Services and Support for People who have Dementia

1. Early Concerns

Often the first signs that cause concern for people and their relatives are when an individual becomes forgetful of confused. This is a difficult time for people who naturally may fear the worst, and may try to deny the problem, or put off doing anything about it. However, when they do seek advice, this is often from the GP. If appropriate, having screened out immediate physiological causes, the GP will refer the person to secondary health services for assessment and diagnosis.

2. Referral and Diagnosis

2.1. Non-emergency

Referral to the joint Community Mental Health Team – Older Adults (CMHT-OA) is through the BHFT Common Point of Entry (CPE), where referrals are screened to determine the most appropriate next steps for the individual. If it seems appropriate, the referral will then be passed to the locality team for assessment. Assessment and diagnosis is through the Memory Clinic.

Memory Clinic staff are-

- Consultant in Psychiatry of Old Age
- Staff Grade Psychiatrist
- 2 specialist nurses
- Psychologist

Assessments can be carried out at Church Hill House where the team is based, or in the person's home.

When a referral is received, the information is considered at the weekly allocations meeting, and the most appropriate workers are assigned to complete the assessment.

The assessment will consider a range of potential causes for the symptoms presented, and will test for these to rule our any causes that are reversible or indicate causes other then dementia. Often physical illnesses such as infections can give rise to confusion and forgetfulness, and treatment can see the person return to full health. These tests will include full blood screening, and may also include scans. This service is also available to younger people who may have a dementia, and these individuals should always be referred to Neurology.

2.2. Emergency

There are occasions where a more urgent response is required, and it is inappropriate to wait for the weekly allocations meeting. This may be, for example, where an individual has been found wandering, or has become distressed. In these circumstances, prioritisation is made and allocation takes place immediately.

3. Causes of Dementia

There are several diseases and conditions that result in dementia. These include:

- **Alzheimer's disease** − The most common cause of dementia. During the course of the disease the chemistry and structure of the brain change, leading to the death of brain cells. Problems of short-term memory are usually the first noticeable sign.
- **Vascular dementia** − If the oxygen supply to the brain fails due to vascular disease, 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 abnormal structures that develop inside nerve cells. Their presence in the brain leads to the degeneration of brain tissue. Symptoms can include disorientation and hallucinations, as well as problems with planning, reasoning and problem solving. Memory may be affected to a lesser degree. This form of dementia shares some characteristics with Parkinson's disease.
- **Fronto-temporal dementia** (including Pick's disease) − In fronto-temporal dementia, damage is usually focused in the front part of the brain. At first, personality and behaviour changes are the most obvious signs.

Rarer causes of dementia

There are many other rarer diseases that may lead to dementia, including progressive supranuclear palsy, Korsakoff's syndrome, Binswanger's disease, HIV/AIDS, and Creutzfeldt−Jakob disease (CJD). Some people with multiple sclerosis, motor neurone disease, Parkinson's disease and Huntington's disease may also develop dementia as a result of disease progression.

Mild cognitive impairment

Some individuals may have noticed problems with their memory, but a doctor may feel that the symptoms are not severe enough to warrant a diagnosis of Alzheimer's disease or another type of dementia, particularly if a person is still managing well. When this occurs, some doctors will use the term 'mild cognitive impairment' (MCI). Recent research has shown that individuals with MCI have an increased risk of developing dementia. The conversion rate from MCI to Alzheimer's is 10-20 per cent each year, so a diagnosis of MCI does not always mean that the person will go on to develop dementia.

Who gets dementia?

- There are about 800,000 people in the UK with dementia.
- Dementia mainly affects people over the age of 65 and the likelihood increases with age. However, it can affect younger people: there are over 17,000 people in the UK under the age of 65 who have dementia.
- Dementia can affect men and women.
- Scientists are investigating the genetic background to dementia. It does appear that in a few rare cases the diseases that cause dementia can be inherited. Some people with a particular genetic make-up have a higher risk than others of developing dementia.

