy, staff were able to say his mother was running a little late and offered him an activity to occupy him which greatly reduced his distress and acknowledged his thoughts and feelings as he experienced them.

Validation therapy can also be useful in helping a service user come to terms with their diagnosis. Denial is often an understandable reaction to a diagnosis of dementia and staff can use validation therapy to acknowledge feelings such as fear and anxiety which may help the service user accept and come to terms with their illness.

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References


Exercise activity and cognitive stimulation

With all of us in mind
5. **What is the evidence that structured exercise activity can help maintain or improve mobility in patients with dementia?**

**Physical activities**

The suggested benefits of exercise programmes for people with dementia include improvements in mobility, walking endurance and urinary continence, but there is a lack of good quality evidence to support this.

**Evidence** (see page 5 for grading of evidence)

<table>
<thead>
<tr>
<th>Grade</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1++</td>
<td>In people aged over 65 with dementia and cognitive impairment, exercise was associated with statistically significant positive outcomes (Heyn, Abreu and Ottenbacher, 2004). The quality of the study was limited by a small sample size and the absence of blinding.</td>
</tr>
<tr>
<td>1+</td>
<td>Evidence from patients in residential care suggests that a combination of conversation and exercise on a structured basis may reduce deterioration in mobility in people with dementia but there is no evidence to support the use of either intervention in isolation (Cott et al, 2002).</td>
</tr>
<tr>
<td>1-</td>
<td>Overall the clinical impact of physical activities on the symptoms of dementia is minimal (Cott et al, 2002; Hopman-Rock et al, 1999; Tappen et al 2000; Netz, Axelard and Argov, 2007).</td>
</tr>
<tr>
<td>1-</td>
<td>Group moderate physical activity of 12-15 participants is feasible and more effective in improving mobility if exercise is performed while standing or walking rather than sitting (Netz, Axelard and Argov, 2007). This study was limited by a small sample size.</td>
</tr>
</tbody>
</table>

**Strength of evidence** (see page 5 for grading of evidence)

✓ For people with dementia, a combination of structured exercise and conversation may help maintain mobility.
Some examples of exercise activity in practice

A Jabadao group is regularly undertaken on the assessment and treatment ward at St Lukes Hospital, Huddersfield. This group is run by the occupational therapists and encourages movement and activities through structured group interactions. A Jabadao group is very creative and fun using for instance, bright coloured objects and textured materials to stimulate the senses and encourage movement. It is a fun session that is popular with the service users and succeeds in getting people active.

A dance therapist is employed in older people’s services in Calderdale. His role includes facilitating activities and cognitive processing through the medium of music and dance. This approach works very well with some dementia sufferers as it “taps into” past memories and is a pleasurable session to participate in.

Across the trust numerous activity sessions occur in older peoples services, some of which are specifically designed for the more frail individuals. An example of this is a chair based exercise session where the aim is to improve strength and co-ordination in a safe way.

Further reading on Jabadao, national centre for movement learning and health:
Crichton, S., 1997. Moving is the language I use - communication is my goal. Journal of Dementia Care, Nov/Dec, 16-17.

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References


6. What is the evidence that cognitive stimulation and Reality Orientation Therapy (ROT) can produce a positive effect on the cognitive abilities of a person with dementia?

**Cognitive stimulation**
Cognitive stimulation may occur informally through recreational activities, or formally, for example through a programme of memory provoking, problem-solving and conversational fluency activities such as face name training.

Cognitive stimulation in groups may involve using techniques such as:
- a programme of memory provoking, problem-solving and conversational fluency activities
- the spaced retrieval method
- face name training

(Davis, Massman and Doody, 2001; Quayhagen et al, 2000; Camp et al, 1996)

**Reality Orientation Therapy (ROT)**
The purpose of ROT is to re-orientate the person with dementia by continuous stimulation and repetitive orientation to the environment. This may be done formally in a daily group session, or informally using a way of communicating that is very individual to the person and involves orientation to time, place and person during every direct contact with the individual (24 hour method).

**Evidence** (see page 5 for grading of evidence)

1+ Formal cognitive stimulation produced a positive clinical impact on cognitive function in people with mild to moderate dementia (Davis, Massman and Doody, 2001; Quayhagen et al, 2000, Woods et al, 2006) and is related to improvements in quality of life (Woods et al, 2006). Although memory of specific pieces of information was improved it did not produce general benefits to memory function (Davis, Massman and Doody, 2001; Quayhagen et al, 2000). These studies did not generalise to overall neuropsychological function and had short follow up (Davis, Massman and Doody, 2001; Quayhagen et al, 2000; Woods et al, 2006).

1- A cognitive stimulation group therapy programme showed significant improvements in cognition and quality of life for people with mild to moderate dementia in residential homes and daycentres, although the study had a very short follow up (Spector et al, 2003).
2+ ROT may slow cognitive decline and delay nursing home placement (Metitieri et al, 2001) The study found that therapy conducted over a long period using the 24 hour method had more benefits than the formal method.

**Strength of evidence** (see page 5 for grading of evidence)

B Cognitive stimulation should be offered to individuals with dementia.

D Reality orientation therapy should be used by a skilled practitioner, on an individualised basis, with people who are disorientated in time, place and person.

Cognitive stimulation training can be carried out at home by a caregiver, with no risk to the person with dementia and with minimal training/education of the carer.

**An example of cognitive stimulation in practice**

In a group situation there is a game called ‘famous faces’ which aims to improve cognitive problem solving and communication. One person is not shown the famous name or picture but has to ask questions of the group such as alive or dead, man or woman until eventually guessing the right one. This is done regularly in the Poplars and Sycamores units in Wakefield.

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**References**


Life story work and reminiscence therapy

With all of us in mind
7. What is the evidence to support the use of reminiscence therapy to improve mood, cognition and general behavioural function of people with dementia?

**Reminiscence therapy**
Reminiscence therapy (RT) involves the discussion of past activities, events and experiences, with another person or group of people. This is often assisted by aids such as videos, music, pictures, archives and life story books. RT is one of the most popular psychosocial interventions in dementia care, and is highly rated by staff and participants. There is some evidence to suggest it is effective in improving mood in older people without dementia. Its effects on mood, cognition and well-being in dementia are less well understood.

**Reminiscence groups**
Typically this involves group meetings where participants are encouraged to talk about past events at least once per week. This is generally aided through prompts such as photographs, household and other familiar items from the past, music and sound recordings.

**Life story**
Life story typically involves individual sessions, in which a person is guided chronologically through life experiences, encouraged to evaluate them and may produce a life story book. Carers are increasingly involved in RT.

**Evidence** (see page 5 for grading of evidence)

1+ A systematic review of RT identified four randomised controlled trials (Woods et al, 2005). They were small studies, or were of relatively low quality, and each examined different types of reminiscence work. Taking the studies together, some significant results were identified: cognition and mood improved 4 to 6 weeks after the treatment, care-givers participating with their relative with dementia in a reminiscence group reported lower strain, and people with dementia were reported to show some indications of improved functional ability. No harmful effects were identified in the outcomes reported.
However, in view of the limitations of the studies reviewed, there is an urgent need for more quality research in the field. A large multi centre trial is currently underway at the Bradford dementia group, for details please visit: http://www.bradford.ac.uk/acad/health/dementia/research/reminiscence.php

Strength of evidence (see page 5 for grading of evidence)

B Although indications from the research provide some encouragement, at this stage there is inconclusive evidence of the efficacy of reminiscence therapy for dementia (Woods et al, 2005; Politis et al, 2004; Ito et al, 2007).

Some examples of reminiscence therapy in practice
Reminiscence therapy has been used when there are difficulties with behavioural changes or low mood. Service users can be encouraged and supported to put together a memory box of things that are important to them about their past, write about their life and use photographs and albums to share their memories.

Life story work can involve building up a storyboard with pictures and other documents relating to time periods such as in particular jobs or life events. This type of work can be a particularly powerful experience for the service user when skills, talents and experiences in their past are acknowledged and celebrated.

Some quotes from people engaged in life story and reminiscence work are:

“You have given me back my life”
“Thank you, thank you”
“Are you interested in me really? That’s lovely”
“That’s my story I have told you”

A quote from a member of staff involved in life story work:
“I can’t put into words what connects me and what I gain, I can only say, I am privileged to be allowed to share their world and their memories.”
Evaluation

This dementia toolkit is designed to be as useful to staff as possible and will be updated every 2 years. Please tell us your views about the toolkit by completing the evaluation form on the back of this folder. Your comments will be invaluable to making sure it is as informative, relevant and user friendly as possible.

References


Staff courses, training opportunities and appendix 1-5

With all of us in mind
8. What training is available for staff working with people with dementia and their carers within South West Yorkshire Mental Health NHS Trust?

Staff training within the Trust is categorised into the following:

- **Statutory training** – annual fire lectures
- **Mandatory training** – this is generally internal courses that staff are required to attend as part of their role. Some training is relevant to all staff, some to care staff or registered professionals only. General details are in the Trust mandatory training policy (see document store within the Trust intranet at http://nww.swyt.nhs.uk/Policies/Docstore/details.aspx?docid=373. More specific details about which courses are relevant for staff working within older people’s services can be found within the draft training plan for older people’s services. Please e-mail Sue Barton for the most up to date version.
- **Additional training** – once staff have attended or booked themselves to attend all the statutory and mandatory training required, there are suggested areas of training and development that have been prioritised within older people’s services.

