Dementia

Integrated Care Pathway

For use by all professionals working in Mental Health Services and Partner Agencies, for all people with a diagnosis of Dementia in Lanarkshire
1. Introduction

Dementia is a syndrome caused by disease of the brain where there is chronic or progressive decline in mental abilities. People with dementia get forgetful and confused beyond a level that would be expected for their age. There are many kinds of dementia but the most common is Alzheimer’s disease. Other kinds of dementia include vascular dementia, Lewy body dementia, frontotemporal dementias (including Pick’s disease) and alcohol-related dementias. It is also possible to have more than one type of dementia; for example Alzheimer’s disease and vascular dementia. What all these diseases have in common is that they damage and kill brain cells, so that the brain cannot work as well as it should. In Scotland, between 58,000 and 65,000 people have dementia. It is most common in older people but can affect people in their 40s or 50s or even younger. It is important to remember though that most old people do not get dementia.

Symptoms can vary from person to person but can include:
- Loss of memory
- Difficulty thinking things through and understanding
- Problems with language (reading and writing)
- Confusion and agitation
- Hallucinations and delusions
- Difficulty controlling movements of the body.

Symptoms usually get worse over time and can become very severe, so that it is difficult for the person to do many daily activities or to care for him or herself (NICE, 2006). Recent guidance from the DVLA states that those diagnosed with dementia may be subject to assessment and annual review regarding fitness to drive (see https://www.dft.gov.uk/dvla/medical/ataglance.aspx ‘At a Glance Guide to the Current Medical Standards of Fitness to Drive’, Feb 2010, p34). Support groups such as Alzheimer Scotland and people with dementia agree that there is a life after a diagnosis of dementia and that people can still have a full life, despite the illness.

Lanarkshire has a strong focus on the care and treatment of people with dementia whilst supporting carers and families within a multidisciplinary and agency framework. The working relationship and approach to care is increasingly seamless with the stronger working ties created by the joint futures agenda. People presenting to the service are robustly assessed and the most appropriate care planned in partnership with the individual and their families within a recovery model of care. The assessment takes in a variety of health professionals and many of the options are provided by partnership agencies with which ties are becoming ever stronger. For more information see www.alzscot.org.

1.1 Rationale for Developing the ICP

The ICP was developed from the NHS QIS standards for mental health integrated care pathways, which specify both generic and dementia-specific care standards. The generic standards are contained in the NHS Lanarkshire Generic ICP and the condition specific standards in this Dementia ICP. These condition specific standards specify care and interventions we would generally expect to be considered for people with dementia.
The QIS Standards provide an illustration of the relationship between the various elements of the ICP as shown in Chart 1.

CHART 1

The ICP has been put together by a local development group consisting of NHS staff, service users and carers, local authorities, voluntary organisations and the independent sector (see Appendix 1, Dementia ICP development group members). In Lanarkshire various terms are used to describe the people who use mental health services which include, “clients”, “patients” and “service users” and to simplify this we have used the single term “patients” in this Generic ICP and this condition-specific ICP.

In addition to the ICP development work, the Mental Health Collaborative Programme work on the Dementia Heat Target (to have achieved improvements in the early diagnosis and management of patients with dementia by 2011); will result in more people being identified for assessment and diagnosis in each locality in Lanarkshire and in an improvement to early management and support. This work will be implemented and monitored through the Dementia ICP.

1.2 How to use the Lanarkshire Dementia ICP

The Generic ICP will automatically be used for people accessing mental health services in Lanarkshire (with the exception of those people with depression who do not require specialist assessment and treatment in which case only the condition-specific ICP for depression will be used). For all others the Generic ICP will apply and if appropriate, this condition-specific ICP will also be used as required. These ICPs are based on a stepped model of care as described in the Lanarkshire Mental Health Strategy. They encompass a culture and values which aim to enable person-centred recovery and strengths-based focus with a move towards positive management of individual risk, maximising choice and access to evidence-based interventions (see Appendix 2, Guidance and Policy Base).

The ICP is designed to be used for any person over the age of 16 who presents with dementia (additionally, people with learning disabilities can access services via the Lanarkshire Learning Disabilities Service). It is intended to provide a standard model of good care based on the current evidence base and expert opinion. It is important to note that the ICP is a guide to good care but it should never replace sound professional judgement. The professionals’ assessment and judgement will always override the advice of the tool where this is necessary. The ICP is part of the patient record and as with all such records, it will be private and confidential with access governed by the usual rules of confidentiality. By using this ICP we will be able to produce data about the care and interventions provided to people in Lanarkshire with dementia. This information (variance data), will allow us to compare the actual care and interventions given with those planned in the ICP and enable us to identify areas where the ICP should be modified to improve the quality of care provided. The variance information will also identify resource issues, gaps in service availability and future staff training and supervision requirements.
2. Treatment for Cognitive Impairment

2.1 Algorithm for Treatment for Cognitive Impairment

NHS Lanarkshire Mental Health Services

Treatment for Cognitive Impairment
May 2010

Referrer
CMHT Allocation Meeting
Memory Service/Outpatient Clinic

History and Examination:
- Including carer, driving

Baseline Investigations:
- MMSE
- Clock (5 point scoring)
- NPI-Q
- GDS

Consider:
- IQCODE
- ACE R
- Neuropsychology
- CT brain, MRI or SPECT

Diagnosis of Dementia?

NO

Unclear – follow up

YES

Consider:
- Social Work, Occupational Therapy and Psychology
- Cognitive Stimulation Therapy
- Psychosocial Interventions
- Capacity
- Adults with Incapacity, e.g. Power of Attorney

Medication?

NO

Further support?

NO

YES

- AChE inhibitors, e.g. Donepezil
- Others

Monitored by GP, CPN and Consultant
2.2 Notes on Treatment for Cognitive Impairment

**ICP Standard 27a:** The care record shows that a treatment algorithm for cognitive impairment based on current national recommendations is followed.