After Diagnosis – "Living Well with Dementia"

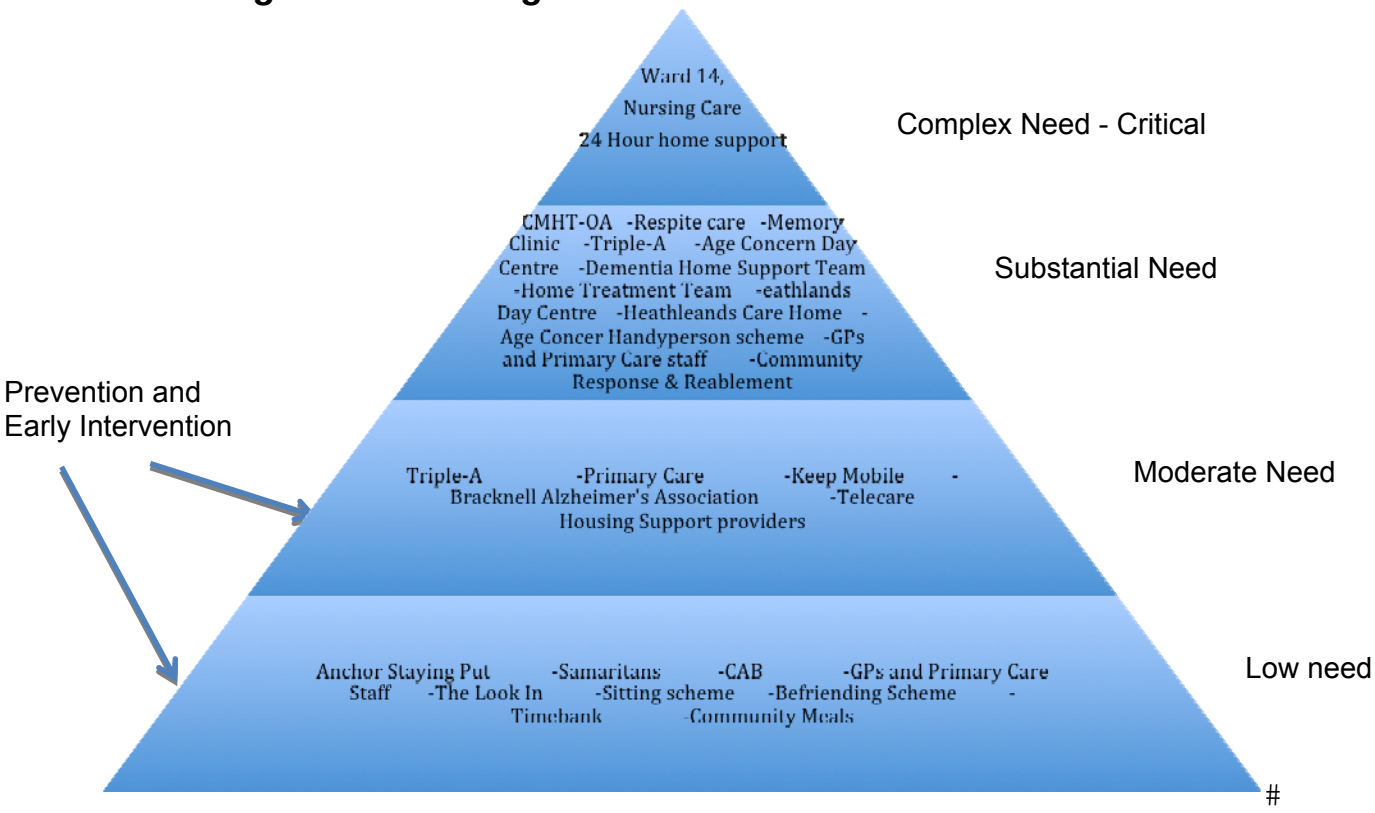

Fig 1: Summary of support

4. Support in the Community

4.1. Support from CMHT-OA

Mental Health Practitioners

- Community Psychiatric Nurses (CPN's)
- Social Workers (SW's)
- Occupational Therapist (OT)
- Community Support Workers (CSW's)
- Speech & Language Therapist (SALT)
- Psychology team
- Home Treatment Team (short term care management) (see below)
- Dementia Advisor

4.1.1. Dementia Advisor

Many people newly diagnosed with dementia do not yet need support from Social Care. However, they have access to the Dementia Advisor, whose role is to give information, advice, and support, and signpost people to where they can find other support available. Further information on this role will be available. The role was first funded as part of a National pilot, and has proven so useful and so popular that permanent funding has been secured, and other localities are following the model.

4.1.2. Care Co-ordination: (by any practitioner in the team)

Assessment, diagnosis and treatment of mental health conditions for older adults are the core business of the team. In addition, those people who have a clinical need for specialised integrated support will be eligible for care management (i.e. where psychiatric knowledge and expertise is essential to achieve effective Care Co-ordination).

Examples of people needing Care Coordination:

- A person with a severe mental illness/dementia with challenging behaviour who is at risk due to a lack of insight into their condition
- Resistant to attempts to provide care/support

Individuals and their families are encouraged and supported to consider a wide range of ways in which their social care needs can be met, in line with the personalisation agenda, and many families have been able to have support arrangements that meet their very individual needs and circumstances.