This resource provides information about all the relevant additional training available for staff in SWYMHT dementia care services.

**Please note:**

Training programmes and events are subject to change and new courses are being developed all the time. You can find out up to date information from your nearest education centre. Please call either Fieldhead education centre Wakefield on 01924 328608 or Yearn to Learn at St Luke’s Huddersfield on 01484 343914.
<table>
<thead>
<tr>
<th>Training area</th>
<th>Suggested training</th>
<th>Additional information</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Person centred care, life story work, dignity and cultural awareness.</strong></td>
<td>Dementia Care Mapping (DCM) 5 day basic user status course – internal (4 day course also available directly from Bradford University) Dementia care mapping 1 day update and refresher sessions for qualified mappers to update from DCM 7 to 8.</td>
<td>Contact Suzanne Wightman on 01484 343499 or Jo Crossland, 01422 281376 and to book on the course Cheryl Slack on 01484 343523 Further details on Trust intranet at: <a href="http://www.swyt.nhs.uk/news/dementiacaremappingtraining.htm">http://www.swyt.nhs.uk/news/dementiacaremappingtraining.htm</a> Contact Andrea Trangmar on 01484 343678 or <a href="mailto:andrea.trangmar@swyt.nhs.uk">andrea.trangmar@swyt.nhs.uk</a> or Suzanne Wightman on 01484 343499</td>
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<tr>
<td></td>
<td>Advanced User Status DCM 3 day course at Bradford University Other relevant external training courses at Bradford</td>
<td>For further details see: <a href="http://www.bradford.ac.uk/acad/health/bdg/dcm/courses/advanced.php">http://www.bradford.ac.uk/acad/health/bdg/dcm/courses/advanced.php</a> or <a href="http://www.bradford.ac.uk/acad/health/dementia">http://www.bradford.ac.uk/acad/health/dementia</a> Telephone: 01274 232323</td>
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<td></td>
<td>Introduction to person centred care 1 day internal course is available to staff in the Calderdale locality only, however planning is in place to develop a course available to all Trust staff. Contact Suzanne Wightman on 01484 343499 for details</td>
<td>For training dates and to book contact Melanie Riley on 01422 884597 or e-mail <a href="mailto:melanie.riley@swyt.nhs.uk">melanie.riley@swyt.nhs.uk</a> For more information about the course contact Rebecca Whelan on 01422 882506</td>
</tr>
<tr>
<td></td>
<td>Life story and memory half day workshops (running from September 2008)</td>
<td>Contact Suzanne Wightman on 01484 343499 or Andrea Trangmar on 01484 343678 or <a href="mailto:andrea.trangmar@swyt.nhs.uk">andrea.trangmar@swyt.nhs.uk</a></td>
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**Supporting documents**


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<thead>
<tr>
<th>Training area</th>
<th>Suggested training</th>
<th>Additional information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Enhancing service user's experiences of receiving medication</td>
<td>The ‘medicines with respect’ project is currently being undertaken within our Trust to support nursing staff in the practice of administering medication to improve medicines management interventions available to service users.</td>
<td>Contact the practice effectiveness manager on 01924 327089 or professional development lead on 01924 512352 for further details.</td>
</tr>
<tr>
<td>Further reading</td>
<td></td>
<td>Relevant Documents</td>
</tr>
<tr>
<td>Non-medical prescribing</td>
<td>No internal training, however training for prescribing can be accessed at a local university. See the Trust framework document for non medical prescribing for details.</td>
<td>Courses available at Huddersfield University in Independent and Supplementary Nurse Prescribing or Supplementary Prescribing for allied health professionals contact admissions on 01484 473015 SWYMHT framework for non medical prescribing see: <a href="http://www.swyt.nhs.uk/Policies/Docstore/details.aspx?docid=533">http://www.swyt.nhs.uk/Policies/Docstore/details.aspx?docid=533</a> 01422 281348 and chief pharmacist on 01422 281352</td>
</tr>
<tr>
<td>Management and leadership development</td>
<td>A total of 30 middleground training modules are offered as part of an internal leadership skills course. These are available to staff Agenda for Change (AfC) band 7 and above who have either supervisory responsibility or a significant leadership role.</td>
<td>For details of which modules are currently available please contact Ros Taylor 01924 327301 or <a href="mailto:ros.taylor@swyt.nhs.uk">ros.taylor@swyt.nhs.uk</a> There may also be ward manager development 3 day programmes available.</td>
</tr>
<tr>
<td>External courses</td>
<td></td>
<td>There are certificates, diplomas and masters degrees courses available, for example: Leading Innovation and Change Masters at York St John University for further details please see: <a href="http://www2.yorksj.ac.uk/apps/Site/Prospectus/default.asp?Course_ID=325">http://www2.yorksj.ac.uk/apps/Site/Prospectus/default.asp?Course_ID=325</a></td>
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<tr>
<td>Training area</td>
<td>Suggested training</td>
<td>Additional information</td>
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<tr>
<td>Record keeping</td>
<td>To avoid breaches of information confidentiality, the NHS is assessing all transfers of personally identifiable information. This includes emails and paper records of patient identifiable information such as name, date of birth, address etc.</td>
<td>Contact Nicola Smith on 01422 281345 or e-mail: <a href="mailto:nicola.smith@swyt.nhs.uk">nicola.smith@swyt.nhs.uk</a> for general information on governance queries.</td>
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<tr>
<td>Training area</td>
<td>Suggested training</td>
<td>Additional information</td>
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<tr>
<td>Psychosocial Intervention Skills (PSI)</td>
<td>2 day introduction to PSI skills course open to all staff, with or without a professional qualification who are involved in delivering packages of care to individuals with psychosis.</td>
<td>Darryl Thompson, psychosocial interventions facilitator, The Education Centre, Fieldhead, Ouchthorpe Lane, Wakefield, WF1 3SP. Tel 01924 328635 (Weds, Thurs &amp; Fridays), or email: <a href="mailto:darryl.thompson@swyt.nhs.uk">darryl.thompson@swyt.nhs.uk</a></td>
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</table>
|                                       | 10 day internal course in psychosocial interventions for psychosis (PSI). Led by Mick Fleming, programme leader from the University of York. Awarded 20 credit points by the University of York, at Level 2 or 3.                                                                                                                    | For further details contact, psychosocial interventions facilitator, The Education Centre, Fieldhead, Ouchthorpe Lane, Wakefield, WF1 3SP. Tel 01924 328635 or email: darryl.thompson@swyt.nhs.uk  
For further details of the 10 day training programme see: http://nww.swyt.nhs.uk/organisation/training/10daypstraining.htm |
|                                       | External courses at diploma or masters level.                                                                                                                                                                                                                                                                                                       | York University, Postgraduate Diploma/Masters in psycho-social interventions, for further details see: http://www.york.ac.uk/healthsciences/gsp/pdpsi.htm                                                                                                                                 |
|                                       |                                                                                                                                                                                                                                                                                                                                               | Leeds Metropolitan University part time degree or diploma in PSI  
http://prospectus.leedsmet.ac.uk/main/detail.htm?&p=58&course_id=7117&attendance=2                                                                                                                                              |
<p>|                                       |                                                                                                                                                                                                                                                                                                                                               | The University of Huddersfield degree in professional studies (mental health): <a href="http://www.hud.ac.uk/hhs/courses/ptug/bscpsmh.htm">http://www.hud.ac.uk/hhs/courses/ptug/bscpsmh.htm</a>                                                                                                              |</p>
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<tr>
<th>Training area</th>
<th>Suggested araining</th>
<th>Additional information</th>
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<tbody>
<tr>
<td><strong>CBT skills</strong></td>
<td>Wakefield staff: A series of 3 workshops are run internally for junior medical staff, ward based and community clinicians to increase their knowledge and understanding of the principles underlying cognitive behavioural therapy.</td>
<td>Wakefield staff can get further details contact Sue Potts at Horbury Health Centre on 01924 327729 or e-mail <a href="mailto:sue.potts@swyt.nhs.uk">sue.potts@swyt.nhs.uk</a></td>
</tr>
<tr>
<td></td>
<td>Calderdale, Huddersfield and Dewsbury staff: Training is currently being developed and may be available from Sept/Oct 2008.</td>
<td>Contact Sheila Lewis or Richard Kerry on Trust e-mail for details.</td>
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<tr>
<td></td>
<td>Postgraduate certificate courses are available at Huddersfield and Bradford University.</td>
<td>Postgraduate certificate course at Huddersfield University (funded places available). See: <a href="http://www2.hud.ac.uk/courses/parttime/0001102.php">http://www2.hud.ac.uk/courses/parttime/0001102.php</a> Postgraduate certificate course at Bradford University: See: <a href="http://www.brad.ac.uk/admin/acsec/ProgSpec/entry2006/School%20of%20Health%20Studies/PGC_Cognitive_Behavioural_Therapy.doc">http://www.brad.ac.uk/admin/acsec/ProgSpec/entry2006/School%20of%20Health%20Studies/PGC_Cognitive_Behavioural_Therapy.doc</a></td>
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<tr>
<td></td>
<td>Different courses are offered depending on current funding – for example course phlebotomy.</td>
<td>For further details contact the head of nursing on 01924 327506 or associate clinical director on 01924 327148.</td>
</tr>
<tr>
<td><strong>Physical care</strong></td>
<td>Additional reading</td>
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<tr>
<td>Training area</td>
<td>Suggested training</td>
<td>Additional information</td>
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<tr>
<td>Eating, drinking and swallowing difficulties</td>
<td>Support is offered from dietitians and in some cases speech and language therapist depending on the current provision available. Contact the relevant dietitian in the first instance. Dietitians offer training on food and fluid modifications.</td>
<td>For Wakefield staff contact the dietitian on 01924 327407 For North Kirklees staff contact the dietitian on 01924 512350 For South Kirklees staff contact the dietitian on 01924 512392 For Calderdale staff contact the dietitian 01422 281362</td>
</tr>
</tbody>
</table>
Evaluation

This dementia toolkit is designed to be as useful to staff as possible and will be updated every 2 years. Please tell us your views about the toolkit by completing the evaluation form on the back of this folder. Your comments will be invaluable to making sure it is as informative, relevant and user friendly as possible.