**ICP Standard 27b:** The care record shows that an appropriate assessment tool has been used to evaluate treatment outcome

- GP should be in agreement with and at very least informed of referral.
- Assessment prior to referral FBC, B12 and Folate, U&E, LFT, TFT.
- Consultant will request ECG and CT brain on selected patients.
- Inform the GP re diagnosis of dementia, using the “Process to identify patients who require to be added to GP Dementia Registers” Flowchart (produced by the Mental Health Collaborative).
- Patient Information offered to patients and carers should be recorded on the Patient Information Form (**Appendix 3**).
- If patient is known to the Learning Disability (LD) team then they should be referred to LD in the first instance. Case by case discussion can take place with Old Age Psychiatry.
- Memantine may be prescribed by Consultant Old Age Psychiatrists in exceptional circumstances after other pharmacological and non pharmacological interventions have been tried and failed to relieve psychiatric or behavioural problems. Memantine is not approved for use by the Scottish Medicines Consortium and is not to be added to the Lanarkshire formulary, as agreed by the Area Drugs and Therapeutics Committee.
- See **Appendix 4**, Neuropsychiatric Inventory Questionnaire (NPI-Q) Assessment
- Driving should be enquired into and patients advised of the requirement to inform DVLA and their insurers if a diagnosis is made, see **Appendix 5**, Driving Questionnaire.
- For people under 65 years of age see **Appendix 6**, Young Onset Dementia Algorithm for Treatment of Cognitive Impairment and Notes.
3. Psychological Interventions

3.1 Psychological Intervention for People with Dementia

The delivery of Psychological Therapies in Lanarkshire is based on the principle of matched care, whereby people referred into the service are matched to the appropriate level of treatment for the level of complexity of their difficulties (NHS Lanarkshire Psychological Therapies Strategy, August 2009). In addition, the recently published Matrix document from the Scottish Government provides health boards with a comprehensive review of the evidence base for psychological therapies and guidance as to how these should be delivered (see Appendix 7 for MATRIX dementia evidence base). Several psychological therapies/interventions are evidence based for dementia and are detailed below. The availability of these interventions in Lanarkshire (together with training and supervision requirements), will be determined through the ongoing implementation of the Psychological Therapies Strategy.

- **Reminiscence** – can be used with individuals, groups or family sessions and can involve simple reminiscence on the past; use as a life reviewing or sometimes conflict resolving approach; or to deal with behavioural and emotional issues to provide resolution - a coming to terms with life events and possible closure.

- **Validation Therapy** – an approach used to communicate with disoriented elderly people which involves acknowledging and supporting their feelings in whatever time and place is real to them, even if this does not correspond to reality.

- **Non-pharmacological Interventions for Behaviour that Challenges** – structured, systematically applied and normally time limited interventions usually carried out by carers or care home staff under the supervision of a professional with expertise in this area.

- **Cognitive Stimulation Therapy** - A brief group based treatment for people with mild to moderate dementia and involves sessions of themed activities, which aim to actively stimulate and engage people with dementia, whilst providing an optimal learning environment and the social benefits of a group.

- **Cognitive Behaviour Therapy for depression in Dementia**: CBT is one of a range of psychological therapies which targets a patient’s difficulties and problems. The focus is on monitoring ones thoughts, beliefs, emotions and behaviours and evaluating these systematically with the view to bringing about positive change.

- **Caregiver Interventions Programmes** – range from simple reassurance to complex multi-faceted interaction with the person with dementia.

**Other Therapies:**

- **Occupational Therapy Interventions** – Occupational Therapy input can be valuable for older adults with dementia at early and ongoing stages of the disease process. In Lanarkshire a recent Allied Health Profession (AHP) project, “Time Capsule Activity Group”, has recently been endorsed by the Scottish Government as a good practice example.

- **Art Therapy** – a project in Lanarkshire in 2008 in Coatbridge showed that individuals in the group did benefit from the aims of art therapy intervention.
4. Behavioural Symptoms

4.1 Notes on Management of Behavioural and Psychological Symptoms

**ICP Standard 28a:** The care record shows that service users who develop behavioural or psychological dementia symptoms have a review of their care plan within 4 weeks.

**ICP Standard 28b:** There is a local system in place for a structured and systematic response to the development of behavioural or psychological dementia symptoms.

**ICP Standard 28c:** The care record shows that an appropriate assessment tool has been used to assess the efficacy of medication.

Behavioural and psychological symptoms in dementia (BPSD) are common. These symptoms include depression, psychosis, agitation and aggression and increase in frequency as dementia worsens. More than one symptom can be present at a time. These symptoms may increase risk and distress for patients and/or carers and cause difficulty in providing appropriate care. Indeed these symptoms can lead to a person no longer being able to be cared for at home and having to move to a care facility. It is not surprising then that in care environments studies have shown higher prevalence of BPSD than in the community. One study by Margallo-Lana et al found that 90% of the residents studied had dementia and that 79% of those had clinically significant BPSD.

BPSD can be difficult to assess and treat. They can be triggered or exacerbated by physical ill health, especially pain, infection or dehydration. A thorough assessment is required before instigating treatment. It is important to consider a broad range of treatments including treating underlying physical conditions and training staff and carers. Pharmacological intervention with psychotropic drugs may be required but careful attention needs to be paid to the risks versus the benefits of any treatment. There have been many recent concerns about the risks in particular of using atypical antipsychotic medications in people with dementia and these need to be borne in mind. However where there is great distress for the patient and/or risk to the patient or others these drugs may need to be used as there is evidence of their efficacy in aggression. They need to be carefully monitored.

The *Checklist for Managing Behavioural and Psychological Symptoms Associated with Dementia* (Appendix 8), is provided to assist with the assessment of BPSD, making a diagnosis and thus providing appropriate care.
5. End of Life Care

5.1 Advanced planning in relation to end of life care

ICP Standard 29a: The care record shows advance planning in relation to end of life care, which is reviewed at least annually, and includes consideration of the preferred place of treatment if the condition worsens.

