DEMENTIA CARE PATHWAY

Referral received identifying possible Dementia

Assessment leading to possible Diagnosis

Management and Treatment including end of life care planning

Evaluation

Discharge / continuing treatment for progressive disorder

Good Practice
- Standards & Guidance
- Dementia Network – to update
- Templates and Forms
  - Variance
  - Contacts

Information for Users/Carers
Information for Professionals
Information for Primary Care

Case Examples - Stepped Care

Professional Roles and Responsibilities
Triggers and Guidelines for Referral to Dementia Pathway

- Use of Plymouth Dementia screening checklist to consider if there are changes for a person.

- Progressive and Unexplained deterioration in the following areas
  - MEMORY
  - SKILLS
  - COMMUNICATION
  - BEHAVIOURS

- Please identify the nature of change and record this.

- The above can often be associated with mood symptoms

- Please rule out – physical health problems, psychosocial factors (possible abuse, bereavement etc.) See Primary Care role

Royal College of Psychiatry and British Psychological Society guidelines
Dementia and People with Intellectual Disabilities (2015)

- There is no definitive test for dementia. Use a baseline assessment preferably established when the person is healthy, ideally around 30 years. Gain clinical history highlighting evidence for change in function from known baseline and excluding other diagnoses that may mimic dementia.
- Decision-making should be based on multi-disciplinary assessments and discussions.
- When informing carers and people with learning disabilities about the nature of the diagnosis, it is important to bear in mind that the diagnosis is often provisional and a true picture may only emerge after a length of time.
- This should however not prevent clinicians considering and implementing the necessary steps to deal with the situation as it currently presents.

Use of Neuroimaging in Dementia in people with Learning Disability

- Neuro-imaging (CT/MRI) is not an essential investigation for the diagnosis of dementia in Down’s syndrome.
- It may be of value where other brain lesions/vascular dementia are suspected.
- New generation CT scanners are as sensitive as MRI scanners and may be more acceptable for people with learning disability.

Consider referral to Mental Health Services for Dementia if appropriate.
**LD Team Role if Dementia Suspected**

1. Check if the [primary care](#) tasks are undertaken already.
   - If not done already, please facilitate that.
   - Consider OK Health Check

2. Check if the core information is completed for the patient
   - Yes – Please update the core information and make an internal referral in to the dementia care pathway.
   - No – Please complete the core information and an initial risk assessment while facilitating the primary care tasks and refer the patient in to the dementia care pathway
   - Please ensure that the referral is discussed within the locality allocation meeting.

3. Arrange for assessment of dementia with Learning Disability Team. Assessment by Psychiatry, Community Nursing and Occupational Therapy in the first instance using other professionals if the persons needs suggest this.

4. Discuss possible diagnosis at MDT review where a co-ordinator will be confirmed.

[Return to Flowchart]
Information and Resources for Professionals

The term dementia applies to a global impairment of higher cerebral functions, including memory, social skills, emotional responses and problem solving ability. The range of impairment is wide and hence the range of services needed for this group of people is wide.

THE CARE PATHWAY
This pathway has been designed to be used by professionals and carers who are supporting adults with learning disabilities who are presenting with symptoms of dementia or who already have a diagnosis of dementia.

PREVALENCE
• People with learning disabilities have an increased risk of developing dementia but those with Down syndrome caused by Trisomy 21 have an earlier age related risk of developing dementia of the Alzheimer type. Around 20% of people with Learning Disabilities have Downs Syndrome.

Estimating prevalence rates of dementia can be problematic because of a number of methodological issues. These include diagnostic difficulties associated with dementia in a population which has pre-existing cognitive and functional impairments and the complexity of establishing accurate population samples of people with intellectual disabilities. However, there is evidence from several studies that people with intellectual disabilities have an increased risk of developing dementia compared to that observed in the general population. In particular, those with trisomy 21 resulting in Down’s syndrome have an earlier age-related risk of developing dementia of the Alzheimer-type. There is very limited research investigating the specific risk of dementia and other age-related disorders in those with other specific syndromes, some of which are associated with a reduced life-expectancy, or with autism.

Prevalence rates of dementia among older people with intellectual disabilities (excluding people with Down’s syndrome)

Several studies have investigated rates of clinical dementia among people with intellectual disabilities living within the community and used established or modified criteria based on systems for the diagnosis of dementia. Moss & Patel (1995) reported that 12% of a group of people with intellectual disabilities over age 50 years had dementia. Cooper (1997) found that the rate of dementia increased as expected in a population-based study with just over 20% of those over the age of 65 years meeting criteria for dementia. Strydom et al., (2007) reported findings from a two stage population based survey of adults with intellectual disabilities (without Down’s syndrome) across several London Boroughs. They found that prevalence rates varied depending on the diagnostic criteria used, with DSM-IV criteria resulting in the highest rate and ICD-10 the lowest. Rates for dementia, of whatever cause, using DSM-IV criteria were 13.1% in those 60 years and over and 18.3% in those 65 years or over. This compares to prevalence rates in the general population of 1% for 60–65 year olds to 13% for 80–85 year olds and 32% for 90–95 year olds (Hofman et al., 1991). See Figure 1 below for a comparison of dementia rates between individuals with Down’s syndrome, intellectual disabilities and the general population.

Return to Flowchart
Alzheimer’s disease was found to be the most common type of dementia, and had a prevalence of 8.6% in those aged 60 and older, three times greater than comparable general older adult population rates but cases of Lewy body dementia, vascular dementia, and fronto-temporal dementia were also identified based on clinical observations while rates varied according to diagnostic criteria used – DSM IV criteria were more inclusive than ICD10 (Strydom et al, 2007). Prevalence rates increased with age though shifted towards younger ages compared to the general population but did not differ significantly between mild, moderate and severe intellectual disabilities groups (Strydom et al., 2009).

Overall, the incidence rate for dementia in those aged 60 and older was estimated to be 54.6/1000 person years with the highest incidence rate in the age group 70–74 (Strydom et al, 2013).

Prevalence and incidence rates of dementia among people with Down’s syndrome

The association between Down’s syndrome and the risk of ‘precipitated senility’ was first reported by Fraser & Mitchell in 1876, with Struwe (1929) describing the significant Alzheimer-like neuropathological changes in the brains of people with Down’s syndrome, and almost all older adults with Down’s syndrome were found to have the neuropathological hallmarks of Alzheimer’s disease at post-mortem (Mann, 1988) which has since also been demonstrated with in-vivo amyloid PET imaging studies (Landt et al, 2011; Hartley et al, 2014).

Studies have reported rates of dementia meeting the necessary criteria that start at a few percent between 30 and 39 years of age, increasing to between 10% to 25% in the 40 to 49 year old group and to 20% and 50% in the 50 to 59 year old group and between 30% and 75% aged 60 years or older (Hewitt et al., 1985; Wisniewski et al., 1985; Lai & Williams, 1989; Holland et al., 1998). Between 50 and 60 years of age the prevalence of dementia doubles with each 5-year interval (Coppus et al., 2006). Studies have varied in their findings beyond the age of 60: some studies have found that prevalence rates continue to increase, with most individuals eventually diagnosed with dementia (Visser et al., 1997; Tyrrell et al., 2001) whilst others described a decrease in prevalence in the older age group due to the increased mortality associated with dementia (Coppus et al., 2006). Incidence increased steadily with increasing age and did not decline after age 60, from 2.5 per 100 person years in those aged <50 to 13.31 per 100 person years in those aged 60 and older (Coppus et al., 2006).