Acknowledgements

Thank you to all the contributors to the information contained in this study and those who took the time to assist with reviewing and developing this resource. This includes group members from the focus group, consensus group, collaborative project group, practice effectiveness group and staff responsible for delivering, developing or coordinating training both internal and external to the Trust.

Author

Rebecca Spencer, Research Fellow, South West Yorkshire Mental Health NHS Trust

Key Contributors

Dr Virginia Minogue, head of West Yorkshire Mental Health research and development consortium
Professor Stephen Curran, old age consultant psychiatrist, South West Yorkshire Mental Health NHS Trust
Ben Boyd, general manager for older people’s services, South West Yorkshire Mental Health NHS Trust
Maggie Bell, assistant director of workforce development, South West Yorkshire Mental Health NHS Trust
Jackie Davies, learning and development manager, South West Yorkshire Mental Health NHS Trust
Robert Maginnis, practice effectiveness manager, South West Yorkshire Mental Health NHS Trust
Ken Gledhill, lead clinical psychologist for older people, South West Yorkshire Mental Health NHS Trust
Ann Hargate, professional and service governance lead, South West Yorkshire Mental Health NHS Trust
Suzanne Wightman, senior manager practice development for older peoples services, South West Yorkshire Mental Health NHS Trust
Jo Crossland, acute services manager, older people’s services, South West Yorkshire Mental Health NHS Trust
Julie Eskins, head of clinical governance, South West Yorkshire Mental Health NHS Trust
Michaela O’Neill, South West Yorkshire Mental Health NHS Trust
Possible areas of focus for the dementia toolkit project

Please rate the following dementia topic areas in order of priority. (1 = highest priority and 9 = least priority)

Please rank the most important areas those that you would benefit most from evidenced based recommendations for use within your practice.

<table>
<thead>
<tr>
<th>Suggested topic</th>
<th>Priority</th>
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<tbody>
<tr>
<td>1. Managing communication difficulties in dementia. eg. speech and language therapies</td>
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<tr>
<td>3. Ethical issues around physical and nutritional health towards end of life care, including the impact this has on carers.</td>
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<tr>
<td>5. Evidence base and uses of Dementia Care Mapping (DCM).</td>
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<tr>
<td>7. Changes in the assessment and diagnosis of patients, particularly with regards to the new NICE guidance.</td>
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<tr>
<td>8. Validity of scales and measure used in the assessment of patients with dementia and important considerations.</td>
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<tr>
<td>9. Training and support for staff within dementia care services to best support and care for patients and carers. eg. DCM</td>
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</table>
Performance Objectives and Personal Development Review

Incorporating performance objectives and the NHS Knowledge and Skills Framework

<table>
<thead>
<tr>
<th>Reviewees details</th>
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<tbody>
<tr>
<td>Individual’s Name</td>
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<td>Job Title</td>
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<td>Place of Work</td>
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<tr>
<th>Reviewers details</th>
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<tr>
<td>Name</td>
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<td>Status</td>
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This review and plan covers the following period (12 months max)

from: ____________________________

to: ____________________________

☐ This is a foundation gateway review (using subset KSF Outline)

☐ This is a second gateway review (using full KSF Outline)

☐ This is not a gateway review

Jan 2008
Any issues relevant to this PDR (e.g. Gateway issues, additional action plans used, outstanding issues from previous PDRs or Personal Development Plans):

Contents

- FORM 1 - Recording Personal Development Review Decisions
- FORM 2 - Performance Objectives
- FORM 2a - Personal Development Plan: Learning & Development
- Summary and sign-off of PDR and PDP

Jan 2008
<table>
<thead>
<tr>
<th>Dimension</th>
<th>Subset Level</th>
<th>Full Level</th>
<th>Level achieved</th>
<th>Evidence for decision</th>
<th>Comments/areas for development (actions detailed in PDP)</th>
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<tr>
<td>Communication</td>
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<td>Personal &amp; People Development</td>
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<td>Health, Safety &amp; Security</td>
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<td>Service Improvement</td>
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<td>Quality</td>
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<tr>
<td>Equality &amp; Diversity</td>
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### SPECIFIC DIMENSIONS (if applicable)

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<tr>
<th>Dimension (code or title)</th>
<th>Subset Level</th>
<th>Full Level</th>
<th>Level achieved</th>
<th>Evidence for decision</th>
<th>Comments/areas for development (actions detailed in PDP)</th>
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Jan 2008
**Performance Objectives**

These will include both organisational and personal objectives

<table>
<thead>
<tr>
<th>Objective</th>
<th>What support do I need and where will I get it?</th>
<th>What are the barriers &amp; how can I overcome them?</th>
<th>How will I know if this activity has been effective</th>
</tr>
</thead>
<tbody>
<tr>
<td>e.g. To reduce sickness and absence figures</td>
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<tr>
<td>e.g. To ensure all staff are compliant with the Mandatory Training policy</td>
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</table>

Jan 2008
# Personal Development Plan - Learning and Development

<table>
<thead>
<tr>
<th>What is the development need? (Mandatory and Essential learning and development research to the role must be prioritized)</th>
<th>Target completion date</th>
<th>KSF Dimension (Dimension and indicators this activity relates to)</th>
<th>How will I know if this activity has been effective</th>
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</tbody>
</table>
Personal Development Review and Plan: summary and sign-off

Summary from reviewee or reviewer (if applicable):

This gateway review was / was not* passed successfully (cross through entire sentence if not a Gateway review)

This Personal Development Review and plan has / has not* been jointly agreed.

Signed: ___________________________________________  Date:____________________
      Reviewee

Signed: ___________________________________________  Date:____________________
      Reviewer

Signed: ___________________________________________  Date:____________________
      Manager

Date of next review:

Jan 2008


**ABC Chart**

This ABC chart can be used to record behavioural concerns.

'A' stands for antecedents, that is, what occurs immediately before the behaviour you observe and can include any triggers, signs of distress or environmental information.

'B' refers to the behaviour itself and is a description of what actually happened or what the behaviour 'looked' like.

'C' refers to the consequences of the behaviour, or what happened immediately after the behaviour and can include information regarding other people's responses to the behaviour and the eventual outcome for the individual. It can also be a good idea to keep track of where and when the behaviour occurred to assist in identifying any patterns.

<table>
<thead>
<tr>
<th>Date and time</th>
<th>Antecedents</th>
<th>Behaviour</th>
<th>Consequences</th>
<th>Other comments</th>
</tr>
</thead>
</table>
The Wakefield Memory Service
SERVICE USERS INFORMATION PACK
## Contents

<table>
<thead>
<tr>
<th>Topic</th>
<th>Page</th>
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</thead>
<tbody>
<tr>
<td>Being told you have dementia?</td>
<td>1</td>
</tr>
<tr>
<td>What is dementia?</td>
<td>2</td>
</tr>
<tr>
<td>Learning to live with dementia and Everyday tips</td>
<td>3</td>
</tr>
<tr>
<td>Planning the future</td>
<td>4</td>
</tr>
<tr>
<td>Where can you get support?</td>
<td>5</td>
</tr>
<tr>
<td>Useful contact numbers</td>
<td>6</td>
</tr>
</tbody>
</table>
A diagnosis of dementia can come as a shock, even if you’ve been half expecting it.

You may be feeling:

**Angry**
- “Why is this happening to me”
- “What did I do to deserve this”

**Worried**
- “How will my family cope”
- “Will my family be OK”

**Sad**
- “Things get on top of me”
- “There doesn’t seem much point in making an effort”

**Guilty**
- “I feel bad asking for help”
- “I don’t want to burden anyone”

**Alone**
- “No one seems to understand”
- “Sometimes I feel I am tackling this on my own”

**Frustrated**
- “I just can’t do the things I used to”
- “Sometimes I just feel like screaming”

You may also feel relieved that there is a medical reason behind the changes you’ve noticed.

- “I had an illness. I wasn’t having a bad dream. I thought well, best foot forward, I can cope with this”
Answers to some commonly asked questions

What is dementia?
■ Dementia is not an emotional or psychological disorder. It is the name given to a range of symptoms caused by physical changes in the structure of the brain. These changes lead to problems with memory, thinking and actions.