Much of this will have happened during assessment and treatment for cognitive impairment as part of Standard 27. Documentation is given to the patient after diagnosis particularly “Facing Dementia” published by Health Scotland. At an early stage of the illness discussion of end of life care can be difficult and inappropriate. However, there is useful guidance in this booklet and when power of attorney, advanced statements and advanced directives (living wills) are all discussed as part of planning for the future it is more acceptable. This can be discussed with the Community Psychiatric Nurse (CPN), memory service link worker, consultant or GP. The patient also has a right not to discuss these if they choose.

Preferred place of treatment if dementia worsens would be appropriate to discuss as part of an advanced statement or advanced directive.

The criteria state reviewed annually. If there are significant changes in the patient’s condition this can be assessed in the annual review by the memory service if under their follow-up or by GP if not. The review will involve discussion with the patient and carer if appropriate and will be tailored to the stage of dementia that the patient is in.

As their dementia progresses and palliative care issues become significant in the last years of life the Gold Standards Framework will come into play. This is a matter for judgement but often the “surprise” question is useful, either:

“would you be surprised if this person were to die in the next 6/12 months”

or another way,

“would you be surprised if this person were still alive in 6/12 months”.

5.2 Gold Standards Framework

The Gold Standards Framework (GSF) was originally developed in 2000 as a grassroots initiative to improve primary palliative care from within primary care. It was developed by Dr Keri Thomas, a GP in West Yorkshire with a special interest in Palliative Care, supported by a multidisciplinary reference group of specialist and generalists. The GSF is a systematic evidence based approach to optimising the care for patients nearing the end of life delivered by generalist providers. It is concerned with helping people to live well until the end of life and includes care in the final years of life for people with any end stage illness in any setting. For more information see [http://www.goldstandardsframework.nhs.uk/About_GSF](http://www.goldstandardsframework.nhs.uk/About_GSF) (National Gold Standards Framework Centre).
In Lanarkshire this work has been led by Dr Rosalie Dunn, the clinical lead for the Lanarkshire Managed Clinical Network (MCN) for Palliative Care and the majority of GP practices take part in the Gold Standards Framework Scotland (GSFS). The framework consists of seven key gold standards of care to aspire to - the 7Cs:

- **C1:** Communication
- **C2:** Co-ordination
- **C3:** Control of Symptoms
- **C4:** Continuity
- **C5:** Continued Learning
- **C6:** Carer Support
- **C7:** Care of the Dying

People with dementia will be assessed by their GP and the GSFS welcome pack used in Scotland includes assessment tools, summary sheets and audit tools. A home pack is also available for patients and carers that includes information leaflets, appointment cards, patient diaries, etc. For more information see http://www.gsfs.scot.nhs.uk/documents/GSFS%20Welcome%20Pack.pdf

### 5.3 Lanarkshire Palliative Care Assessment Tool (LPCAT)

This is the assessment tool developed in Lanarkshire to assess and manage the palliative care needs of people. It is used in community settings and care homes for people on the Palliative Care Register (in acute settings the Modified Early Warning Scoring [MEWS] is in use). The LPCAT has now been rolled out to all localities in Lanarkshire and is currently mainly used by Community Nurses, Macmillan Nurses, and the Lanarkshire Out of Hours Service, although it can be used by other professionals as required, e.g. GPs. For more information see the NHS Lanarkshire MCN for Palliative Care on FirstPort at: http://firstport/sites/mcns/palliativecare/default.aspx or the Lanarkshire Palliative Care public website at: http://www.nhslanarkshire.org.uk/Services/PalliativeCare/Pages/default.aspx.

The introduction of the tool into the patient’s care is through face to face contact by the person responsible for the caseload and a Support Team Assessment Schedule (STAS) tool is used to assess pain. Any symptoms identified by STAS are documented and care is planned accordingly. For dementia patients with cognitive impairment an additional assessment tool (Doloplus 2) can be used as an aid with STAS scoring.

The LPCAT uses a 4-tiered system of intervention, based on STAS scoring. Treatment using the LPCAT means that symptoms identified by high STAS scores (Tier 4: score of 3 – 4) can normally be improved and patients moved back down the tiers to Tier 1 (score of 0 – 1). However, if symptoms do not resolve and STAS scores remain high, then the Liverpool Care Pathway may be identified as the next step in the journey of care.
5.4 Liverpool Care Pathway

The Liverpool Care Pathway (LCP) for the dying patient was developed to transfer the hospice model of care into other care settings. It was developed by the Marie Curie Palliative Care Institute Liverpool (MCPCIL) and is used to,

“... guide the delivery of care for the dying to complement the skill and expertise of the practitioner using it. Once commenced the goals of care prompt staff to consider the continued need for invasive procedures and whether current medications really are conferring benefit. The health care professional is free to use his or her own clinical judgement in this process.”

For more information see the Marie Curie Cancer Care website at http://www.mariecurie.org.uk/forhealthcareprofessionals/liverpoolcarepathway

In Lanarkshire there are three versions of the LCP in use - community, hospital and care homes. Criteria for use of the LCP are the clinical judgement of the professionals involved in the care of the patient that:

♦ All possible reversible causes for the current condition have been considered
♦ The multi-professional team has agreed that the patient is dying, and two of the following may apply:

<table>
<thead>
<tr>
<th>The patient is bed-bound</th>
<th>Semi-comatose</th>
</tr>
</thead>
<tbody>
<tr>
<td>Only able to take sips of fluid</td>
<td>No longer able to take tablets</td>
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</tbody>
</table>

NHS Lanarkshire has an LCP Team who provide an acute and community service and who are responsible for supporting the implementation and continuous evaluation of the LCP throughout Lanarkshire. They also provide training and awareness raising. For more information see the Lanarkshire MCN for Palliative Care at the address noted above.
6. ICP Monitoring

Monitoring of the service provided to each person will take place using:

- **Variance Analysis** - questions to be agreed in conjunction with ICP development groups and national QIS ICP programme team.
- **Staff, Patient and Carer Surveys** - to be developed in conjunction with ICP development groups, national QIS public involvement group, etc.
### Appendix 1 - Dementia ICP Development Group Members