Case reports, cross-sectional and longitudinal studies have all confirmed an increase in the prevalence rates of clinically diagnosed dementia with increasing age that starts when people with Down’s syndrome are in their 30s and steadily increases in prevalence into the 60s. These rates are not as great as neuropathological studies initially suggested would be the case and, whilst the precise rates differ between studies, it is clear that not all people with Down’s syndrome present with the pattern of memory loss and functional decline characteristic of dementia in later life. Nevertheless, using cumulative incidence rates it has been calculated that nearly 70% of older adults with Down’s syndrome are likely to develop dementia symptoms should they all live to age 70 (Zigman et al., 2002).
Recent analysis by the ADSID collaboration (Strydom 2014) using data from assessment clinics across England (n = 338 cases with Down’s syndrome and dementia) established that the majority of individuals with Down’s syndrome who are diagnosed with dementia presented in their 50’s (interquartile range 50.9 – 59.3 years), with a mean age at diagnosis of approximately 55 years (SD 6.5). A quarter was diagnosed before the age of 50, and a quarter after age 60. Survival varied considerably, but did not appear to be much shorter than the general population with a mean survival time of 4 years following diagnosis.

Figure 1

Figure 1 summarises the age-related prevalence rates of dementia in people with Down’s syndrome, those with intellectual disabilities without Down’s syndrome, and in the general population. The exact rates have to be considered with caution but the trend represented in this figure is now increasingly accepted. The early presentation and course of dementia is now well established for people with Down’s syndrome. For those with intellectual disabilities but without Down’s syndrome, age-related prevalence rates are brought forward to a small degree compared to the general population but not to the same extent as for people with Down’s syndrome. This latter group would appear to have a uniquely early risk for developing dementia, almost invariably of the Alzheimer’s-type. For the former group the full range of causes of dementia is observed.
Amyloid is the protein that, in an insoluble form, forms the neural plaques characteristic of Alzheimer's disease. The gene coding for the Amyloid Precursor Protein (APP) is located on chromosome 21, and this is likely to account for the increase in risk of Alzheimer's disease in people with Down's syndrome. Children with Down's syndrome have been found at post mortem to have evidence of diffuse cerebral amyloid deposition and in adult life plaques and tangles characteristic of Alzheimer's disease are found. The assumption therefore is that this slow deposition of amyloid in the brain leads to a cascade of adverse neural events over time and ultimately to the full pathology of Alzheimer's disease. Further evidence implicating the extra copy of the APP gene in Alzheimer's disease in Down's syndrome was reported in a rare case of partial trisomy 21 without triplication of the APP gene. Neuropathological changes associated with Alzheimer's disease did not occur; neither did clinical dementia develop despite the advanced age of the individual (Prasher et al., 1998). However, whilst the brain pathology characteristic of Alzheimer's disease would seem to be near universal in later life, it is clear that not all of the older people with Down's syndrome with full trisomy 21 develop the clinical features of dementia. The reason for this remains unclear.

1. **ALZHEIMERS DISEASE**: This is a degenerative disease with no known cause. No single factor has been identified as a cause. It is likely that a combination of factors including age, genetic inheritance, environmental factors, diet and overall general health are responsible. The onset is usually slow but steadily develops over a period of years. This can be as short as 2–3 years or considerably longer. Although there are common features the course of the disease may be quite different for each individual. The onset of the disease can be middle adult life or even earlier (There is an increased incidence of 'early onset' Dementia in adults with Down’s syndrome). The onset of Alzheimer's is more likely in later life though and the course tends to be longer when the onset is later. Onset before the age of 65-70 is also more likely to be linked to a family history of a similar condition.

2. **VASCULAR DEMENTIA**: Typically there is a history of transient ischaemic attacks (mini strokes) with a brief impairment of consciousness or visual loss. Risk factors include high blood pressure, heart problems, high cholesterol and diabetes. The dementia may also follow a succession of acute cerebral- vascular accidents, or less commonly a major stroke. Onset is usually in later life and can be abrupt.
PREVENTION AND EARLY INTERVENTION

The National Dementia Strategy (2009) talks about the importance of ‘Improving public and professional awareness and understanding of dementia’ as key to assist with the prevention of dementia. This document says that the ‘current evidence base suggests that up to 50% of dementia cases may have a vascular component’ ‘What's good for your heart is good for your head. The biggest message in prevention of dementia is better heart health. Our risk of dementia may be reduced if we protect our general health, e.g. by eating a healthy diet, stopping smoking, exercising regularly, drinking less alcohol and generally protecting the brain from injury. This pathway aims to inform early intervention by setting out what needs to happen and by time limiting the initial assessment to 6 weeks. The National Dementia Strategy’s focus is ‘making the diagnosis well, breaking the diagnosis well to the person with dementia and their family and providing directly appropriate treatment, information, care and support after diagnosis’.

Prospective monitoring

Prospective monitoring entails checking for early signs of dementia by repeating the baseline assessment at regular intervals. This necessitates, as do baseline assessments, having a register of all adults with Down’s syndrome and additionally a method of recalling people for a re-assessment. Jethwa & Cassidy (2010) and O’Caoimh et al., (2013) suggest an accurate and extensive record of baseline skills levels in people with intellectual disabilities is crucial and regular comparison with baseline is key to early diagnosis.

The frequency of prospective monitoring for dementia should be matched to the rising risk with age. For example, the baseline assessment should take place at 30 years; then every two years for those in their 40s; and annually for those aged 50 and over. Assessment is non-invasive and is usually enjoyable for the participant (see Section 6).

Additional benefits of regular assessment

One argument in favour of prospective screening concerns the known health risks for all people with Down’s syndrome. Many treatable illnesses can produce symptoms of cognitive decline independent of dementia. The evidence is that all too often, such disorders remain undetected in intellectual disabilities populations (Watchman, 2014). This applies particularly to people with Down’s syndrome who are prone to certain health problems (Coppus, 2014). Many carers and indeed some GPs are not aware, for example, of the need for routine thyroid function tests for adults with Down’s syndrome. There are useful factsheets, available free of charge on the internet from the Down’s Syndrome Association that can be used to raise awareness of this issue.

A review of six months of routine prospective screens carried out in one intellectual disability service showed that of 33 prospective assessments of apparently healthy adults with Down’s syndrome, 12 (36%) revealed concerns that had not previously been identified by carers. These included dementia-like symptoms (memory and behavioural change), physical or mental health concerns that could be immediately treated, and action required by social services, including one requiring the instigation of the safeguarding protocol (Major & McBrien, 2011). It is hoped that improved access to regular heath screening (e.g. annual GP health checks) will help to minimise the prevalence of undetected physical and mental health concerns.
Prospective assessments - should we or shouldn’t we?

The evidence does not currently indicate a need for prospective screening for people with intellectual disabilities without Down’s syndrome. Screening for people with Down’s syndrome needs to be justified in terms of likely gain, the demands placed on the service, and there needs to be consideration of the issue of informed consent. Some services may decide against it for reasons of intrusion, commissioning intentions and/or resource limitations. Apparent changes in scores on cognitive assessments do not in themselves indicate dementia but do require further investigation.

Ongoing Monitoring

Regardless of whether a service offers prospective monitoring, once the person is suspected of having dementia, it is important that a programme of regular monitoring and reassessment is established. This will enable the progression of the disease to be described, suitable medical, psychosocial and environmental interventions to be put in place, and the quality outcome for the person to be measured.

PROGRESSION OF DEMENTIA

The division between early and late stage in management is arbitrary. It is classified in this way to show the change in the emphasis in the approaches

- Early Stage – with the emphasis on maximising skills and maintaining the person in the same environment. See page … for flow chart on this
- Late Stage - with emphasis on safety, comfort and dignity towards the end of life. See page … for flow chart on this

For More Information Please see The Joint RCPsych British Psychology Society Report on Dementia in People with LD and the Good Practice Standards at the end of this document

SAFEGUARDING

There are 850.000 people with dementia in the UK. Two thirds of people with dementia live in the community and are cared for by 670.000 informal unpaid carers in England. One third of people with dementia live in care homes. People with dementia can be subject to abuse in all care settings by formal care workers as well as by informal carers. People with learning disabilities and dementia are vulnerable to abuse and may have an “inability to speak out”, “low expectations” and suffer “fear and intimidation”. “Carers need a range of services which provide emotional and practical support, and empower the carer to care for a person with dementia”.