Illnesses which cause dementia
■ Alzheimer’s Disease
This is the most common form of dementia. During the illness physical changes take place in the brain. ‘Plaques’ and ‘tangles’ made from proteins develop in the brain tissue. This leads to the death of brain cells and dementia.
■ Vascular dementia
Blood normally takes oxygen to the brain cells. If the blood supply is disrupted, as a result of a stroke for example, brain cells may die. This may lead to dementia.
■ Dementia with Lewy Bodies
In this form of dementia small protein bodies – or ‘Lewy bodies’ – develop in the brain. This causes the death of brain cells.
■ Pick’s disease or front-temporal dementia
This is one form of fronto-temporal dementia. These are just a few of the many different types of dementia.

Dementia is not:
■ A normal part of ageing
■ Contagious
■ Something to be ashamed of

What are the symptoms?
Dementia is more than just forgetfulness. You find that you:
■ Have problems remembering
‘When I try to remember things, it goes further away from me’
■ Sometimes find it hard to find the right words
‘I don’t put the right word in the right place’
■ Can’t understand what people are saying
‘A direct question brings me up short’
■ Have problems recognising people
‘I knew him from somewhere, but I couldn’t remember where’
■ Find it more difficult to complete tasks and solve problems
‘Cooking has become more difficult. I have problems working out what comes next’
■ Find it harder to concentrate
‘My mind wanders sometimes’

Is there a cure for dementia?
There is no cure yet for dementia. Drugs are now available to treat some of the symptoms of Alzheimer’s disease. They are usually given to people in the early to middle stages of the illness. They don’t work for everyone.

Who gets Dementia?
Dementia affects people of all ages, although it is more common in older people. Over 700,000 people in the UK have dementia. You are not alone!

Will my children inherit my dementia?
It is unlikely. Scientists are currently researching the question of whether you can inherit dementia. We are likely to know more over the next few years.

At the moment we do know that some rare forms of dementia are inherited. These are usually the types of dementia that affect younger people (under the age of 65).

Further information
Learning more about dementia and its potential implications can help you to recognise any changes that take place, and help you understand more clearly what is happening.
Learning to live with dementia

Remember:
You are not alone in facing dementia. Many people have been through a similar experience. Here are some tips from other people with dementia. There’s a lot you can do to make your life easier.

Talking helps
■ If you can, talk to your friends and family about your worries. Don’t bottle things up. “If you keep it in it sends you up the wall”

Get Support
■ We all need extra help at some point in our lives – don’t be afraid of asking for support. Think about joining a group with other people with dementia.
“Having someone to turn to is very important”

Find out about dementia
■ You have the right to know about your illness and what will happen in the future.
“I want to know. I want to be fully armed so I can get the most out of my life”

Tell other people about dementia
■ Explain what you know about dementia. Other people need to understand what you are going through, they may be able to help.
“People know very little about this, very little. It’s ignorance I know, but if I know more I can tell them more”

Stay as active as you can
■ Maintain your interests, see your friends. Carry on with life.
“It lifts my spirits, makes me feel useful and gives me a sense of purpose”

Everyday tips
These tips have been suggested by people with dementia.

Keep a note book or diary
■ Write down important things you want to remember. This might include appointments, people’s names, a list of things to do, any thoughts and ideas you want to remember.

Have a daily newspaper delivered
■ The date and the day of the week are always on the front page. Or buy a clock with the date on it.

Have a routine
■ Doing things in the same order each time can help.

Write reminders to yourself
■ Lock the door at night or put the rubbish out on a certain day, for example. Put a note on the front door to remind yourself to take your keys with you.

Maintain your skills by doing the things you enjoy
■ Your local occupational therapist can advise you on what equipment might help you. They can be contacted through your GP consultant or through social services.
4 Planning for the future

Working
If you are working you may be having some problems in your job as a result of your dementia. When you feel ready, speak to your employer about your diagnosis. It will be easier if they are involved from the beginning.

Get help
■ From the start, seek advice and support. This could be from your trade union, your local citizens advice bureau or from the disability employment adviser at your local job centre.
■ You can also discuss the effect that dementia has on your work with your GP or consultant. These people can help you think things through. They can also support you through the process of speaking to your employer.

Carrying on in work
■ Your employer should consider what they could do to help. They might, for example, consider reducing your hours or modifying your role/job.
■ Financial assistance is sometimes available for employers to meet the cost of supporting someone in their job. The disability employment advisor at your local job centre will be able to help.

Can I still drive?
A diagnosis of dementia is not in itself a reason to stop driving. You will eventually have to stop, but many people continue to drive safely for some time after their diagnosis. Regular reviews and support can help you decide how long you can continue to drive.

Who to inform
■ You must, by law, inform the Driver and Vehicle Licensing Authority (DVLA) that you have dementia. The DVLA will make a decision about your ability to continue driving. Contact the Drivers Medical Group, DVLA, Swansea, SA19 1TU.
■ You must inform your car insurance company of your diagnosis. This is to ensure that your car insurance continues to be valid.

Living Wills
Advance directives (also known as living wills) allow you to outline the treatment and care you would like in the future.

In an advance directive you can
■ Give your consent to particular forms of treatment.
■ Refuse certain treatments
■ Give the name of someone you want to make decisions about care and treatment on your behalf.

An advance directive doesn’t allow you to
■ Ask a doctor to do anything unlawful. You cannot ask a doctor to help you die, for example.
■ Refuse basic care – this includes food, drink and pain relief.

Setting up an advance directive
You can set up an advance directive through a solicitor, or you can fill in a prepared form. It should be reviewed regularly to ensure it is up to date. Speak to your close friends or relatives. Involving them will help them understand your wishes.

Sorting out financial affairs
It is important to sort out your money.

This will
■ Ensure things are set up in the way you want.
■ Make sure all your important papers are in order. These might include bank and buildings society statements, mortgage, rent, insurance, wills, tax and pension details. Consider setting up direct debits and standing orders for your regular bills.
■ Think about discussing your plans with someone you trust so they are aware of your wishes.
■ Your can arrange for someone to collect pensions and benefits. Inform the benefits agency that you wish to make regular arrangement for someone to collect any benefits on your behalf.

Enduring power of attorney
An enduring power of attorney is a legal way of appointing someone you trust to manage your financial affairs. The person you nominate must be appointed now, when you feel able to organise your own affairs. They will only take over if and when you can no longer manager on your own.

Wills
■ A will ensures that your money and possessions are given to those close to you when to die.

Trusts
■ Consider setting up a trust if you own your own home or have a lot of savings. A trust can administer your money and property for your benefits.

Ways of getting extra money
■ You may be entitled to a number of benefits. These may include attendance allowance, disability living allowance, income support, incapacity benefit, council tax discount and housing benefit. You may also be eligible for help with your mortgage payments.

These benefits are yours by right, if you qualify. They could make a real difference to your life.

For information on benefits and how to apply for them contact:

The local Benefits Agency
Wakefield: 01924 453600
Pontefract: 01977 692800
Hemsworth: 01977 624000
National: 0800 882200

Wakefield and Five Towns Branch of the Alzheimer’s Society
01924 373264

Age Concern
Wakefield: 01924 305733
Castleford: 01977 552476

Legal advice
■ When completing all legal documents it is advisable to seek advice from a solicitor. A solicitor can ensure that documents are completed in the correct way. They will make sure they are legally valid.
■ The Alzheimer’s Society has a list of solicitors who have helped other people with dementia.

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You may feel perfectly well, physically fit and that there are no problems, which is great. However, most illnesses that cause dementia are progressive, which means that eventually, you will find things difficult and will need extra help. It’s a good idea to learn about additional support now, so that when you actually need help, you and your family will know where to go.

Support from Social Services
- Social Care Direct covers the Wakefield and Five Town’s area. They are a dedicated social work team who are the first point of contact for social care services and deal with new requests for services.
  
  Telephone: 01924 303456 (24 hours a day)

Support from your doctor
Your GP and/or hospital consultant can help you through problems and decisions. They may also be able to put you in contact with other local services.
- Community psychiatric nurses can help with practical and emotional issues
- Occupational therapists can provide advice on equipment and ways of making life easier
- Physiotherapists can give advice on keeping mobile
- Speech therapists can help with language problems

Support from a counsellor
- Some people find talking to a counsellor a great help. A counsellor is someone who is trained to listen. It’s important to find the right counsellor. You must feel comfortable talking to them.

- Counsellors are registered by the British Association for Counselling. To find out about registered counsellors in your area contact your GP, consultant, your local citizen’s advice bureau or library.