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
<th>Employer</th>
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<tbody>
<tr>
<td>Francesca Aaen</td>
<td>Clinical Pharmacist</td>
<td>NHS Lanarkshire</td>
</tr>
<tr>
<td>George McDermid</td>
<td>Consultant Psychiatrist</td>
<td>NHS Lanarkshire</td>
</tr>
<tr>
<td>Elizabeth Aims</td>
<td>Community Psychiatric Nurse</td>
<td>NHS Lanarkshire</td>
</tr>
<tr>
<td>Rosaline McGarry</td>
<td>Team Leader</td>
<td>South Lanarkshire Council</td>
</tr>
<tr>
<td>Lesley Bodin</td>
<td>Head of Occupational Therapy</td>
<td>NHS Lanarkshire</td>
</tr>
<tr>
<td>Nicola McLatchie</td>
<td>Clinical Governance Assistant</td>
<td>NHSL</td>
</tr>
<tr>
<td>Angela Campbell</td>
<td>Mental Health Liaison - Care Homes</td>
<td>NHSL</td>
</tr>
<tr>
<td>Frank McMenemy</td>
<td>Fieldwork Manager</td>
<td>South Lanarkshire Council</td>
</tr>
<tr>
<td>Tracy Condie</td>
<td>NTL Older Adult</td>
<td>NHS Greater Glasgow and Clyde</td>
</tr>
<tr>
<td>Douglas Mole</td>
<td>Service User/Carer</td>
<td>Lanarkshire Links</td>
</tr>
<tr>
<td>Claire Donaghey</td>
<td>Clinical Psychologist</td>
<td>NHS Lanarkshire</td>
</tr>
<tr>
<td>Anne Marie Murphy</td>
<td>Senior Charge Nurse</td>
<td>NHS Lanarkshire</td>
</tr>
<tr>
<td>Kathie Ellis</td>
<td>Senior Charge Nurse</td>
<td>NHS Lanarkshire</td>
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<tr>
<td>Ann-Marie Newman</td>
<td>Manager</td>
<td>Lanarkshire Links</td>
</tr>
<tr>
<td>Stephen Gallagher</td>
<td>Senior Charge Nurse</td>
<td>NHS Lanarkshire</td>
</tr>
<tr>
<td>Karen Reid</td>
<td>Senior Charge Nurse</td>
<td>NHS Lanarkshire</td>
</tr>
<tr>
<td>Joe Hands</td>
<td>Clinical Governance Co-ordinator</td>
<td>NHS Lanarkshire</td>
</tr>
<tr>
<td>Melinda Shakespeare</td>
<td>Senior Officer</td>
<td>North Lanarkshire Council</td>
</tr>
<tr>
<td>Tyra Hogben</td>
<td>GP, MacInnes Medical Centre</td>
<td>Lanarkshire</td>
</tr>
<tr>
<td>Fiona Taylor</td>
<td>Service Manager</td>
<td>North Lanarkshire Council</td>
</tr>
<tr>
<td>John Horsburgh</td>
<td>Committee Member</td>
<td>Lanarkshire Links</td>
</tr>
<tr>
<td>Vicky Thurlby</td>
<td>Clinical Psychologist</td>
<td>NHS Lanarkshire</td>
</tr>
<tr>
<td>Nicola Hughes</td>
<td>Staff Grade in LD Psychiatry</td>
<td>NHS Lanarkshire</td>
</tr>
<tr>
<td>Brenda Vincent</td>
<td>Service Manager</td>
<td>Equals Advocacy Partnership</td>
</tr>
<tr>
<td>Clare Kane</td>
<td>Senior Charge Nurse Liaison</td>
<td>Older People, NHSL</td>
</tr>
<tr>
<td>Fiona Young</td>
<td>Senior Charge Nurse</td>
<td>NHS Lanarkshire</td>
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<tr>
<td>Winnie Manning</td>
<td>Consultant Psychiatrist</td>
<td>NHS Lanarkshire</td>
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### ICP Team

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
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<tbody>
<tr>
<td>Patricia Kent</td>
<td>ICP Manager</td>
</tr>
<tr>
<td>Janis Dickson</td>
<td>Mental Health ICP Project Assistant</td>
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dementia integrated care pathway
Appendix 2: Guidance and Policy Base to Support Values

Guidance and Policy Base to Support Values (2010)

The Mental Health (Care and Treatment) (Scotland) Act 2003 is underpinned by the Milan principles of reciprocity, respect for equality and diversity in a non-discriminatory manner.

The 10 Essential Shared Capabilities for Mental Health promotes working in partnership, challenging inequalities (social inequality and exclusion), promoting recovery, providing service user centred care and making a difference.

The Scottish Recovery Indicator states the service should provide interventions designed specifically to promote participation in life’s roles, to self manage illness and to enhance relationships with others.

NHS Lanarkshire’s Organisational Values which commit to quality, patient focused services; quality healthcare environment; continuous improvement; involvement; communication; respect, fairness and consistency; competence and continuous learning.

Better Health, Better Care, Scottish Government (2007), Better Together, Patient Experience Programme and the Quality Strategy (2010), Scottish Government. These documents set out the Six Dimensions of Quality which focus on providing safe, effective care that enhances the patient’s experience of our services:

1. Person centred: providing care that is responsive to individual personal preferences, needs and values and assuring that patient values guide all clinical decisions
2. Safe: avoiding injuries to patients from care that is intended to help them
3. Effective: providing services based on scientific knowledge
4. Efficient: avoiding waste, including waste of equipment, supplies, ideas and energy
5. Equitable: providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location or socio-economic status
6. Timely: reducing waits and sometimes harmful delays for both those who receive care and those who give care.