Return to Flowchart
SOCIAL INCLUSION

This is an even bigger issue for people with learning disabilities suffering from dementia. The ability to “participate in all the aspects of community – to work, learn, get about and meet people, be part of social networks and assess goods and services and to have the support to do so”. (Valuing People Now DH.gov 2009) is vital. The intervention and support part of the pathway (page 6) is all about maximising and maintaining skills which support social inclusion.

Resources

- Joint Royal College of Psychiatrists and British Psychology Society Good Practice Guidance on Dementia in people with LD
- About Dementia
- About my friend
- After the diagnosis getting the care right
- Communicating (Alzheimer’s Society)
- Coping with Dementia
- Dementia Care Pathway Easy Read - In draft
- Dementia Awareness Training Notes
- Edinburgh principles
- Factsheets on dementia
- Learning Disability Dementia Network - To Update
- Funeral Planning
- Memory clinic
- Plymouth
- Mini Mental State Examination
- National Dementia Strategy (Living well with Dementia)
- Promoting health in people with downs syndrome
- Rights, Risks and Restraints
- Sight Problems (RNIB guidance)
- Supporting People with Dementia (NICE guidance)
- Types of Dementia including Rarer causes of dementia
- End of life handbook

Patient Related Outcome Measure (PROM)

QOMID
Role of Primary Care Professional
GP Health Check to exclude and treat illness which may account for the person’s changes or symptoms

Plymouth Dementia Screening Checklist being piloted in GP Practices currently, for prospective screening.

1. Ensure a thorough physical examination is undertaken and any physical or mental health problems identified treated appropriately.

2. The following Blood tests are recommended in an individual with LD when dementia is suspected
   - Full blood counts
   - Urea and Electrolytes
   - Blood Glucose (Fasting Blood Sugar is ideal)
   - Liver and Thyroid Function Tests
   - B12 and Folate levels
   - Calcium level
   - Other blood tests as indicated by the physical examination and history

3. Psychosocial causes (bereavement, abuse etc)

4. Refer the person for a specialist assessment
   - Consider if a referral to memory clinic is appropriate (when the person has mild LD)
   - People with moderate or Severe LD or multiple disabilities could be referred to the specialist LD service
Information and Resources for Users and Carers

USERS WITH LD

- Royal College of Psychiatrists web site has accessible information on mental health conditions including dementia
- Easy Read Good Practice Standards
- ‘About my Friend’ Dementia Leaflet
- easy read about dementia care mapping
- easy read dementia pathway

CARERS OF PEOPLE WITH LD

- About Dementia
- Alzheimers Society website/fact sheets
- Coping with dementia booklet
- Easy Read dementia care pathway - In draft
- Age Concern document on coping with Funeral
- End of Life Care Handbook
- Useful Contacts
CASE EXAMPLES FOLLOWING THE STEPPED CARE MODEL

Step 1

Background
Georgina is aged 54 and lives in a supported house with home help and close family contact. She has always held a job in a local café. She is able to self care fully. Has good contact with GP, and a Health Action Plan includes regular dentist, optician, podiatry appointments and management of eczema.

Trigger for Dementia Pathway
Georgina seems to be having some problems keeping up with taking orders for food in the café. She has also forgotten to bring her uniform with her on a number of occasions.

Assessment
Georgina visits her GP with her brother and tests to rule out any physical health problems are carried out. She is complaining of feeling dizzy sometimes and is able to tell the doctor about not being able to see as well as she could.

Georgina’s GP feels that she may be suffering from an underlying heart condition, her blood pressure and cholesterol levels are high. This might indicate that she is in the early stages of vascular dementia.

Intervention/Treatment
Georgina’s GP starts her on medication to treat her heart condition and advises a healthier lifestyle. A referral is made to the community dietician and Georgina and her family are given the details of a local support group run by the Community Mental Health Team.

Follow up
Georgina will see her GP regular to review her health. Should vascular dementia be confirmed she may need support in the future from the Mental Health Service.


Step 2

**Background**
Clara is aged 44 has Downs Syndrome and lives at home with her Mother. She has an active lifestyle, which includes attendance at Further Education Classes and she is very much part of the local church community. Clara visits her GP to monitor her congenital heart condition and she has regular appointments with Hearing Services to evaluate the use of a hearing aid.

**Trigger for Dementia Pathway**
The vicar at the church has visited home to express concerns about Clara being less involved in the meetings and that on a number of occasions she has forgotten where the rooms are in the Community Centre. Clara’s Mother has noticed that she looks sad at times and had some problems remembering her friend’s names.

**Assessment**
Clara and her Mum visit her GP. A physical examination and bloods taken to check for reasons for her symptoms. The GP wanted to carry out a memory assessment but found this difficult. Plymouth Dementia Screening Checklist completed which identified the need to make a referral for some assistance to assess Clara’s memory and thinking ability to the Learning Disability Community Team
The LD Team are able to offer a 6 week assessment package, with the Community Nurse, Psychiatrist and Occupational Therapist getting involved. The GP also arranges for a brain scan for further information.

**Follow up**
The further assessment suggest that Clara may be suffering from Alzheimer’s disease and because of her age it is decided that a referral to the Mental Health Team is appropriate. Cara is able to communicate quite well with others and the GP, Mum and LD Team felt that she would be able to access generic Mental Health Services for her treatment.
Step 3

David is 58 years old and lives in a residential care home for people with learning disabilities. David was given a diagnosis of Dementia 8 years ago and as a result of his symptoms becoming worse is having difficulty attending his day service. David suffers from Epilepsy and is registered partially sighted.

David was originally referred to the LD Team by staff at the residential home who had been concerned about David no longer being able to do some things that he used to be able to. At that time the staff had looked at a Dementia baseline screening form that had been completed when David was 40 and they had been able to see some changes were happening for him. His GP had been involved in ruling out other physical health causes and contact had been made to the LD Team. The LD Team were able to use the QOMID assessment to look at the quality outcomes for David. The LD Team have been able to offer advice to David and some training for the staff over the last 8 years, but mostly he has been able to be supported by the residential home staff.

Intervention and support to maximise and maintain skills and health
David is under threat of being excluded from his day service as a result of him refusing to get on the bus to come home from the day unit. The LD Team are part of a regular review for David and at this meeting information from the Psychiatrist, Community Nurse and Occupational Therapist is shared. The Psychiatrist is concerned that David is having more seizures and that he is not sleeping well. His anticonvulsant medication will be reviewed and sleep hygiene is discussed.

The Day Unit have been trying to help David with problems about him wandering in the unit, not wanting to get on the bus and have noticed that he is less able to eat his meal without much support.

It is recommended that a referral be made for an eating/drinking assessment. Also the Community Nurse and Occupational Therapist were able to carry out a dementia care map at the day unit for extra information about David’s quality of life when he is there.

The Social Worker is looking at what other day services might be available for David, should his current provision become inappropriate.

Follow up
There are some issues regarding David’s peers in the residential home. To consider sessions on Dementia for them so they understand more about David’s needs.