Other voluntary organisations
- The Wakefield Branch of the Alzheimer’s Society 01924 373264 offers information, advice and support. Alternatively you could ring the National Helpline Number on 0845 300 0336.
- MIND Matters counselling services can provide information on services and where to get help Telephone: 01924 360880.
- Age Concern offers services for older people, including advice and information: Telephone: 01977 552476/552475.
- Wakefield Samaritans provide emotional support for people in a crisis. You can call them any time, day or night. Telephone: 01924 377011

Additional information
- Contact your local social services department, library or citizens advice bureau for further information on services in your area.
Useful contact numbers

Age Concern
Wakefield: 01924 305733
Castleford: 01977 552114

Alzheimer's Society
Wakefield: 01924 373264
Helpline: 0845 300 0336

Benefit Enquiry Line
Tel: 0800 882200
Textphone: 0800 243355

Alzheimer's Society
Helpline: 0845 300 0336

Benefit Enquiry Line
Tel: 0800 882200
Textphone: 0800 243355

Community Mental Health Teams
Ossett: 01924 327787
Castleford: 01977 605507

Continence Advisory Service
01977 605516

Sir Jules Thorn Centre
01977 605530

Help the Aged
0808 8006565

Memory Service
01924 328637

NHS Direct
0845 4647

Pals Office
(patient advice & liaison service)
Wakefield: 01924 212672
Pontefract: 01977 606232

Samaritans
01924 377011

Social Care Direct
01924 303456

Carers Wakefield & District
01924 305544

If you would like the information contained in this document in another language please telephone the Wakefield Memory Service for assistance.
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1 What is dementia?
If you have a friend or relative that has been diagnosed with dementia you may be feeling anxious or confused. You may not know what dementia is.

The term “dementia” is used to describe symptoms that occur when the brain is affected by specific diseases and conditions. These include Alzheimer’s disease and stroke.

Dementia is progressive. This means the symptoms will gradually get worse. How fast dementia progresses depends on the individual. Each person is unique and will experience dementia in their own way.

**Symptoms of dementia include:**
- Loss of memory - the person with dementia may forget the way home from the shops or be unable to remember names and places
- Mood changes – particularly as the parts of the brain that control emotion are affected by the disease
- Communication problems – there may be a decline in the ability to talk, read or write

In later stages of dementia, the person affected will have problems carrying out everyday tasks and will become increasingly dependent on other people.

**What causes dementia?**
There are several diseases and conditions that cause dementia. These include:
- Alzheimer’s disease. This is the most common form of dementia. During the course of the disease the chemistry and structure of the brain changes, leading to the death of brain cells.
- Vascular disease. The brain relies on a network of blood vessels to bring it oxygen-bearing blood. If the oxygen supply to the brain fails, brain cells are likely to die and this can cause the symptoms of vascular dementia. These symptoms can occur either suddenly, following a stroke, or over time through a series of small strokes.
- Dementia with Lewy Bodies. This form of dementia gets its name from tiny spherical structures that develop inside nerve cells. Their presence in the brain leads to the degeneration of brain tissue. Memory, concentration and language skills are affected. This form of dementia shares some characteristics with Parkinson’s disease.
- Fronto-temporal dementia (including Pick’s disease). In front-temporal dementia, damage is usually focused in the front part of the brain. At first personality and behaviour are more affected than memory.
- Rarer causes of dementia. There are many other causes of dementia including Supranuclear Palsy, Korsakoff’s Syndrome, Biswanger’s Disease, HIV and Creutzfeldt-Jakobs Disease.

**Who gets dementia?**
There are about 750,000 people in the UK with dementia.
- Dementia usually affects older people
- Both men and women get dementia
- Scientists are investigating the genetic background to dementia. It does appear that in a few rare cases dementia can be inherited.

**Can dementia be cured?**
Most forms of dementia cannot be cured, although research is continuing into developing drugs, vaccines and treatments. Some drugs have been developed that can temporarily alleviate some of the symptoms of Alzheimer’s disease in the early to middle stages. These drugs are:
- Aricept
- Exelon
- Reminyl

A new drug called Ebixa was launched in 2002. This works in a different way and is suitable for people in the middle to late stages of dementia. None of these drugs will cure Alzheimer’s Disease but they may stabilize some of the symptoms for a limited period of time.

**Diagnosing dementia**
It is very important to get a proper diagnosis
- A diagnosis will help the doctor rule out illnesses that might have similar symptoms to dementia including depression
- Having a diagnosis may mean it is possible to be prescribed drugs for Alzheimer’s Disease
- It can help you plan for the future.

A doctor, either a GP or a specialist, diagnoses dementia. The specialist may be a geriatrician, a neurologist or a psychiatrist. The doctor may carry out a number of tests. These are designed to test memory and the ability to perform daily tasks.

**Can dementia be prevented?**
At present we are not sure what causes most of the diseases that lead to dementia. This means it is difficult to be sure what we can do to prevent dementia.

However, the evidence seems to indicate that a healthy diet and lifestyle may help protect against dementia. In particular, not smoking, exercising regularly, avoiding fatty foods and keeping mentally active into old age may help to reduce the risk of developing vascular dementia and Alzheimer’s Disease.
Once dementia has been diagnosed it is important to consider what to do next.

**Services and support**
Accessing services and support at the right time can make a great difference, both to the person with dementia and their family and friends. The local authority has a duty to carry out a community care assessment, which will assess the person’s needs and decide which services can be arranged to meet them. An assessment can be made by contacting Social Care Direct on Wakefield 01924 303456.

Services arranged by local authorities are known as community care services. These may include:
- Home Care
- Equipment and Adaptations
- Day Care Services
- Respite Care and Residential or Nursing Care

The financial situation of the person with dementia will be taken into account. They may have to pay something towards the cost of the services.

Voluntary organisations provide services for carers such as information, helplines, support groups, lunch clubs and home care schemes. You can contact the Alzheimer’s Society for further details.

**Financial and legal affairs**
The person with dementia should arrange their affairs while they are still able to do so.

You should obtain advice from a solicitor when completing legal documents. A list of solicitors who have experience of helping people with dementia can be obtained by contacting Law Net on 01926 886990.

You should also make sure that important papers are in order and can be easily found. These might include bank and building society payments, insurance policies, a will, pension details etc. Consider setting up direct debits or standing orders for regular bills, so that no one has to remember to pay them.

**Benefits**
It is important to check that both the person with dementia and their carer claim all the benefits to which they are entitled. You could make enquiries through the following places who can give advice about benefits and how to make a claim:
- The government website: www.dwp.gov.uk
- The benefits enquiry line Tel: 0800 88 22 00
- Your local dept for work and pensions:
  - Wakefield: 01924 433600
  - Pontefract: 01977 692800
  - Castleford: 01977 464111
  - Hemsworth: 01977 624000

You should ask whether the person with dementia is eligible for Disability Living Allowance or Attendance Allowance and whether, as a carer, you are eligible for Invalid Care Allowance.

**Enduring power of attorney**
Anyone with dementia who owns a property or investments, or has an income other than benefits, should consider making an enduring power of attorney. It is not too late if the person with dementia can show that they are aware of what is involved.

More information about this can be found in the leaflet ‘Financial and Legal tips’ which is available by contacting the Alzheimer’s Society on 01924 373264.

**Health**
A person with dementia should see their GP if they feel unwell or if there are any concerns about their health. Even minor complaints can make a difference to a person’s well being and ability to cope. Many conditions, such as infected leg ulcers, constipation or chest infections, can cause additional confusion and distress that often diminish once treated.

Depression is very common in early-stage dementia and the GP should be consulted if this is suspected. The GP can refer people to other health professionals, such as community nurses and specialists.

If the person with dementia is already on medication, they should check with their GP whether it is essential. Some medication can cause side effects that can lead to confusion. The same applies to over-the-counter medication.

At present there are no treatments that can reverse the progress of dementia once it has developed. However, there are some medications, which can alleviate some of the symptoms of Alzheimer’s disease for a limited period of time, although they don’t work for everyone.

People with vascular dementia will be treated for their vascular disease to try to prevent it from worsening. This may involve taking drugs to lower blood pressure and making lifestyle changes.

The person with dementia should have regular sight, hearing and dental check ups:
- Problems with sight can exacerbate confusion
- Hearing difficulties can increase feelings of isolation
- Problems with teeth, gums or dentures can result in discomfort and distress
**Driving**
A person diagnosed with dementia does not necessarily have to stop driving immediately but it is important to ensure that they are still driving safely:
- They must inform the Driver and Vehicle Licensing Authority (DVLA) of their diagnosis, Tel: 0870 600 0301 or write to DVLA Driver’s Medical Unit, Longview Road, Swansea, SA99 1TU
- They must inform their insurance company of their diagnosis, or their insurance may become invalid.

The DVLA will ask for medical reports and possibly a driving assessment in order to decide whether the person is able to continue driving.

**Working**
If the person with dementia is still working and is experiencing any difficulties in their job, they should talk to their employer or get advice as soon as possible. Advice is available from:
- Their human resources department or trade union
- A local Citizens Advice Bureau
- A disability employment adviser at their local Job Centre

Their employer may be able to adjust their job to meet their changing needs. Financial assistance may be available to help meet the cost of supporting the person at work. The disability employment officer can give advice on this.

If the person decides to stop working, they should get advice about their pension from their employer or pension company. They should also find out what benefits they are eligible for.

If the person feels that they have been treated unfairly by their employer, they can seek advice from the Disability Rights Commission Helpline on 08457 622633 or write to: Disability Rights Commission, Freepost, Mid 02164, Stratford upon Avon, CV37 9BR.
3 Carers - looking after yourself
It is all too easy to ignore your own needs when caring for someone with dementia and forget that you matter too. It is important to take steps to safeguard your own health and well being, so that you can continue to cope and retain your confidence.