Caring and Compassionate Practice is the work of a group from the Nursing, Midwifery and Allied Health Profession (NMAHP) Practice Development Centre in NHS Lanarkshire. It sets out a list of people’s expectations accompanied by statements that set the minimum practice standards for new nurses, midwives, allied health professionals and support workers must work on a day to day basis:

- To be valued as a person
- To feel and be safe
- To be cared for with dignity
- To see NMAHPs make the best possible effort
- To experience courtesy
- To be respected
- To receive kindness.
Appendix 3: Patient Information Form

Patient Information

This form should be completed to evidence all documentation given to a user/carer of mental health services in NHS Lanarkshire, this information should be offered in line with NHS Lanarkshire standards and guidance in relation to patient information for Dementia.

Was the patient given the publication “Facing Dementia?” □ Yes □ No
For people receiving a diagnosis at a more moderate or advanced stage of the disease then other publications may be more appropriate depending on circumstances.

If yes, publication given by: ___________________________ Date: ___/___/____

If No, reason for patient not receiving:
□ Publication Unavailable □ Patient Declined □ Not offered

Please note for other available information, the mental health collaborative dementia sub-group has still to agree a standard for inclusion below.

Other available information offered:

<table>
<thead>
<tr>
<th>Publication</th>
<th>Signed</th>
<th>Dated</th>
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<tbody>
<tr>
<td>Coping with dementia – a practical handbook for carers</td>
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<td>Don’t make the journey alone</td>
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<td>Drug treatments in dementia</td>
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<td>Power of attorney: A brief guide</td>
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<td>Financial benefits for people with dementia/benefit maximisation</td>
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<tr>
<td>Worried about your memory?</td>
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<td></td>
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<tr>
<td>Dementia – Money and legal matters (Alzheimer’s Disease)</td>
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<tr>
<td>Understanding and managing the symptoms of Alzheimer’s Disease</td>
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<td>Useful telephone numbers</td>
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<td>Driving</td>
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<td>CMHT Information leaflet</td>
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If additional information has been given to the patient/carer that is not listed above please document overleaf.
**Appendix 4: Neuropsychiatric Inventory Questionnaire (NPI-Q)**

**Study Name or Acronym:**

**NEUROPSYCHIATRIC INVENTORY QUESTIONNAIRE (NPI-Q)**

<table>
<thead>
<tr>
<th>SUBJECT ID</th>
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<tr>
<th>DATA SOURCE</th>
<th>SITE NO</th>
<th>VISIT DATE</th>
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**Please ask the following questions based upon changes.**

**Indicate “yes” only if the symptom has been present in the past month; otherwise, indicate “no.”**

**Rate the SEVERITY of the symptom (how it affects the patient):**
- 1 = Mild (noticeable, but not a significant change)
- 2 = Moderate (significant, but not a dramatic change)
- 3 = Severe (very marked or prominent; a dramatic change)

**Rate the DISTRESS you (the caregiver) experience because of the symptom (how it affects you):**
- 0 = Not distressing at all
- 1 = Minimal/slightly distressing, not a problem to cope with
- 2 = Mild (not very distressing, generally easy to cope with)
- 3 = Moderate (fairly distressing, not always easy to cope with)
- 4 = Severe (very distressing, difficult to cope with)
- 5 = Extreme or very severe (extremely distressing, unable to cope with)

**DELUSIONS**

1. Does the patient believe that others are stealing from him or her, or planning to harm him or her in some way?
   - Present in the past month: 0 = No, 1 = Yes
   - Rate SEVERITY: 1.1, Rate DISTRESS: 1.2, 1.3

**HALLUCINATIONS**

2. Does the patient act as if he or she hears voices?
   - Does he or she talk to people who are not there?
   - Rate SEVERITY: 2.1, Rate DISTRESS: 2.2, 2.3

**AGITATION OR AGGRESSION**

3. Is the patient stubborn and resistant to help from others?
   - Rate SEVERITY: 3.1, Rate DISTRESS: 3.2, 3.3

**DEPRESSION OR DYSPHORIA**

4. Does the patient act as if he or she is sad or in low spirits? Does he or she cry?
   - Rate SEVERITY: 4.1, Rate DISTRESS: 4.2, 4.3

**ANXIETY**

5. Does the patient become upset when separated from you? Does he or she have any other signs of nervousness, such as shortness of breath, sighing, being unable to relax, or feeling excessively tense?
   - Rate SEVERITY: 5.1, Rate DISTRESS: 5.2, 5.3

**ELATION OR EUPHORIA**

6. Does the patient appear to feel too good or act excessively happy?
   - Rate SEVERITY: 6.1, Rate DISTRESS: 6.2, 6.3

**APATHY OR INDIFFERENCE**

7. Does the patient seem less interested in his or her usual activities and in the activities and plans of others?
   - Rate SEVERITY: 7.1, Rate DISTRESS: 7.2, 7.3
Study Name or Acronym: NEUROPSYCHIATRIC INVENTORY QUESTIONNAIRE (NPI-Q)

SUBJECT ID

VISIT NO

Disinhibition
8. Does the patient seem to act impulsively?
   For example, does the patient talk to strangers
   as if he or she knows them, or does the patient
   say things that may hurt people’s feelings?

   0 = No
   1 = Yes

   Rate the severity
   of the symptom
   (how it affects the patient):
   1 = Mild (noticeable, but not a
      significant change)
   2 = Moderate (significant, but
      not a dramatic change)
   3 = Severe (very marked or
      prominent; a dramatic
      change)

   Rate the distress you (the caregiver)
   experience because of the symptom
   (how it affects you):
   0 = Not distressing at all
   1 = Minimal (slightly distressing, not a
      problem to cope with)
   2 = Mild (not very distressing, generally
      easy to cope with)
   3 = Moderate (fairly distressing, not
      always easy to cope with)
   4 = Severe (very distressing, difficult to
      cope with)
   5 = Extreme or very severe (extremely
      distressing, unable to cope with)

   Present
   in the
   past
   month:

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</table>

Irritability or Lability
9. Is the patient impatient and cranky? Does he
   or she have difficulty coping with delays or
   waiting for planned activities?