4.1.3. Support for Carers

Carers are entitled to an assessment and there are a range of options for support, including voluntary organisations. (see Fig.1). As part of the approach to personalised support arrangements carers can have a direct payment to organise support or activities that help them in their caring role. They can also use the Timebank (further information to be circulated).

4.1.4. Occupational Therapy:

Occupational Therapist runs weekly Cognitive-Stimulation Therapy groups and carries out assessments of functional ability in individuals' own homes. Following assessments, recommendation will be made to support individuals to regain or retain skills for as long as possible.

4.1.5. Speech & Language Therapy:

This involves assessment of communication skills or memory, and feeding/swallowing difficulties, and development of programmes to support retention of skills.

4.1.6. Psychology:

Can provide in-depth neuropsychological assessments where required, also psychological based interventions on an individual or group basis

4.1.7. Memory Clinic reviews

These can be led by the nurse, doctor or psychologist, and monitor the individual and their treatment to ensure that it is as effective as possible, as the dementia progresses. The work of the Consultant Psychiatrist contributes to national research into the treatment of Dementia.

4.1.8. Understanding Dementia Carers Courses

The memory clinic staff run a course for carers of people with dementia. This is 8 sessions over 8 weeks, and is run at Heathlands, where the individual with dementia can receive day care if necessary. Aware of the fact that it may be difficult for some carers to attend, the team are intending to run an alternative course over one day.

4.2. Home Treatment Team (HTT)

'A specialist, multidisciplinary mental health team which aims to provide short-term, intensive, home based assessment and treatment as an alternative to inpatient care'

This differs from the Community Mental Health Team in the following ways:-

- It has the capacity to visit up to 4 times per day, for up to 12 wks
- It operates 7 days a week, 365 days per year
- It provides support outside of office hours

HTT and CMHT OA are key elements of the wider Community Mental Health Services for Older People. Both work together very closely and share a work base.

Main Functions of HTT:

- Crisis response
- Person-centred risk assessment and management
- Provide community treatment during most severe phase of illness
- Provide telephone advice and support
- Monitor mental well-being and response to treatment
- Support patients to take active part in decisions about their mental health care and recovery
- Educate and empower people/carers to manage symptoms
- Help people maintain links with their social support network

4.3. Home Support

If individuals and their families need day to day support with tasks of daily living, or personal care, then this can be provided by:-

- Regular visits by support workers from a domiciliary care agency, either arranged by the Council or through a Direct Payment.
- The council's specialist dementia home support team (usually for people with more complex needs)
- Having a live-in carer which can also be arranged through an agency or Direct Payment
- Employment of personal assistants using a Direct Payment
- Using the befriending scheme run by BFVA
- Using the Timebank

4.4. How to refer

Referrals detailing personal, medical and psychiatric history, any screening results and the presenting problem/reason for referral, should be sent to the Common Point of Entry for all Mental Health Services across Berkshire.

The number to contact is: 0300 365 0300

5. Residential Care

People are supported to remain in their own homes for as long as possible. However, for some people there may come a time when this is no longer possible, for example because:-

- Family carers are no longer able to provide the level of care required, even with additional support
- The individual has no family, and the risks of living alone have become too great even with a package of support.

In these circumstances, the practitioner from the team will, in consultation with the individual and family and friends, identify a suitable care home. All care homes where people are funded by the Council have rigorous checks for quality, and are monitored closely through the Care Governance arrangements.

6. Hospital Care

6.1. Charles Ward

The Older Adults inpatients wards in the East have historically remained under-occupied for a number of years. This has resulted in an inefficient use of the available resources for older adult's inpatient provision. BHFT reviewed the opportunity to consolidate ward 14, Heatherwood Hospital with the current activity on Charles Ward by June 2011.

6.2. Support in Acute Hospitals

The fact that people with dementia do not always receive good care in acute hospitals has been well publicised.

Heatherwood and Wexham Park Hospital Trust have undertaken a programme of work to determine what they need to do to address this, and as a result have instigated a range of initiatives, including the following:-

- Established a team with particular expertise in dementia, to advise staff on surgical and medical wards how they should support individuals. They are alerted whenever a person who is known to have dementia, or who appears may have dementia, and they visit and tailor their advice accordingly
- Use a discrete system to identify to ward staff when a person has dementia to indicate that they need specific support
- specialist dietetics advice
- Liaison Psychiatry service: this service carries out urgent old-age psychiatric assessments, and will assess before hospital discharge if it is inappropriate to wait for a memory clinic appointment.
- Staff training for local care homes

Royal Berks Hospital Trust also has a liaison psychiatry service

Frimley Park Hospital Trust has a specialist liaison nurse who works with individuals to facilitate safe hospital discharge

6.3. Discharge from Hospital (for people living in their own homes)

Individuals may have been in hospital for one of two main reasons:-

- Assessment and treatment of dementia
- Treatment for a physical condition

and may require reablement or intensive support for a period of time after they are discharged.