**Help that is available**
Try to discover what help is available in caring for the person with dementia before you might need it. That way when you do need to access services you will know who to turn to. The Alzheimer’s Society can provide information on all dementias, put you in touch with local support groups, help you to access services and provide a listening ear.

Ask for an assessment of the needs of the person you are caring for, if one has not already been carried out. Your needs as a carer should be taken into account in any assessment. The Carers (Recognition and Services) Act 1995 gives carers the right to a separate assessment of their needs. Ask social services about this.

**Family and friends**
Even though you may be coping well at present you need to realise that caring for a person with dementia will probably become more and more demanding, both physically and emotionally.
- Try to involve other family members right from the start so that the responsibility does not all rest with you. Even if they cannot offer day-to-day care, they may be able to look after the person while you have a break. Or they may be able to contribute financially to the cost of care
- Always try to accept help from friends or neighbours when it is offered. If you say you can manage they may not think to ask you again
- Suggest ways in which people could help. For example, you might ask them to stay with the person for an hour or go for a walk with them, so that you can get on with something else.
- Make it clear that you value people’s support and that just popping in for a chat or a regular phone call to see how you are can make all the difference
- Explain to your family and close friends how dementia can affect a person’s behaviour. Share the information you have with them. They will then be more able to understand the apparent contradictions in the behaviour of the person and just how much you have to do.

**Your health**
See your GP on a regular basis to check up on your own health and make sure they are aware of any stresses and problems you are experiencing:
- If you start feeling depressed, anxious or stressed, see your GP as soon as possible. This is easier to tackle at an early stage before it gets out of hand
- Try to ensure you eat a balanced diet. It will help you feel and cope better
- Make sure you get enough sleep. If your sleep is continually broken, ask your doctor, social worker or community psychiatric nurse for advice
- Take care to avoid damaging your back if you are helping the person to move
- Regular exercise is vital for your health and will give you more energy. Try to walk in the fresh air each day or do some exercises at home.

**Legal and financial**
Your financial and legal situation may be affected if you are caring for a person with dementia:
- If you are working and have to give up either temporarily or permanently, check your pension position
- Check whether you are entitled to benefits and if so which ones
- Check your own position with regard to the person’s home and finances if they go into long-term care or die.

**Time to yourself**
Make sure that you have some time to yourself to relax or to do something that is just for you. If the person you are caring for cannot be left alone ask whether there are any services for the person with dementia that could relieve you of some of the stress. The Alzheimer’s Society can help you to access this information.

**Support**
Every carer needs support and people with whom they can discuss their feelings.

You may get the support you need from friends and family, from understanding professionals or from a local support group where you can chat to others who have had similar experiences and who really understand what it is like.

**Congratulate yourself**
You may sometimes feel that you have a thankless task. The person with dementia may no longer seem to appreciate your efforts and others may be unaware of just how much you do. You need to pat yourself on the back from time to time:
- For managing to cope day in day out with a very difficult situation
- For becoming more flexible and tolerant and finding new strengths and skills which you did not know you possessed
- For being there for someone who needs you.
4 How health professionals can help
The NHS can be a major source of help for people with dementia and their carers – from chiropody to dentistry, physiotherapy to continence advice. Finding out what services are available while the dementia is still at an early stage will save you time when the need arises.

**General Practitioners**
The GP should be the first point of contact if you are worried about your own memory or concerned about someone close to you. The GP will talk to the person being diagnosed and observe their behaviour. They may decide to offer a referral to a specialist consultant.

**Consultants**
Consultants are doctors who have had specialist postgraduate training. The speciality of the consultant you will see will depend on the age and symptoms of the person being diagnosed and the way services are organised in your area. The consultants may be a specialist in neurology, geriatrics or psychiatry.

- Neurologists specialise in disorders of the brain and the nervous system
- Geriatricians are doctors who specialise in the physical illnesses and disabilities of old age and the care of older people
- Psychiatrists diagnose and treat a wide range of mental health problems
- Old age psychiatrists have received further training in the mental health problems of older people

The consultant usually works with a number of qualified doctors at various stages in their medical training. You may be seen by one of these doctors rather than the consultant. During the diagnosis the consultant may carry out a physical examination. They may also arrange for a number of tests, including a memory test and/or a brain scan.

If Alzheimer’s disease has been diagnosed, the consultant may decide to prescribe Aricept, Exelon or Reminyl. These drugs help maintain levels of an important chemical messenger in the brain acetylcholine. These drugs are not a cure for Alzheimer’s but may halt symptoms in the early to middle stages of Alzheimer’s disease in the short term.

**Community Mental Health Nurses (CMHN’s)**
CMHN’s are mental health nurses who work in the community, supporting people with mental health problems and their families. CMHN’s carry out assessment of people in their own homes and can advise carers and people with dementia. They do not normally carry out physical nursing tasks. The Memory Clinic has dedicated CMHN’s who specialise in this area.

**Nurse Consultants**
Nurse consultants are highly trained and specialised professionals. The Wakefield Memory Clinic has a nurse consultant who specialises in the assessment and treatment of those persons exhibiting memory problems.

**District Nurses**
District nurses have had extra training to nurse people at home. They work with other community nurses and nursing auxiliaries as part of a team. Visits can be arranged through a GP.

**Health Visitors**
Health visitors are nurses who have had further training to advise people in the community on health care issues. They can advise on benefits, provide information on services etc. Health visitors generally work alongside GP’s.

**Physiotherapists**
Physiotherapists can advise on exercise for people at all stages of dementia. They can also advise carers on ways of safely lifting and moving someone with mobility problems. Home visits can be arranged. The GP or consultant will be able to refer you to a hospital physiotherapy department or community physiotherapy service.

**Chiropodists**
Healthy pain free feet are important to maintain mobility. Chiropody services are available free on the NHS for women over 60 and men over 65. It may be possible to arrange a home visit. You should ask your GP for a referral.

**Dentists**
Professional dental advice should be obtained as soon as dementia has been diagnosed. If any major treatment is needed it should be carried out as soon as possible as dental treatment may become more difficult as the dementia progresses.

It is important to try to find a dentist that you trust, someone who will continue to provide treatment as the dementia progresses and who is prepared to visit your home or a residential nursing home. NHS home visits are free but the normal charges for treatment may apply, depending on income.

**Continence Advisors**
A continence advisor can advise on problems associated with incontinence. They also give information on the use of aids, ranging from commodes to incontinence pads. Your local continence advice centre is the Sir Jules Thorn Centre, Castleford and Normanton Hospital, Lumley Street, Castleford. Tel: 01977 605516
5 Understanding and respecting the person with dementia
If you are caring for a person with dementia you will want to ensure that they are always treated with respect and dignity. They are a unique and valuable human being.

**Always remember that:**
- Each person with dementia is a unique individual with their own very different experiences of life, their own needs and feelings and their own likes and dislikes.
- Although there are symptoms of dementia which are common to everyone, each person will be affected by their dementia in a different way.
- Everyone reacts to the experience of dementia in an individual way. The experience means different things to different people.

If you are caring for a person with dementia you will need to take into account their abilities, interests and preferences. You need to be aware that these things may change as the dementia progresses. You should be prepared to respond in a flexible and sensitive way.

**The life story of the person**
The more background you give other people who are involved in the care of the person, as well as their present situation, the better it will be. This information will make it easier for other people to see the person as a whole person rather than simply as someone with dementia.

People involved in their care and support may then feel more confident about finding topics of conversation or suggesting activities that the person may enjoy.

You may need to remind other people that:
- Dementia is nothing to be ashamed of. It is no one’s fault.
- Dementia may cause the person to behave in ways that other people may find irritating or upsetting but that this is not deliberate.
- A person with dementia may often remember the distant past more clearly that the recent past and the present. They are often happy to talk about their memories. But remember past memories may be painful.

**Treating the person as an adult**
It is important that everyone continues to treat the person as an adult and with courtesy, however advanced his or her dementia. Try to imagine how you would like to be spoken to if you were in their shoes.
- Be kind and reassuring without talking down to the person as though they were a child.
- Never talk across them or over their heads as if they were not there.
- Do not talk about the person with other people while the person is present. Always include them in the conversation.
- Avoid scolding or criticising the person – this will make them feel small.
- All these things will attack the fragile sense of self-worth of the person.
- Look for the meaning behind words even if, on the surface, they do not seem to make much sense. The person is almost certainly trying to communicate with you about how they feel.

**Focus on the remaining abilities**
Avoid situations in which the person is bound to fail since this can be humiliating. Look for tasks they can still manage and activities they can still enjoy.
- Give them plenty of encouragement.
- Let them do things at their own pace and in their own way.
- Do things with the person, rather than for them, so that they can preserve some independence.
- Break activities down into small steps so that they feel a sense of achievement, even if they can only manage part of a task.
- Our self-respect is often bound up with the way we look. Encourage the person to take a pride in their appearance and give them plenty of praise.