   0 = No
   1 = Yes

   Rate the severity
   of the symptom
   (how it affects the patient):
   1 = Mild (noticeable, but not a
      significant change)
   2 = Moderate (significant, but
      not a dramatic change)
   3 = Severe (very marked or
      prominent; a dramatic
      change)

   Rate the distress you (the caregiver)
   experience because of the symptom
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   5 = Extreme or very severe (extremely
      distressing, unable to cope with)

   Present
   in the
   past
   month:

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<td>9.3</td>
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</table>

Motor Disturbance
10. Does the patient engage in repetitive activities,
    such as pacing around the house, handling
    buttons, wrapping string, or doing other things
    repeatedly?

   0 = No
   1 = Yes

   Rate the severity
   of the symptom
   (how it affects the patient):
   1 = Mild (noticeable, but not a
      significant change)
   2 = Moderate (significant, but
      not a dramatic change)
   3 = Severe (very marked or
      prominent; a dramatic
      change)

   Rate the distress you (the caregiver)
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      distressing, unable to cope with)

   Present
   in the
   past
   month:

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<td>10.2</td>
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</table>

Nighttime Behaviors
11. Does the patient awaken you during the night,
    rise too early in the morning, or take excessive
    naps during the day?

   0 = No
   1 = Yes

   Rate the severity
   of the symptom
   (how it affects the patient):
   1 = Mild (noticeable, but not a
      significant change)
   2 = Moderate (significant, but
      not a dramatic change)
   3 = Severe (very marked or
      prominent; a dramatic
      change)

   Rate the distress you (the caregiver)
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      cope with)
   5 = Extreme or very severe (extremely
      distressing, unable to cope with)

   Present
   in the
   past
   month:

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<td>11.3</td>
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</tbody>
</table>

Appetite and Eating
12. Has the patient lost or gained weight, or had a
    change in the food he or she likes?

   0 = No
   1 = Yes

   Rate the severity
   of the symptom
   (how it affects the patient):
   1 = Mild (noticeable, but not a
      significant change)
   2 = Moderate (significant, but
      not a dramatic change)
   3 = Severe (very marked or
      prominent; a dramatic
      change)

   Rate the distress you (the caregiver)
   experience because of the symptom
   (how it affects you):
   0 = Not distressing at all
   1 = Minimal (slightly distressing, not a
      problem to cope with)
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      always easy to cope with)
   4 = Severe (very distressing, difficult to
      cope with)
   5 = Extreme or very severe (extremely
      distressing, unable to cope with)

   Present
   in the
   past
   month:

<table>
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<th>3</th>
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<tr>
<td>12.3</td>
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</table>
### Appendix 5: Driving Questionnaire

**Patient Name:**                              **Date of Assessment:**

# DRIVING QUESTIONNAIRE

<table>
<thead>
<tr>
<th></th>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Do you still drive?</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>If NO – stop here</strong></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Have you experienced any problems when driving?</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Have you found yourself getting lost in familiar routes?</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Have you mixed up the accelerator and brake pedals?</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Have you mixed up other controls e.g. window wipers, indicators etc?</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>Have you found yourself having problems with your road positioning i.e. bumping into kerbs, crossing over white lines or problems with parking, etc?</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>Have you found yourself not giving way at junctions/roundabouts?</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>How do your passengers respond to your driving?</td>
<td></td>
</tr>
</tbody>
</table>
**DRIVING QUESTIONNAIRE**  
Continued.

**If a relative is present:**

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
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<tbody>
<tr>
<td>9</td>
<td>How do you feel about the patient’s driving?</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>Do you agree with the above responses?</td>
</tr>
<tr>
<td></td>
<td>Would you be happy to let your grandchildren ride in the car?</td>
</tr>
</tbody>
</table>

**Clinician’s view of collateral history from relatives:**

<p>| | |</p>
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<thead>
<tr>
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<tbody>
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</table>

**ACTION TAKEN**

<table>
<thead>
<tr>
<th>ACTION TAKEN</th>
<th>Date</th>
<th>Signature</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pass the information onto patient’s GP</td>
<td></td>
<td></td>
</tr>
<tr>
<td>With patient’s consent, refer him/her to Scottish Driving Assessment Service</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Advise the patient that failure to inform appropriate authorities may invalidate insurance payouts</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Driving advice sheet given</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Discuss at MDT meeting</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Date:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Outcome:</td>
<td></td>
<td></td>
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</tbody>
</table>
Appendix 6: Algorithm for Young Onset Dementia Treatment for Cognitive Impairment
Notes on Young Onset Dementia Treatment for Cognitive Impairment

1. The general expectation in NHS Lanarkshire is that patients under 65 with memory/cognitive problems will be seen by general adult psychiatry and if dementia diagnosed then transferred to local old age services, after discussion on a case by case basis between consultants.

2. Old age psychiatry consultants will be happy to discuss cases and appropriate investigations prior to diagnosis and potential transfer.

3. To balance workload sensibly, general adult services will hold onto “graduates” over 65 until their condition makes it more appropriate for old age psychiatry to take over their care. Again discussion should happen on a case by case basis between consultants.

4. GP should be in agreement with and at very least informed of referral.

5. Assessment prior to referral FBC, B12 and Folate, U&E, LFT, TFT.

6. Consultant will request ECG and CT brain on selected patients.

7. Young onset dementia patients should have access to inpatient beds within general adult wards or old age psychiatry wards whichever most appropriate for their care. They will remain responsibility of whichever general adult or old age psychiatrist is principally dealing with them at that time. Potential transfer case by case as above.

8. Young Onset nurses should not be sent referral to do an Addenbrooke’s assessment as all CMHT should have training in this and if not can access this via Old Age Psychology CMHTOP service via Airbles Road, Motherwell. Tel: 01698 261331.

9. SPECT scanning requests can be made by adult psychiatrists who are advised to write to Southern General, 1345 Govan Road, Glasgow. Tel: 0141 201 2032. They would require to log their details including GMC number with Spect Scanning before they can refer.