This would be a good time to begin to consider what David and his carers wishes are for the future. This could be discussion based or if there are any signs that David is reaching towards the end of his life the ‘Promote Safely, Comfort and Quality of Life’ part of the pathway along with use of the End of Life Handbook might be appropriate.
Step 4

**Background**
Peter is 58 years old and lives on his own in a flat with support staff visiting 3 times a week. He has been having difficulties finding that he is missing belongings and has got lost whilst going about his home and journeys around his community have become problematic as he has had to be brought home by the police having ended up taking the wrong bus.

**Intervention and Support**
Peter has been admitted to the Treatment Unit for assessment. This has proved necessary as he has also not been eating/drinking well and has become very angry with his Support Workers when they try to assist him.

Mental Health/Dementia Assessment and Observations/Dementia Care Mapping.
Assessment suggests Alzheimer’s disease. Peter is started on anti-dementia medication.

**Follow Up**
Plans for discharge include re-assessment of supported living to include daily contact, dementia care mapping to give opportunities to improve Peters quality of life and attendance at daytime activities/day unit for People with Dementia . Regular monitoring from Community Teams perhaps using the QOIMID to measure the quality of outcomes.

Return to Flowchart
WHAT ASSESSMENT MAYBE NEEDED?

Cognitive functioning assessment
- Information from carers
- Direct assessment

Daily living skills assessment
Capacity assessment
Sensory screening
Mental health assessment
Communication assessment
Risk assessment
Environmental assessment
Activity assessment
Carer’s assessment
Carer’s knowledge & expectations of dementia
Nutritional screening
Pressure area assessment

INDIVIDUAL WITH LEARNING DISABILITY
Use their Person Centred Plan, Health Action Plan, Communication Passport

CARERS
Provision of direct care
Sharing information

COMMUNITY NURSE
Health screening
Liaison with primary care
Dementia scale (DLD)
Risk assessment

PSYCHIATRIST
Cognitive assessment
Mental health assessment
Diagnosis of Dementia

OCCUPATIONAL THERAPIST
Assessment of Functional Skills

SOCIAL WORKER
Community Care Assessment
Carer’s Assessment

CLINICAL PSYCHOLOGIST
Assessment of Complex Issues

PHYSIOTHERAPIST
Mobility Assessment
Mobility Aids / Equipment

SPEECH & LANGUAGE THERAPIST
Communication Assessment
Eating & Drinking Pathway

CONSIDER SCREENING ONTO CARE PROGRAMME APPROACH
CONSIDER DEMENTIA CARE MAPPING

Return to Flowchart
INTERVENTION AND SUPPORT
To Maximise and Maintain Skills and Health as Condition Progresses

INDIVIDUAL WITH LEARNING DISABILITY
Use their Person Centred Plan, Health Action Plan, Communication Passport

CHANGE IN SKILLS
- Compensatory Techniques
- Adaptation
- Additional Support
- Opportunities for New Skills
- Support for Social Inclusion

MONITORING & INTERVENTION
- Physical Health
- Seizures
- Mental Health
- Behaviour
- Eating & Drinking
- Communication
- Risk Management
- Outcome measurement,

PLANNING FOR FUTURE
- Person’s Wishes
  (may include capacity assessment)
- Carer’s Wishes
- Support Decisions
- Advocacy

Speech & Language Therapist
Monitoring of Communication
Eating & Drinking Pathway

Social Worker
- Ongoing Review of Community Care Monitoring
  - Liaison with other Professionals.

GP
Monitor and Treat Physical Health

Dietician
Nutritional Monitoring and Weight Loss Management

Advocate
Support the Individual and Their Carers with Decision Making

Clinical Psychology
Carer and Peer Support

Physiotherapy
Mobility Monitoring

Neurology
Management of Seizures

District Nurse
Continence Care
Pressure Area Care

Younger Persons Dementia Service/MHSOP
Consider Screening Onto Care Programme Approach

Consider Dementia Care Mapping

MDT Review at Least Annually More Often If Needs of Person Are Changing or Unmet

Outreach
Behavioural Management

Occupational Therapist
Sensory Monitoring
Skills Adaptations & New Skills Monitoring Motor Processing Dementia Care Mapping

Community Nurse
Monitor Physical & Mental Health, Raise Awareness & Support of Carers. Dementia Care Mapping

Carers
Direct Support and Work with Others

Psychiatrist
Anti Dementia Drug Treatment Manage Seizures, Behaviour, Monitor Mental Health

Return to Flowchart
INTERVENTION AND SUPPORT
To Promote Safety, Comfort, Quality of Life and Dignity Towards the End of Life

CARERS
DIRECT SUPPORT AND WORK WITH OTHERS

PSYCHIATRIST
REVIEW OF MEDICATIONS
MONITOR & MANAGE SEIZURES
SUPPORT & INFORMATION FOR CARERS

COMMUNITY NURSE
MONITOR MENTAL & PHYSICAL HEALTH
CO-ORDINATION OF CARE
LIAISON WITH OTHER PROFESSIONALS
SUPPORT FOR CARERS & PEERS

CLINICAL PSYCHOLOGY
CARER, FAMILY & PEER SUPPORT
BEHAVIOUR MANAGEMENT
PREPARING FOR LOSS

SPEECH & LANGUAGE THERAPIST
ADVICE ON IMPROVING COMMUNICATION
ADVICE ON EATING AND DRINKING ISSUES
(EATING & DRINKING PATHWAY)

PHYSIOTHERAPIST
REVIEW MOBILITY MONITORING

PALLIATIVE CARE
CARER SUPPORT
MANAGEMENT OF PAIN & OTHER DISTRESSING SYMPTOMS
Care in the last days of life/ SPICT-PALLIATIVE CARE INDICATORS TOOL
DECIDING Right personalised care plan.

INDIVIDUAL WITH LEARNING DISABILITY
Use their Person Centred Plan, Health Action Plan,

SUPPORT / MANAGEMENT WITH:
PAIN CONTROL
BREATHING DIFFICULTIES
RESPIRATORY SECRETIONS
NUTRITION
SAFE EATING & DRINKING
CONTINENCE
MOBILITY/FALLS
CONTROL OF SEIZURES
COMMUNICATION
PRESSURE AREA CARE
MENTAL HEALTH BEHAVIOUR
ENVIRONMENTAL ADAPTATIONS
DAILY LIVING ACTIVITIES
RISK MANAGEMENT

ANTICIPATION / PREPARATION FOR END OF LIFE- SEE HANDBOOK
STOP UNNECESSARY TREATMENT
DECISION MAKING (including capacity assessment)
SUPPORT FOR CARERS
SUPPORT FOR PEERS
BEREAVEMENT SUPPORT
SPIRITUAL

CONSIDER SCREENING ONTO CARE PROGRAMME APPROACH

MDT REVIEW
6 MONTHLY OR MORE OFTEN IF NEEDS OF THE PERSON ARE CHANGING OR UNMET

CONSIDER DEMENTIA CARE MAPPING

OCCUPATIONAL THERAPY
SUPPORT FOR CARERS & PEERS
REVIEWING EQUIPMENT
SENSORY/RELAXATION WORK
REVISING OT TREATMENT PLANS
MONITORING PERSON'S FUNCTIONING

GP
MONITOR AND TREAT PHYSICAL HEALTH
GOLD STANDARD FRAMEWORK

SOCIAL WORKER
REVIEW OF PLACEMENT & SUPPORT

DISTRICT NURSE
CONTINENCE CARE

DIETICIAN
SUPPORT AND ADVICE WITH NUTRITION
WEIGHT LOSS MANAGEMENT

ADVOCATE
SUPPORT WITH BEST INTEREST DECISIONS
CARER SUPPORT

OLD AGE PSYCHIATRY
USE OF ASSESSMENT BEDS,
DAY HOSPITAL

RETURN TO FLOWCHART
### Professional Roles and Responsibilities

**Stepped Care Model**

What Community LD Teams/LPT offer at each stage:

<table>
<thead>
<tr>
<th>Tier 1: Stable, no-to-low risk low or moderate levels of needs</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Person experiencing mood changes, memory problems, loss of skills, reduced communication or behavioural issues.</strong></td>
</tr>
<tr>
<td>- Advise assessment via GP to look at physical causes for changes and symptoms.</td>
</tr>
<tr>
<td>- Treatment offered by GP, Health action plan updated or started.</td>
</tr>
<tr>
<td>- Community Team has made GP aware of the Pathway.</td>
</tr>
<tr>
<td>- Community Team has assisted early diagnosis by raising awareness of the issues of people with Learning disabilities and Dementia including the usefulness of early baselines of skills and abilities. Recommended used of Plymouth Dementia Screening Checklist.</td>
</tr>
<tr>
<td>- Community Teams signpost the Mental Health Service Younger Persons and Older Persons Teams and their role with people with Learning Disabilities and Dementia.</td>
</tr>
<tr>
<td>- Provide advice as needed.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Tier 2: Temporary / longer term small health risk, low or moderate levels of need</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Assessment</strong></td>
</tr>
<tr>
<td>- GP has ruled out other causes for symptoms and asks for a dementia assessment from the Learning Disability Community Team.</td>
</tr>
<tr>
<td>- Psychiatrist, Nurse and Occupational Therapist offer an initial 6 week assessment.</td>
</tr>
</tbody>
</table>

[Return to Flowchart]
- The assessment is shared at a multidisciplinary meeting and a lead professional identified.
- CPA considered.
- Client and Carers offered information about dementia and a possible diagnosis.
- Sign posting to Mental Health Service may be appropriate.
- Community Care and Carers assessment is carried out.
- Risk assessment and problem solving.

**Psychiatry Education and Support**

- Advice to all members of the MDT team about potential causes of behaviour including ruling out physical causes and consideration of mental illness. Involvement would be largely be liaison and advice with/to MDT rather than direct patient review.
- Training mainstream services (adult mental health services, other community and hospital health services) about Learning Disability, to build capacity within these services.
- Educating primary care, secondary health care services, social care services, other statutory services and voluntary care services about the role of specialist LD services, with a view to improve the access and quality of referrals in to the LD service.

**Assessment**

- Assessment of suspected dementia and co-morbidity including physical health issues, mental illness and other aetiological factors. Clinical investigations e.g. imaging and blood tests to rule out other causes of symptoms.

**Intervention**

- Giving information to carers / users regarding the diagnosis and prognosis.
Psychology
Assessment
• Cognitive assessment (reading notes, interpretation and scoring as well as administration of specific assessments)
  Formulation
• Guidelines for Carers / Staff (preparation / teaching)
• Transitions consultation
• MCA
  Assessment / Consultation
• Best Interests

Community Nursing
Education and support:
• Training and Support – families, carers, peers
Assessment:
• DLD assessment tool (open case baseline and reviews)
• Care Mapping
Intervention:
• Desensitisation
• Monitoring meds / compliance
• Anxiety Management – guidance to support
• Behaviour Management
• Memory Aids
• Memory book / life stories
• End of Life liaison and support  GP and MDT

Speech and Language Therapy
Education and support:
• A range of education, supervision and mentoring activities to enable mainstream services to address the communication and dysphagia needs of people with learning disability and Dementia. The aim is to enable them to make reasonable adjustments and meet the 5 Good Communication standards and safe eating and drinking guidelines.
• Contributing to general dementia awareness training regarding Role of SALT with people diagnosed with dementia.
• Signposting and providing general communication information for people with Dementia.

Assessment:
• Provide a brief assessment of the specific communication environment in relation to the 5 Good Communication Standards.
• Provide tools to support services to develop a basic communication passport for an individual.
• Skilling staff to recognise communication and eating and drinking issues and make appropriate referrals.

Intervention:
• Onward referral and signposting.
• Provide findings of an individual’s communication or eating and drinking assessment to support mainstream services to address their communication or eating and drinking needs.
  Provide mentoring and support for staff working in main stream services to enable them to make reasonable adjustments in relation to communication and Dementia.
• Provide general advice, information and resources to support safe eating and drinking.
• Provide information and guidelines on best practice. Share resources and tools to support good communication.
• Joint working with staff from other services.
• Support the development and use of communication passports to inform other staff of the best ways of communicating with individuals.
Occupational Therapy
Education and Support: General information /training- Basic dementia awareness training and Dementia Care mapping.

Assessment: Dementia Care mapping.

Intervention: Recommendations to meet low/moderate level of need. Refer on to generic services and provide support re LD. Make recommendations for further OT involvement to generic services/memory clinics and provide input re: learning disability if required.
Dementia review specific to earlier OT interventions identified.

Tier 3:
Temporary / longer term moderate health risk, substantial or critical level of need
- Maximising and Maintaining Health and Skills.
  - Managing emerging physical health complications (example – falls, Tissue viability, Eating and Drinking)
  - Managing Epilepsy
- Lead Professional facilitates regular reviews of need and care (Memory Clinic).
- Monitor changes in skills and advise on compensatory techniques, adaptation, provide extra support, opportunities for new skills and support for inclusion.
- Monitoring and intervention of health needs.
- Consider value of CPA.
- Consider value of dementia care mapping.
- Consider using QOMID.
- Planning for the future.

All professionals continue roles as above
Tier 4:
Temporary / longer term high health risk, substantial or critical level of need

- Multidisciplinary Review.
- Crisis intervention (CPA).
- Possible admission to Assessment and Treatment Unit.
- Possible admission to Acute Hospital.
- Consider referral to Mental Health Service.
- Review Mental Health.
- Review Physical Health.
- Review Communication.
- Consider Dementia Care Mapping.
- Behavioural Management.
- Assist in plans for the future.

**Psychiatry**
**Education and Support**

- Advice to all members of the MDT team about potential causes of behaviour including ruling out physical causes and consideration of mental illness. Involvement would be largely be liaison and advice with/to MDT rather than direct patient review.
- Training mainstream services (adult mental health services, other community and hospital health services) about Learning Disability, to build capacity within these services.
- Educating primary care, secondary health care services, social care services, other statutory services and voluntary care services about the role of specialist LD services, with a view to improve the access and quality of referrals in to the LD service.

**Assessment**

- A full history of the nature, onset and progress of the changes noticed.
- A detailed mental health assessment with emphasis on the assessment of cognitive changes.
- Regular reviews by inpatient consultant in MDT ward rounds.
Evaluation of the findings from the investigations (blood tests, scan etc) already carried out by the GP / other specialist (e.g. Neurologist); DMR and Vineland Scale ratings; and reports from other professionals such as Occupational Therapists to diagnose dementia. (This process is vital as the diagnosis of dementia requires the exclusion of a number of physical as well as mental health problems.)

**Intervention**

- Giving information to carers / users regarding the diagnosis and prognosis.
- Management of any mental health problems.
- Treat seizures.
- Decisions regarding drug treatment of dementia.
- Medication management (especially in the case of Lewy Body dementia)
- Agreed management plan within MDT environment.
- Regular involvement as inpatient and follow-up by outpatient consultant team.

**Speech and Language Therapy**

**Education and support:**

- Specific training to support learning disability environments and community teams working with people with dementia to meet the changing communication needs of people with dementia. This may include specific training in signing, objects of reference, communication passports etc.
- Individualised communication training for staff supporting individuals referred to the service including how to communicate in the best way with the person and how to help the person to understand their diagnosis of dementia when appropriate.
- Contribution to training for other people with LD living with a person with dementia to help them to understand the changes in behaviour of the individual.
Assessment:

- Formal and/or informal assessment of communication involving both the individual and key communication partners. The aim is to identify areas of communication difficulty experienced by the individual and communication partners including considering whether current behaviour has a communicative function.
- Assessment of communication as a diagnostic indicator of dementia.
- Contribution of information on premorbid communication abilities to contribute to diagnostic process.
- Providing supervision to specialist LD services to ensure that communication impairment is taken into account during administration and interpretation of cognitive assessments.
- Contributing to capacity assessments when appropriate.
- Completion of formulation providing a framework for describing communication issues and the development of an action plan, underpinned by clinical reasoning, to overcome these difficulties and plan for anticipated changes in communication ability as dementia progresses.