**Respecting privacy**
Try to make sure that the person’s right to privacy is respected.
- Suggest that people always knock on their bedroom door before entering, for example.
- If the person needs help with intimate personal activities, such as washing or using the toilet, this should be done in a sensitive way. Make sure the door of the bathroom or the toilet is kept closed if other people are around.
Offering choice
It is important that the person is informed and whenever possible consulted about matters that concern them. They should be given every opportunity to make appropriate choices.
- Even if you are unsure how much the person can understand, always explain what you are doing and why. You may then be able to judge their reaction from their expression and body language.
- Although too many choices can be confusing you can continue to offer choice by phrasing questions that only need a ‘yes’ or ‘no’ answer, such as ‘Would you like to wear your blue jumper to-day?’ rather that ‘Which jumper would you like to wear to-day?’

Expressing feelings
Dementia affects the thinking and reasoning part of the brain and the memory. It does not mean that the person no longer has feelings. A person with dementia will probably be sad or upset at times. They have the right to expect those caring for them to try to understand how they feel, and to make time to offer support rather than ignoring them or ‘jollying’ them along.

In the earlier stages the person may want to talk about their anxieties and the problems they are experiencing. It is important that other people do not brush these worries aside, however painful they may be, but listen and show them that they are for them.

Feeling valued
The person with dementia needs to feel respected and valued for what they are now, as well as for who they were in the past. It helps if those caring are:
- Flexible and tolerant
- Can make time to listen and have a chat and enjoy being with the person
- Can show affection as appropriate.
6 Activities
If you can help the person with dementia to find activities that they enjoy you will improve their and your quality of life. You will need to be imaginative and flexible in adapting activities to the person’s changing capabilities and to their different moods.

How activities can help
- Activities can help a person maintain their skills and give them a sense of achievement.
- Activities can be interesting and fun. They can help the person feel better about themselves and be more alert and interested in what is going on around them.
- Activities can help a person with dementia express their feelings. Talking about the past while looking at old photographs or listening to music may trigger strong emotions and you will need to be sensitive to this. It is the memory and the thinking and reasoning parts of the brain that are damaged in dementia, not the emotions. We must always be aware of that.

Gains for the carer
If a person is occupied in a pleasant way they will not get bored or frustrated. Sharing an activity which you both enjoy may help you find new ways to relate to the person and bring you closer.

Exercise
- Walking is good exercise. It uses up adrenaline, which is produced by stress and frustration. You will probably both benefit from a walk.
- It is good for you both to get out and about and many carers find ingenious ways of arranging little trips even if it is only to the coffee shop at the local supermarket.

Reminders of the past
People with dementia usually find it easier to remember events which happened when they were much younger rather than those in the recent past. If you can find a way to trigger these far-off memories you may find that the person becomes more lively and interested.
- Look at and talk about old family photos or books with pictures from the past.
- You may like to make up a rummage box of old objects of interest to the person you are caring for. Actually handling articles may trigger memories more effectively than looking at pictures of them.

Early stages
In the early stages of dementia the person will want to do things they have always done. You are the best person to help them because you know them so well. Activities can be enjoyed by the person on their own.
- They will need encouragement from you and reminders.
- They will need you to put any equipment in a place where they can easily see it.
- Use short sentences when advising the person what to do.
- Music is a great resource for people with dementia. People may still enjoy singing or dancing and listening to music. You might like to record a tape of favourite pieces of music or songs for the person to listen to.

Later stages
As the dementia advances the person will still be able to carry out very familiar tasks. They will probably be much more interested in the process of doing the activity than in the end result.
- Directions for an activity need to be broken down into small, manageable chunks and should be very simple.
- At this stage, the person will probably enjoy tasks with one step such as sweeping, dusting, or winding wool.
- Although the reasoning parts of the brain and language are breaking down in the later stages of dementia, the person’s sense of taste, touch and smell are still functioning.

Sensory stimulation
As dementia progresses people find comfort in touching or stroking pieces of fabric or a cuddly toy. The person may find a hand massage, using scented oil such as lavender very soothing, while a fish tank, mobile or a pleasant view can have a calming effect and be satisfying to look at together.

No one likes having nothing at all to do. We are all happier being occupied. The secret seems to be realising the different type of activities which people can do as dementia progresses and being flexible.
7 Communication
People with dementia should be encouraged to communicate in whatever way seems most appropriate. This will help them to preserve their own sense of identity and improve their quality of life.

**Language skills**

A person with dementia maybe unable to find the right words – particularly names of objects. They may substitute another incorrect word or they may be unable to find a word at all. As the dementia progresses, they will be less able to start a conversation and the carer may have to become accustomed to taking the initiative.

Try to avoid asking direct questions. In the early stages of dementia they will be able to express these feelings, but later on they may respond with general irritation or even aggression.

**Tips to help with communication**

**Listening**

- Always try to listen carefully to what the person is saying and encourage them. At all costs, do not patronise them. Most of us react badly to being treated as if we were small children – and people with dementia are no different in this respect.
- If the person has difficulty in finding the right word, or in finishing a sentence, ask them to explain in a different way. Listen for clues.
- If speech has become hard to understand, use the knowledge that you both have about each other to interpret what you think they may be trying say. Always check back with them to see if you are right. It can be infuriating to have your sentence finished incorrectly by someone else.

**Gaining attention**

- Try to catch and hold the attention of the person before you start to communicate.
- Try to position yourself so that they can see you clearly.
- Make eye contact. This will help them to focus on you.
- Try to minimise competing noises, such as the radio or TV or conversation of other people.

**Body language**

- Try to remain calm and still while you are speaking. This will convey the message that you are giving the person your full attention and that you have time for them.
- A person with dementia will read your body language. Agitated movements or a tense expression on your face may upset them and make communication more difficult.
- Try to find ways to relax so that your body language communicates calmness and confidence.
- You can pick up clues about the way the other person is feeling from their body language, even if words fail them. The expression on their face and the way they hold themselves and move about can give clear signals about how they are feeling.

**Speaking**

- Speak clearly and calmly. Try not to speak sharply or raise your voice. This will distress the other person, even if they are unable to follow the sense of the words.
- Use simple, short sentences.
- The person will need longer than they used to in order to process information – so allow enough time. Try not to hurry them. If you do they will feel that you are putting them under pressure, even if it is not your intention.
- Try to avoid asking direct questions. But if you have to, ask the questions one at a time and phrase them in a way that allows for a ‘yes’ or ‘no’ answer.
- People with dementia find it hard to make choices and are likely to become confused and frustrated if they are asked to do so.
- If the person does not understand what you are saying, don’t keep repeating the same words. Try using an alternative format.

**Encourage spontaneity**

- Humour can help to bring you closer together and is a good safety valve. Laughing together about misunderstandings and mistakes can help.
- If the other person is feeling sad they have a right to express these feelings. All you can do is show them that you care.

**Showing respect**

- Never speak down to the other person or treat them as if they were a child, even if they appear to understand very little of what you say. Do not allow other people to do this either.
- Try to include the person with dementia in conversations with others. You may find that you can slightly alter the form of words other people are using to help the conversation along. Including people with dementia in social groups helps to preserve their fragile sense of their own identity. It also helps to protect them from the feelings of exclusion and isolation, which can be overwhelming.
- It is important not to converse across the person with dementia as if they were not present. People with a variety of disabilities complain of being treated this way.

**Keeping close**

Affection can help to keep you close even when conversation becomes more difficult. You can communicate your care and affection by the tone in your voice and the touch of your hand. The reassurance you can give by holding the person’s hand or putting your arm around them (if that is appropriate) should never be underestimated. Here again we can see that actions speak louder than words.
8 General Health
Staying healthy
If you are caring for someone with dementia you will want to ensure that they remain as fit and healthy as possible. The better the person feels the more enjoyment they are likely to get from life and the easier it will be for both of you to manage.

Checkups
You can ask the person’s GP to do a general health check if you are worried about their health or if it would simply put your mind at rest. Incidentally, anybody over the age of 75 is entitled to an annual health check from their GP practice. If you have a different GP from the person with dementia, you will need to make contact yourself.

If there are areas of particular concern, such as high blood pressure or diabetes, make sure that the person has regular checkups at the doctor’s surgery.

Eyes, ears and teeth
It is also a good idea to check all other relevant aspects of the health of the person, such as their eyes, ears and teeth. This should be done as soon as possible after diagnosis while:
- The person is still able to give information about themselves
- The person is more able to adjust to any changes that may be needed, such as new glasses, a different hearing aid or new dentures

Regular checkups will also be easier if the professional concerned has been able to establish a relationship with the person at an early stage.

Medication
In general, the fewer the drugs the person has to take, the better for both their dementia and their general health. This includes prescription and over-the-counter drugs.
- As soon as possible after diagnosis, check with the GP to make sure that the person is not taking unnecessary drugs. People sometimes continue with repeat prescriptions longer than is needed. Drugs which have been prescribed to manage behaviour should be reviewed very regularly
- Check too that they are taking the lowest possible effective dose of any drug that they need. Older people need smaller doses of drugs than younger people in many cases
- Some drugs or combinations of drugs may increase the person’s confusion or have other unwanted side effects. Always let the GP know if you suspect that this is happening. You will need to find ways to ensure the person with dementia takes the right medication at the right time
- If the person has only mild memory problems, the chemist may be able to help by providing a box with compartments labelled with the day and time for a whole week, or by providing tablets on a sheet with day and time labels
- If memory problems are more severe you may have to supervise their medication in case they overlook a dose or take an extra dose by mistake. Place medicines out of reach and out of sight as an extra precaution.