10. If history of alcohol abuse and current heavy drinking then would need to discuss this consultant to consultant. Korsakoff’s psychosis/alcohol related brain damage is not a progressive dementia and may not be appropriate for transfer to dementia services.

11. Agreed that Young Onset Dementia patients who have been assessed by psychology and remain unclear regarding diagnosis should be followed up by Young Onset Nurses in 6 months time and re-referred for further investigation if concerns remain apparent or deterioration noted.
## Appendix 7: MATRIX Evidence Base for Dementia

<table>
<thead>
<tr>
<th>Level of severity</th>
<th>Level of service</th>
<th>Intensity of Intervention</th>
<th>What intervention?</th>
<th>Recommendation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild/Moderate</td>
<td>Secondary Care/Day Hospital</td>
<td>Low (formal caregivers)</td>
<td>Reminiscence</td>
<td>B (1, 8)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Validation Therapy</td>
<td>C (1, 9)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Behaviour that Challenges.</td>
<td>B (1, 3, 4)</td>
</tr>
<tr>
<td></td>
<td>Secondary Care/Specialised</td>
<td>High (specialist)</td>
<td>Cognitive Stimulation Therapy</td>
<td>A (1, 2, 3)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Cognitive Rehabilitation/Cognitive Training</td>
<td>C (1, 6)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Cognitive Behaviour Therapy for depression in Dementia</td>
<td>B (1, 3, 5, 6)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Caregiver Interventions</td>
<td>A (1, 3, 5, 6, 7)</td>
</tr>
</tbody>
</table>

### NOTES:
- There is no evidence that Validation therapy, cognitive stimulation therapy, and reminiscence reduce behaviour that challenges in people with dementia (NICE Guidelines 42)
MATRIX DEMENTIA REFERENCES

Recommendations are based on SIGN guideline criteria for evaluating the efficacy of interventions.

1. SIGN (86) Management of Patients with Dementia: A National Clinical Guideline. Edinburgh: Scottish Intercollegiate Guidelines Network. Behaviour management may be used to reduce depression in people with dementia. Multilevel behavioural management interventions may be more effective than individual interventions at improving behaviour and well-being in people with dementia.


A large number of studies were identified of which ten were considered high quality (level one). The authors of this high quality review report that there is ‘consistent, excellent evidence’ that individual behavioural management techniques produce positive outcomes for reducing depression in caregivers. Good evidence also exists for individual and group coping strategies for reducing depression symptoms in caregivers. Education alone and supportive therapy appears ineffective.


Three categories of evidence-based treatments for caregiver distress were found to be efficacious; multicomponent programmes, psychotherapy and symptom focused skills-enhancing psychoeducation interventions. Individualised CBT caregiver interventions are most efficacious for caregivers with significant levels of depression and group based CBT interventions are most efficacious for caregivers exhibiting high levels of stress but without overt symptoms of depression.


No evidence for cognitive training and insufficient evidence for individualised cognitive rehabilitation in dementia


Although the data is relatively small beneficial impact of reminiscence in cognition and mood were reported. In addition beneficial outcomes for caregivers were also reported.

## Appendix 8: Checklist for Managing Behavioural and Psychological Symptoms Associated with Dementia

### Checklist

<table>
<thead>
<tr>
<th>Patient Name:</th>
<th>Date of Birth:</th>
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<tbody>
<tr>
<td>Assessor:</td>
<td>Date:</td>
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</tbody>
</table>

This checklist should be used to aid the review of patients who develop BPSD. These symptoms may develop acutely or gradually. It is important to bear in mind that the acute onset of BPSD is often linked to physical illness. This checklist aims to provide a structured review of the BPSD and precipitating factors and the information sought is therefore related to the timescale of the BPSD. Ideally physical and environmental factors will be checked prior to mental health referral but are included to ensure complete assessment.

<table>
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<th>Investigation</th>
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<th>Comment</th>
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<tr>
<td>Urine</td>
<td>□</td>
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<tr>
<td>Bowel monitoring</td>
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<tr>
<td>Pain Assessment Tool</td>
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<tr>
<td>Medication reviewed</td>
<td>□</td>
<td>□</td>
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<tr>
<td>Sight and/or hearing deficits</td>
<td>□</td>
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<tr>
<td>Fluid intake checked</td>
<td>□</td>
<td>□</td>
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<tr>
<td>Dietary intake checked</td>
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<tr>
<td>Sleep hygiene checked</td>
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### Psychological/Behavioural Factors

Please indicate if the following signs/symptoms are present:

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<th>Symptom/Sign</th>
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<th>Yes</th>
<th>Comment</th>
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<td>Low mood</td>
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<td>□</td>
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<tr>
<td>Tearful</td>
<td>□</td>
<td>□</td>
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</tr>
<tr>
<td>Agitation</td>
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<tr>
<td>Seizure activity</td>
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<tr>
<td>Retardation</td>
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<tr>
<td>Isolating self</td>
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<td>Aggression</td>
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<td>Disinhibition</td>
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<td>Anxiety</td>
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<td>Vocalisation</td>
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<tr>
<td>Pacing</td>
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<tr>
<td>Irritability</td>
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<td>□</td>
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<tr>
<td>Hallucinations</td>
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<td>Sundowning</td>
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## Environmental Factors

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<td>Change of carer or relationship</td>
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<tr>
<td>Carer approach assessed</td>
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<tr>
<td>Other environmental stressors</td>
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</tbody>
</table>

### Assessment Tool Used

- NPI-Q  
- BPSD  
- Other  
- None  

### Summary and planned interventions for both patient and carer


### Follow-up


References

10. Art Therapy Pilot Project, Elderly Community Mental Health Team, Coathill Hospital, Coatbridge, 2008.
11. Occupational Therapy Practice Based Evidence: Promotion of leisure occupations and its impact on active ageing for community based older participants, Upasana Sallis, 2009
### Glossary/Abbreviations