Intervention:

- Direct work with an individual to enhance their communication skills including reinforcing simpler methods of communication eg Objects of Reference to be used consistently to prepare for the future deterioration of higher level language skills such as verbal communication.
- Direct work with the individual together with other MDT members to support them to understand their dementia diagnosis and the health changes they are experiencing and to express their views and feelings.
- To provide supervision to other LD professionals to ensure their interventions are at appropriate communication level e.g. reminiscence work, life story work etc.
• Work with key communication partners to develop their communication skills and support them to implement SALT recommendations and consistently follow the Communication Passport. To work with key partners to ensure strategies are in place to meet the changing communication needs of the person with dementia.

• Work with key partners to promote maintenance of ongoing interpersonal relationship between individual and carers including introduction of specific communication tools such as Intensive Interaction to improve positive communication as communication abilities decrease.

• Working with key partners together with MDT to improve person’s ability to maintain their independent functioning in their environment such as environmental signposting (photo cues on doors etc).

• Work with key communication partners to ensure that individual is enabled to be involved as possible in making choices and decisions about their life.

• Supporting improvements in the communication environment by enabling services to achieve the 5 Good Communication standards for an individual.

• To work together with the individual and their carers to enable the person to be fully involved in decisions about their end of life care and preparing for a good death.

**Physiotherapy**

**Education and support:**

• Advise carers on safe practices when using equipment.

• Recommendations for safe manual handling and around mobility needs of clients.

• Delegation of task for mobility/positioning programmes.
**Assessment:**
- Detailed physiotherapy assessment of posture and functional ability.
- Mobility/falls assessment to include Tinetti, Berg Balance, Elderly Mobility scale.
- Baseline respiratory assessment and signpost to specialist service if required.
- Physical activity assessment /falls prevention work.
- Postural Management, specialist sleep system, and seating systems. Waterlow and Disdat if indicated.
- Consider assessment of posture for safe eating and drinking in liaison with SALT.
- Hospital discharge: liaise with discharge team.

**Intervention:**
- Core strengthening and coordination work; falls prevention work.
- Provision of mobility aids and mobility and manual handling advice/recommendations. May include delegation of treatment programmes.
- Provision of specialist seating (wheelchairs and easy chairs).
- Referral to district nurses re TV needs and to orthotics for footwear.
- Attend meetings regarding CHC, best practise, Palliative care.
- End of life: input in to end of life care.
- Positioning for management of secretions.
- Positioning for tissue viability needs/ comfort/ protection of body shape.
- High falls risk.
- Unsafe hospital discharges.
- Safeguarding in relation to the above.
Review

- Who to include?
  - All professionals involved, carers as well as the individual with LD

- Reviews should be at least every 6 months, but more often if the needs of the person are changing or unmet. Consider using QOMID to look at outcomes.

- Update of all assessments / Interventions - Share information

- Medication review
  - All medications including antidementia Medication should be reviewed with a view to discontinue medication if no longer required

- Dementia care mapping considered if more information needed about quality of life and ideas to improve this.

- Update Core Info where there is a significant change of needs

- Plan treatment and support for client/carers
Considering Discharge for Person with LD & Dementia?

- Follow the guidance on Discharge

- Does the person live in a supportive environment? Weigh up the difference of someone living alone or with an older carer or do they live in a staffed residential home? If living in a specialist LD/Dementia home what involvement is really necessary?

  Is the person near to or in end stage dementia?

- Are they and their carer's in contact with Palliative Care Services (see End of Life Guidance & Handbook). make sure up to date one is there any further facilitation required to enable access to Palliative Care Services.

- Consider relationship with person and carer, could you lessen the visits if there is contact needed from the LD professional?
End of Life Care

- Advance Decisions to Refuse Treatment
- Artificial Nutrition and Hydration
- Disability Distress Assessment Tool (DIS DAT)
- End of Life Care / Do Not Attempt Resuscitation (DNAR) – East Midlands Ambulance Service
- End of Life Guidance
- End of Life Handbook
- End of Life Care Strategy - DoH
- Preferred Priorities for Care (Easy read)
- Implantable cardio-verter defibrillators in patients who are reaching the end of life
- Symptom Management in the Last Days of Life
- Deciding right personalised care plan
- SPICT , Palliative care indicators tool
- What is Palliative Care?
Variance

Variance analysis is a critical part of using this care pathway. Variance can identify deviations from the expected pathway and if so, for what reasons. This can be used to amend the care pathway itself or the processes followed. Variance will be monitored through RIO systems via the assessment and treatment waiting times and can also be recorded on the CORE information when the care pathway is identified.

LD Care Pathway

<table>
<thead>
<tr>
<th>Date assigned to Care Pathway</th>
<th>Status</th>
<th>Care Pathway</th>
<th>Date Closed</th>
<th>Comments</th>
<th>Variance Record</th>
</tr>
</thead>
<tbody>
<tr>
<td>✔ 31 July 2014</td>
<td>✔ Current</td>
<td>✔ Dementia</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
</tr>
</tbody>
</table>
Appendices

Professional and Carer Roles and Responsibilities
- Carer
- Psychiatrist
- Community Learning Disability Nurse
- Occupational Therapist
- Physiotherapist
- Social Worker
- Speech and Language Therapist
- Clinical Psychologist
- Outreach Nurse

Useful Contacts
- Glossary of Terms
- Reference List

- ‘About My Friend’ Dementia Leaflet
- Dementia Questionnaire for people with Learning Disabilities (DLD)
- Memory Clinic
- Quality Outcome Measure for Individual with Dementia (QOMID)
- Good Practice Standards
- End of Life Care Handbook
- Dementia Care Pathway (Easy Read Version)

In Draft

Return to Flowchart
Carers both family carers and paid carers support people with LD who develop dementia.

They need to seek professional advice on noticing the Trigger symptoms for dementia in an individual with dementia. Use of the Plymouth Dementia Screening Checklist

Carers where possible need to note the following and share with GP in the first instance:
1. The point at which they noticed any change
2. The nature of change
3. Any reasons for the change that they are aware of
4. What was the individual like before having these changes
5. Any significant health problems that the individual has at present or had in the past
**Psychiatrist**

The Psychiatrist is responsible for making the decision with regards to diagnosis; they will be reliant on the information and assessments of other professionals to assist in this process. The Psychiatrist will then decide on the most appropriate treatment for treating the mental health symptoms of the condition.

**Role in the Assessment of dementia**
- A full history of the nature, onset and progress of the changes noticed.
- A detailed mental health assessment with emphasis on the assessment of cognitive changes.
- Assessment and management of associated mental health conditions or neurological conditions like epilepsy.
- Ensure Physical health problems are identified and treated by GP.
- **Diagnosis of Dementia**: Evaluation of the findings from the investigations (blood tests, scan etc) already carried out by the GP / other specialist (e.g. Neurologist); DLD and reports from other professionals such as Occupational Therapists to diagnose dementia. (This process is vital as the diagnosis of dementia requires the exclusion of a number of physical as well as mental health problems.)

**Management**
- Giving information to carers / users regarding the diagnosis and prognosis.
- Management of any mental health problems.
- Treat seizures.
- Drug treatment of Dementia.
- Advice and support to the MDT in the overall management.