Diet
An adequate and balanced diet is essential for good health. Eating too little or missing out on essential nutrients will reduce the person’s resistance to illness and may also increase the degree of confusion.
- The person may forget to eat if they are on their own. You may need to try and arrange for someone to be with them at mealtimes. After a certain point, having meals on wheels delivered may no longer be appropriate because the person may forget to eat them
- If the person refuses to eat the sort of food that you feel they need to keep healthy the GP may suggest alternatives or prescribe vitamins or other supplements
- Eating high calorie and sweet foods is comforting. However, this can lead to considerable weight gain which may lead to further health problems
- If the person is eating so much they are actually making themselves feel uncomfortable, try tactfully to limit the amount of food available or offer low calorie foods as snacks
- It is important that the person drinks enough every day otherwise they may become dehydrated which is a risk to health and can lead to increased confusion.

Sleep
The person with dementia may become confused about night and day and may get up in the night and get dressed thinking that it is morning. It is important to everyone to get a good nights rest wherever possible:
- Try not to allow the person to take too many daytime naps by encouraging activities, providing stimulation and preventing boredom
- Limit fluids in the evening and avoid stimulating drinks like tea and coffee
- Encourage the person to take some form of exercise during the day
- Find soothing and relaxing ways to encourage the person to sleep such as giving a warm milky drink at bedtime.
Hearing
Poor hearing can add to the person’s confusion and feelings of isolation.
- If you think the person has a hearing problem, a GP can refer them for a free hearing test. NHS hearing aids are also free
- If they use a hearing aid make sure that it is switched on and working properly. As the dementia progresses the person may find that the hearing aid is too difficult to manage and this simply adds to the confusion
- You may need to attract the attention of the person before speaking to them. A touch on the arm will indicate where you are. Face them so that they can see you, then speak slowly and clearly. If they do not understand you, try to alter the form of words you are using rather than repeating the same phrase more loudly. Make sure that there is no distracting noise such as television, radio or loud voices.

Sight
Problems with sight can also increase confusion and can make it harder for the person to recognise people or objects.
- An optometrist can test a person with dementia’s sight. There are special techniques for assessing sight even for people in late dementia
- The optometrist should also check for cataract and glaucoma, both of which can lead to blindness if left untreated. They can also check for certain other medical conditions
- Tactfully remind the person to wear their glasses if necessary and check that the lenses are clean.

Teeth
- Regular dental care is important to make sure that there are no problems with teeth or gums or with the way that dentures fit. Any pain or discomfort will distress the person and may lead to difficulties with eating and drinking. This may increase confusion. Tell the dentist that the person has dementia. This will help them to treat the person more effectively
- Encourage or help the person to clean their dentures regularly
- Let the dentist know at once if you notice any problems such as swollen gums, ulcers, broken teeth or missing fillings.

Feet
Healthy feet are essential if the person with dementia is to remain mobile and active
- Check that their shoes fit well. Although slippers are comfortable they should not be worn for more than a few hours at a time as they do not offer enough support to the feet
- Keep feet clean and dry, and toenails cut short
- If the feet or any part of a foot becomes swollen or painful or there is a change in the colour of the skin, contact the GP as soon as possible
- If there are problems such as corns or growing toenails for example, consult a state registered chiropodist.

Exercise
Regular exercise is good for the health of us all including a person with dementia
- It will enable them to remain mobile and therefore independent for as long as possible
- It will improve circulation and help to prevent stiffness and muscle wasting
- It will help the person to feel better and to sleep better
- It can help to reduce anxiety, stress and depression.

Mobility
The more mobile the person remains the better it will be for their health and the easier it will be for you to manage. Look for ways to help the person to remain mobile.
- If the person becomes unsteady on their feet, seek advice from an occupational therapist on aids and equipment which can be installed in the house such as grab rails to enable them to move more safely
- The person may spend quite a lot of time seated. If this is the case, a firm, comfortable chair that is easy for them to sit down in and get up from is more important
- If the person needs your support when they move, seek advice from an occupational therapist or physiotherapist so that neither of you is harmed.

Depression and anxiety
A certain amount of depression or anxiety is very common, particularly in the early stages of dementia when the person is likely to be aware of their declining abilities.
- If the person is able to talk about what is troubling them, listen and show that you are trying to understand their feelings. Do not brush their feelings aside or attempt to jolly them along. These feelings are very real. The person has a lot to be depressed and anxious about
- Offer affection, reassurance and support
- If you feel that the person is extremely depressed or anxious ask the GP for advice. It is often easier to deal with this type of problems at an earlier stage.
**Well-being**
Feelings of well-being are an important aspect of good health. The person with dementia needs
- Affection and reassurance from you that they are still valued and that they do matter to you
- Freedom from as much outside stress as possible
- Appropriate activities and stimulation to enable them to remain alert and motivated for as long as possible.
9 Living alone
If a person with dementia is living on their own, there are likely to be some concerns about their ability to cope, especially as their dementia progresses. Where possible, the person with dementia, their friends and family members and experienced professionals should discuss these concerns together.

Much can be done to enable someone with dementia to remain in their own home, even when their dementia is quite advanced. Familiar surroundings and routines can be reassuring for people who are confused. Many people with dementia are happier if they can live in their own home for as long as possible. Some people’s dementia progresses quite quickly once the person moves, whether to live with a family member or to enter a care home.

A person with dementia will need increased support as their dementia progresses. Get in touch with the appropriate services at an early stage. Do not wait until a crisis develops.

**What can friends and family do?**

It is common for one member of the family to assume responsibility for the person with dementia as the main carer, and for others to be unaware of the stress that this can cause. It is particularly exhausting when the main carer has other commitments and feels pulled in different directions.

The main carer should make it clear that they need regular support. They are entitled to a life of their own and they will not be able to help anyone if they wear themselves out.

It is usually easier for others to contribute to care if they are involved from the start. It can be a good idea to hold a family meeting at an early stage to work out what each member of the family can realistically offer, now and in the future. This may help avoid later feelings of resentment or guilt. Support might range from regular visits or help with practical tasks, such as shopping, to financial help with care services if the person lives too far away to help directly themselves.

**Tell other people**

Friends and family can explain the person’s dementia to friends, neighbours local shopkeepers and anyone else whom the person has regular contact. These people may have time to chat, offer assistance in various ways or help the person if they ‘wander’ away from the house and forget their way home.

Ensure that helpful information is accessible. A notice board with helpful telephone numbers (including emergency numbers) on it may be useful for the person with dementia in the early stages, as well as for relatives or professionals visiting the home. The notice board could also provide information such as the location of the stopcock, gas and electricity meters and the first aid box.

A week at a time diary, containing details about who is visiting and when can also be helpful and reassuring for the person.

**Help with managing finances**

It can help if all regular household bills are paid by direct debit. If this is not possible, or the person prefers to pay their own bills, the relevant gas and electricity and water companies should be informed, so that the supply is not suddenly cut off.

If the person with dementia does not want to pay for outside care, or forgets to do so, payments can usually be made on their behalf.

Anyone handling money for the person with dementia should keep a careful account of what is spent to avoid any potential problems later. Family members may want to know where the money is going, the person with dementia may also forget what has been arranged and, in some cases, even become concerned that people are stealing from them. The Alzheimer’s Society can provide you with more information regarding the handling of money if you require it.

**Outside help**

People with dementia do not always realise when they need help. Some people find it more helpful if a carer takes them out while someone else cleans their home.

The person should be receiving all the benefits to which they are entitled. Disability Living Allowance or Attendance Allowance is awarded in order to pay for extra care.

Carers should be aware that they may be criticised by the person with dementia and that their attempts to help may be sometimes ignored. Although this can be hurtful, it should not be taken personally. The person with dementia may not always understand or remember everything that is being done for them.
Home workers
Home workers or care attendants can help with personal care. The frequency of visits can vary depending on the person’s needs. They can help by:
- Supporting the person getting up
- Washing
- Dressing
- Using the toilet
- Doing laundry
- Supervising meals
- Helping to bed at night

Domestic help
Help with tasks such as shopping or housework can be arranged through Social Services. If help is arranged privately then references must be checked and candidates interviewed to ensure that they are suitable and understand dementia. You should still inform Social Services if you decide to employ someone privately.

Day Care
Social Services can arrange day care at a local day care centre. Day centres can provide company and activities. They often provide other facilities such as hairdressing, chiropody and bathing. Transport to and from days care can be arranged.
Useful contact numbers

Age Concern
Wakefield: 01924 305733
Castleford: 01977 552114

Alzheimer's Society
Wakefield: 01924 373264
Helpline: 0845 300 0336

Benefit Enquiry Line
Tel: 0800 882200
Textphone: 0800 243355

Community Mental Health Teams
Ossett: 01924 327787
Castleford: 01977 605507

Continence Advisory Service
01977 605516

Sir Jules Thorn Centre
01977 605530

Help the Aged
0808 8006565

Memory Service
01924 328637

NHS Direct
0845 4647

Pals Office (patient advice & liaison service)
Wakefield: 01924 212672
Pontefract: 01977 606232

Samaritans
01924 377011

Social Care Direct
01924 303456

Carers Wakefield & District
01924 305544

If you would like the information contained in this document in another language please telephone the Wakefield Memory Clinic for assistance.