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
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<tbody>
<tr>
<td><strong>Addenbrooke’s Cognitive Examination Revised (ACE-R)</strong></td>
<td>A brief cognitive test that assesses five cognitive domains, namely attention/orientation, memory, verbal fluency, language and visuospatial abilities. Total score is 100, higher scores indicate better cognitive functioning.</td>
</tr>
<tr>
<td><strong>Behavioural and Psychological Symptoms of Dementia (BPSD)</strong></td>
<td>Usually identified on the basis of observation of the patient, including physical aggression, screaming, restlessness, agitation, wandering, culturally inappropriate behaviors, sexual disinhibition, hoarding, cursing, and shadowing. <strong>Psychological symptoms:</strong> Usually and mainly assessed on the basis of interviews with patients and relatives; these symptoms include anxiety, depressive mood, hallucinations, and delusions.</td>
</tr>
<tr>
<td><strong>Cognitive Stimulation Therapy (CST)</strong></td>
<td>A brief group-based treatment for people with mild to moderate dementia and involves sessions of themed activities, which aim to actively stimulate and engage people with dementia, whilst providing an optimal learning environment and the social benefits of a group.</td>
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<tr>
<td><strong>CMHT</strong></td>
<td>Community Mental Health Team.</td>
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<tr>
<td><strong>CPN</strong></td>
<td>Community Psychiatric Nurse.</td>
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<tr>
<td><strong>Computerised Tomography (CT)</strong></td>
<td>A CT scanner is a special kind of X-ray machine. Instead of sending out a single X-ray through your body as with ordinary X-rays, several beams are sent simultaneously from different angles. It produces multiple images or pictures of the inside of the body and can help doctors diagnose and treat medical conditions.</td>
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<tr>
<td><strong>Diagnostic and Statistical Manual of Mental Disorders (DSM IV)</strong></td>
<td>Psychiatric diagnoses are categorized by the Diagnostic and Statistical Manual of Mental Disorders. The manual is published by the American Psychiatric Association and covers all mental health disorders for both children and adults. It also lists known causes of these disorders, statistics in terms of gender, age at onset, and prognosis as well as some research concerning the optimal treatment approaches.</td>
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<tr>
<td><strong>Electrocardiogram (ECG)</strong></td>
<td>A test that measures the electrical activity of the heart, commonly used to detect abnormal heart rhythms and to investigate the cause of chest pains.</td>
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<tr>
<td><strong>Geriatric Depression Scale (GDS)</strong></td>
<td>A screening test for depressive symptoms in the elderly; ideal for evaluating the clinical severity of depression, and therefore for monitoring treatment. It is easy to administer, needs no prior psychiatric knowledge and has been well validated in many environments.</td>
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<tr>
<td><strong>International Classification of Diseases (ICD 10)</strong></td>
<td>This is the international standard diagnostic classification for all general epidemiological, many health management purposes and clinical use. It is used to classify diseases and other health problems recorded on many types of health and vital records including death certificates and health records. In addition to enabling the storage and retrieval of diagnostic information for clinical, epidemiological and quality purposes, these records also provide the basis for the compilation of national mortality and morbidity statistics by WHO Member States.</td>
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<tr>
<td><strong>Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE)</strong></td>
<td>A questionnaire that can be filled out by a relative or other supporter (the informant) of an older person to determine whether that person has declined in cognitive functioning. The IQCODE is often used as a screening test for dementia. If the person is found to have significant cognitive decline, then this needs to be followed up with a medical examination to determine whether dementia is present.</td>
</tr>
</tbody>
</table>
Liver Function Tests (LFT) - Liver function tests, which include liver enzymes, are groups of clinical biochemistry laboratory blood assays designed to give information about the state of a patient's liver.

Magnetic Resonance Imaging (MRI) - A medical imaging technique most commonly used in radiology. MRI scanning is particularly useful at providing highly detailed images of soft tissues. MRI scanning can also provide images in various planes without movement of the patient.

NHS Quality Improvement Scotland (QIS) - NHS Quality Improvement Scotland was established as a Special Health Board by the Scottish Executive in 2003, in order to act as the lead organisation in improving the quality of healthcare delivered by NHS Scotland. By 'improve', they mean the improving of the experiences of patient/clients and the outcomes of their treatment while in the care of NHS Scotland. They work to achieve these goals through an analysis of scientific evidence, by listening to the needs and preferences of patient/clients and carers, as well as the experiences of healthcare professionals. Web address: www.nhshealthquality.org.

National Institute for Clinical Excellence (NICE) - NICE is part of the NHS. It is the independent organisation responsible for providing national guidance on treatments and care for those using the NHS in England and Wales. Its guidance is for healthcare professionals and patient/clients and their carers, to help them make decisions about treatment and healthcare. NICE guidance and recommendations are prepared by independent groups that include healthcare professionals working in the NHS and people who are familiar with the issues affecting patient/clients and carers. Website address: www.nice.org.uk.

Neuropsychiatric Inventory Questionnaire (NPI-Q) - The Neuropsychiatric Inventory is a clinical instrument for assessing behavioural and psychological symptoms in dementia. It is based on an interview with the primary caregiver.

Scottish Intercollegiate Guidelines Network (SIGN) - SIGN was established in 1993 by the Academy of Royal Colleges and Faculties in Scotland. Its objective is to improve the quality of healthcare for patients in Scotland by reducing variation in practice and outcome, through the dissemination of national clinical guidelines containing recommendations for effective practice based on current evidence. For further information contact: www.sign.ac.uk.

Single Photon Emission Computed Tomography (SPECT) - A nuclear medicine technique which is used to image brain function.

Thyroid Function Test (TFT) - A collective term for blood tests used to check the function of the thyroid.

Urea & Electrolytes Test (U&E) - U&E is often used as a screening test for patients who are generally unwell, to detect abnormalities of blood chemistry, including kidney failure and dehydration.

World Health Organisation (WHO) - WHO is the directing and coordinating authority for health within the United Nations system. It is responsible for providing leadership on global health matters, shaping the health research agenda, setting norms and standards, articulating evidence-based policy options, providing technical support to countries and monitoring and assessing health trends.