<table>
<thead>
<tr>
<th>Tier 2</th>
<th><strong>Education and Support</strong></th>
</tr>
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<tbody>
<tr>
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</tr>
<tr>
<td></td>
<td>Training mainstream services (adult mental health services, other community and hospital health services) about Learning Disability, to build capacity within these services.</td>
</tr>
</tbody>
</table>
**Tier 3 Education and Support**

- Advice to all members of the MDT team about potential causes of behaviour including ruling out physical causes and consideration of mental illness. Involvement would be largely be liaison and advice with/to MDT rather than direct patient review.
- Training mainstream services (adult mental health services, other community and hospital health services) about Learning Disability, to build capacity within these services.
- Educating primary care, secondary health care services, social care services, other statutory services and voluntary care services about the role of specialist LD services, with a view to improve the access and quality of referrals into the LD service.

**Assessment**

- Review of patient regularly – co-morbid mental health issues such as depression, seizure frequency and ongoing monitoring of cognitive decline (review of DLD scores and clinical assessment).

**Intervention**

- Anti-dementia drug treatment (prescription), managing seizures, behaviour and monitoring mental health.
- Giving information to carers / users regarding the diagnosis and prognosis.

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**Assessment**

- Assessment of suspected dementia and co-morbidity including physical health issues, mental illness and other aetiological factors. Clinical investigations e.g. imaging and blood tests to rule out other causes of symptoms.

**Intervention**

- Giving information to carers / users regarding the diagnosis and prognosis.
**Education and Support**

- Advice to all members of the MDT team about potential causes of behaviour including ruling out physical causes and consideration of mental illness. Involvement would be largely be liaison and advice with/to MDT rather than direct patient review.
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**Assessment**

- A full history of the nature, onset and progress of the changes noticed.
- A detailed mental health assessment with emphasis on the assessment of cognitive changes.
- Regular reviews by inpatient consultant in MDT ward rounds.
- Evaluation of the findings from the investigations (blood tests, scan etc) already carried out by the GP / other specialist (e.g. Neurologist); DMR and Vineland Scale ratings; and reports from other professionals such as Occupational Therapists to diagnose dementia. (This process is vital as the diagnosis of dementia requires the exclusion of a number of physical as well as mental health problems.)

**Intervention**

- Giving information to carers / users regarding the diagnosis and prognosis.
- Management of any mental health problems.
- Treat seizures.
- Decisions regarding drug treatment of dementia.
- Medication management (especially in the case of Lewy Body dementia).
- Agreed management plan within MDT environment.
- Regular involvement as inpatient and follow-up by outpatient consultant team.
Community Learning Disability Nurse

The key role of the community nurse is to maximise the health and wellbeing of an individual. Looking at the individual from a holistic perspective the nurse will promote good health with proactive strategies, minimise health risks through assessment and care planning.

The community nurse will use a variety of assessment tools and give advice on care delivery including:

- **OK Health Assessment, Health Action Plans**
- Facilitate GP appointment for further investigation of physical health, e.g. Thyroid function
- **DLD assessment to inform initial diagnosis and to monitor progression of dementia**
- Medication monitoring for benefits and side effects, and liaison with Psychiatrist.
- Referral to other members of the team as appropriate (SALT, OT, Physio, Dietician) to assist in diagnosis and ongoing care
- Arrange multi-disciplinary team meeting to evaluate the evidence in order for the psychiatrist to make a decision about diagnosis
- Usually acts as co-ordinator for the CPA process or care in general (although it may be more appropriate for another professional to take on this role if they are more involved with the individual)
- Ongoing health monitoring – evaluation of the OK Health Check/Health Action Plans
- Provide training for carers with regards to Epilepsy awareness, Rectal Diazepam, Buccal Midazolam
- Provide training and information about dementia to patient, carers, family and peers
- Provide support (basic counselling) to patient, carers, family and peers
- Ongoing liaison with the other professionals involved with the individual’s care
- Ensure that links with primary care agencies are well established, as the individual will need increasing support from the GP and District Nurse
- Be involved with planning for providing the care to meet the future needs of the patient

<table>
<thead>
<tr>
<th>Tier 2</th>
<th><strong>Education and support:</strong></th>
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<tbody>
<tr>
<td></td>
<td>Dementia Awareness Training and Support – families, carers, peers.</td>
</tr>
<tr>
<td></td>
<td>Training around recording observations, evidence of changes etc.</td>
</tr>
<tr>
<td></td>
<td>Awareness training to consider physical health needs.</td>
</tr>
</tbody>
</table>

<p>| Assessment: |
| DLD assessment tool (open case baseline and reviews). |</p>
<table>
<thead>
<tr>
<th>Tier 3</th>
<th><strong>Intervention:</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>• Signposting to relevant Services, for example GP, LD Services, Social Service.</td>
</tr>
<tr>
<td></td>
<td>• DST screening tool to be considered if appropriate.</td>
</tr>
<tr>
<td></td>
<td>• Consider Legal requirements ie DoLs.</td>
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<tr>
<td></td>
<td>• Consider reasonable adjustments in conjunction with MDT members.</td>
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<table>
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<tr>
<th>Tier 3</th>
<th><strong>Education and support:</strong></th>
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<tbody>
<tr>
<td></td>
<td>• Training and Support – families, carers, peers</td>
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</thead>
<tbody>
<tr>
<td>• DLD assessment tool (open case baseline and reviews)</td>
</tr>
<tr>
<td>• Care Mapping by trained Nurses</td>
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</table>

<table>
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<tr>
<th><strong>Intervention:</strong></th>
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</thead>
<tbody>
<tr>
<td>• Desensitisation</td>
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<td>• End of Life liaison and support GP and MDT</td>
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</tbody>
</table>
Occupational Therapist

The primary goal of Occupational Therapy is to enable people to participate in the activities of everyday life. Occupational Therapists engage with clients using activities that are meaningful and purposeful to them to assess and treat the physical, psychological and social needs of the individual and their environment to enable them to reach or retain their optimum potential.

Although dementia is a progressive condition, the person will be able to continue with many activities of daily living for some time. It is important that the person’s skills are maintained and supported for as long as possible, and that they are given the opportunity to fulfil their potential. However, the experience of failure can be frustrating and upsetting so it is important to find a balance between encouraging independence and ensuring that the person’s self esteem and dignity are not undermined.

OTs use a range of different assessment methods, looking at functional and cognitive skills, for activities of daily living, activity levels sensory needs and well-being.

Depending on problem areas identified, the following strategies may be useful for supporting people with dementia.