6.3.1. Physical reablement – Intermediate Care

The Council manages the intermediate care service for people with physical reablement needs. This is run in partnership with Berkshire Healthcare NHS Foundation Trust (BHFT), and has two main components:-

- The Bridgewell Centre, which offers reablement in a care home setting, and
- the domiciliary team, which provides reablement service in people's own home.

Bridgewell will soon be opening a separate wing, which will offer physical reablement for people with dementia. The domiciliary will shortly be receiving specialist training to ensure that they can respond appropriately to the physical reablement needs of people with dementia.

Both Bridgewell and the domiciliary intermediate care team also provide intensive support to people who need it to prevent hospital admission.

6.3.2. Dementia-related hospital discharge

The Home Treatment team will provide the short term intensive support that may be required following hospitalisation because of dementia. See 4.2 above.

7. Safeguarding

People with Dementia are among the most vulnerable in the community. The Council leads the local approach to safeguarding adults in partnership with other agencies. Further detail is available, and the Annual Report for 2011-12 will be published in June.

7.1. Mental Capacity Act 2005 (MCA)

The MCA consolidates common law, and sets out the requirements for making decisions about care and treatment for people who lack capacity to make their own decisions. The MCA is quite complex but in brief:

Key principles of MCA are:

- The assumption of capacity unless determined otherwise
- Every possible step must be taken to enable the individual to make their own decisions
- Unwise decisions do not indicate lack of capacity
- Decisions made on behalf of the individual must be made in their best interests
- The least restrictive course of action must be followed.

The Act established the role of IMCA (Independent Mental Capacity Advocate) to act as an advocate for those individuals who lack capacity, but have no relatives or friends to advocate for them. They also have a specific role if consideration is being given to depriving an individual of their liberty in a care home or hospital for the purposes of receiving care or treatment. There are very clearly prescribed processes for this call the Deprivation of Liberty Safeguards (DoLS).

7.1.1. Assessment of Capacity

If it is thought that an individual may lack capacity to make a particular decision, then their ability to do so must be assessed. To demonstrate capacity in relation to the **specific decision** in question, the individual must be able to:-

- Understand the relevant information
- Retain the relevant information
- Weigh up the information and understand the implications to the decision in question
- Communicate that decision.

7.1.2. Best Interests Decisions

If an individual is assessed as lacking capacity to make a specific decision then the "Best Interests decision" must be made on their behalf.

The complexity and seriousness of the decision will determine who needs to be involved. Some decisions will require information and expertise from multi-disciplinary teams.

7.1.3. Lasting Powers of Attorney (LPA)

Whilst an individual still has capacity, they can authorise another individual to make decisions on their behalf. There are two kinds of LPA:

- Personal welfare, including healthcare
- Property and affairs (financial matters)

7.1.4. Advance Decisions

Before losing capacity individuals should be encouraged to consider making Advance Decisions. This usually relates to refusing treatment in certain circumstances. If an advance decision is properly written, signed and witnessed, then it must be honoured.

7.2. Court of Protection

In circumstances where there is disagreement in relation to whether an individual has capacity, or what decision id in their best interests then the matter can be referred to the Court of Protection for a ruling. They may request independent expert assessments, to assist in making their determinations, and may appoint a deputy to act for someone who is unable to make their own decisions. The Council hosts the Deputyship function for individuals who may not have other people available to take on this role.

8. End of Life Care

Wherever possible, people are supported to receive end-of-life care in accordance with their wishes. Where people have made an advance decision to refuse treatment (see 7.1.4) then this must be respected.

Often the final cause of death is a physical illness, rather than the dementia. Palliative care can be provided in individuals' own homes, or in appropriate care home settings, supported by input from appropriate community nursing services such as Marie Curie, or Macmillan or specialists in Parkinson's disease.

Carer Support

Alzheimer's Society 0845 306 0868 www.alzheimers.org.uk

Alzheimer's Dementia Support (Local):

Terrie: 07516165647; Christine: 07516165665
www.alzheimersdementiasupport.co.uk

Princess Royal Trust for Carers: 0800 988 5462 / 01628 777217; Email: helpline@prtberks.plus.com; Web: www.carers.org

Counsel and Care (Advice Service): 0845 300 7585; Web: www.counselandcare.org.uk