- Joint Occupational Therapy and Physiotherapy assessment, to assess and treat an individual’s motor function.
- To advise and recommend equipment to compensate for loss of skills whilst maintaining existing skills.
- To advise and make recommendations on environmental adaptations required to meet individual needs.
- Occupational Therapists can assess individual’s personal and domestic activities of daily living skills and can provide advice to enable an individual to function to the best of their ability, for example advice on cognitive skills, such as attention level, memory, sequencing and decision making, or orientation skills such as planning and organising daily routine.
- Occupational Therapists can be involved if the person develops challenging behaviours, for example relaxation techniques, anxiety management, coping strategies, positive thinking.
- Working with the person and carers on developing activities, which maintain and develop skills and abilities, provide enjoyment and stimulation, support people to engage, and promote positive behaviour and feelings of self-esteem.
- Occupational Therapists can be involved in carrying out dementia care mapping and providing advice on outcomes of observations.
| Tier 2 | **Education and Support:** General information /training- Basic dementia awareness training and Dementia Care mapping.  
**Assessment:** Dementia Care mapping.  
**Intervention:** Recommendations to meet low/moderate level of need. Refer on to generic services and provide support re LD. Make recommendations for further OT involvement to generic services/memory clinics and provide input re: learning disability if required. Dementia review specific to earlier OT interventions identified. |
| Tier 3 | **Assessment:** OT’s use a range of different assessment methods looking at functional and cognitive skills, for activities of daily living, activity levels, sensory needs and well being, in order to understand the progressive nature of dementia and make appropriate advice/recommendations.  
Assessment used:  
- Pool Activity Level  
- Dementia care Mapping  
- AMPS  
- MOHOST  
- OT in House ADL assessments  
**Intervention:**  
- To provide guidelines to support completion of daily living activities using graded approach.  
- Adapting equipment to compensate for loss of skills whilst maintaining existing skills.  
- Giving advice regarding maintaining the individual’s cognitive skills in areas such as attention level and span, comprehension, memory, sequencing, and decision making.  
- Working on the individual’s ability to orientate themselves, e.g. where they are, who they’re with, day and time etc. |
- To provide guidance to reduce/manages challenging behaviours.
- To provide guidelines on meaningful activities which enable individuals maintain and promoting skills and abilities, thus promoting positive behaviour and feelings of self-esteem.
- To provide guidelines regards environmental adjustments.
- To provide guidelines required regards potential sensory needs/sensory diet.

**Tier 4**

**Assessment:** All of tier 3 but there would be an expectation that in tier 4 the person would have more complex needs and we would be working as part of an MDT approach. The allocation of this case is dependent of skill level and experience, case complexity.

**Intervention:** As tier 3 as above. Joint OT and Physiotherapy assessment re physical needs.
**Physiotherapist**

Physiotherapists are responsible for promoting mobility to the optimum level for as long as possible and then for assessing and providing additional support and mobility aids when necessary.

- Promoting physical and mental well being through physical exercise
- Promoting mobility through physical activities and exercise
- Promoting the psychological benefits of physical exercise by reducing anxiety and depression
- Reducing the risk of falls and bone fracture through promoting muscle strength, balance and joint range.
- Postural management in order to optimise present abilities and prevent the development/progression of secondary complications such as pain, fatigue, muscle shortening, joint deformity, respiratory complications and pressure ulcers.
- Assessment of postural management equipment needs such as standing aids, specialist seating provision and sleep systems. Liaising with company representatives and the Disabled Services Centre.
- Postural management in order to facilitate eating and drinking abilities
- Postural management in order to improve respiratory function
- Treating and managing acute injuries that present
- Gait analysis
- Orthotic / surgical appliances assessment / recommendations
- To promote physical activity in order to reduce the incidence of obesity, improve cardiac, circulatory, pulmonary, bowel and bladder function.
- Regular monitoring and updating of interventions
- Assist and facilitate support workers in promoting physical exercise for their clients
- Advice regarding manual handling as physical health needs change.

<table>
<thead>
<tr>
<th>Tier 2</th>
<th>The Physiotherapy role in this pathway is in relation to other pathways and different branches of the Complex Physical Pathway in terms of mobility assessment; falls prevention/advice, Postural management, equipment, SEAD.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><strong>Education and support:</strong> Signpost to Generic services GP, Orthotics, Specialist mobility centre for wheelchairs.</td>
</tr>
</tbody>
</table>
| Tier 3 | **Education and support:**  
|--------|-------------------------------|
|        | • Advise carers on safe practices when using equipment.  
|        | • Recommendations for safe manual handling and around mobility needs of clients.  
|        | • Delegation of task for mobility/positioning programmes.  

| Assessment:  
|-------------|-------------------------------------------------|
|             | • Detailed physiotherapy assessment of posture and functional ability.  
|             | • Mobility/falls assessment to include Tinetti, Berg Balance, Elderly Mobility scale.  
|             | • Baseline respiratory assessment and signpost to specialist service if required.  
|             | • Physical activity assessment /falls prevention work.  
|             | • Postural Management, specialist sleep system, and seating systems.  
|             | Waterlow and Disdat if indicated.  
|             | • Consider assessment of posture for safe eating and drinking in liaison with SALT.  
|             | • Manual Handling Assessment (multi-disciplinary).  
|             | • Hospital discharge: liaise with discharge team.  

| Intervention:  
|----------------|---------------------------------------------------------------------------------|
|                | • Core strengthening and coordination work; falls prevention work.  
|                | • Provision of mobility aids and mobility and manual handling.  
|                | • Advice/recommendations. May include delegation of treatment programmes.  
|                | • Provision of specialist seating (wheelchairs and easy chairs).  
|                | • Referral to district nurses re TV needs and to orthotics for footwear.  

| Tier 4 | **Education and support:**  
|--------|-------------------------------|
|        | • Advise carers on safe practices when using equipment.  
|        | • Recommendations for safe manual handling and around mobility needs of clients.  
|        | • Delegation of task for mobility/positioning programmes.  

Return to Flowchart
**Assessment:**
- Detailed physiotherapy assessment of posture and functional ability.
- Mobility/falls assessment to include Tinetti, Berg Balance, Elderly Mobility scale.
- Baseline respiratory assessment and signpost to specialist service if required.
- Physical activity assessment /falls prevention work.
- Postural Management, specialist sleep system, and seating systems. Waterlow and Disdat if indicated.
- Consider assessment of posture for safe eating and drinking in liaison with SALT.
- Hospital discharge: liaise with discharge team.

**Intervention:**
- Core strengthening and coordination work; falls prevention work.
- Provision of mobility aids and mobility and manual handling advice/recommendations. May include delegation of treatment programmes.
- Provision of specialist seating (wheelchairs and easy chairs).
- Referral to district nurses re TV needs and to orthotics for footwear.
- Attend meetings regarding CHC, best practise.
- Palliative care.
- End of life: input in to end of life care .
- Positioning for management of secretions.
- Positioning for tissue viability needs/ comfort/ protection of body shape.
- High falls risk.
- Unsafe hospital discharges.
- Safeguarding in relation to the above.
**Social Worker**

**Service User**
Assessment of need under the Community Care Act. There is an expectation that there is input by all the multi-disciplinary team. This may be in the form of a report attached, or it may be details of discussion with that person.

The areas covered are:
- Service users / Carer / Significant others views
- How are needs currently met
- Potential for promotion of independence/rehabilitation
- Mental health, emotional and psychological needs
- Social, learning, recreational and employment needs
- Cultural, religious and spiritual needs
- Functional assessment, which covers personal care, physical abilities, domestic abilities and transport
- Specific risks identified to self and others
- Financial assessment – benefits check (sign post for making a will)
- Significant life events
- Physical health
- Accommodation - environment

The conclusion summarises the identified needs and risks to independence in the following areas: Autonomy, Health and safety, Managing daily routines, Involvement.
Under Fair Access to Care Services (FACS) (Putting People First 2010) if they are deemed to have either a substantial or a critical risk in any of the above areas then they will be offered services.

Under the Personalisation and Choice Agenda, Service Users’ choice may include: - choice of provider, professional service, timing or access.

The services will be detailed on a Care Plan, which is the legal agreement with providers when a service is commissioned.

As a person’s needs increase a Continuing Health Care Checklist Assessment maybe completed to see if they qualify for Continuing Health Care Funding or Complex Care Funding, in line with Department of health guidelines.
Services will be commissioned and then reviewed initially annually, but normally in the case of dementia more regularly as the person’s needs change. There may be the need for a Social Care OT assessment for aids and adaptations in the home.

In the last few years we have worked with private providers and there are now several residential care homes that have developed an expertise in caring for people with a learning disability and dementia. We would however wish to support a person and their carers at home if at all possible.

**Carers**

Carers would be offered a Carers’ Assessment, which may be part of the Community Care Assessment or it may be separate. The package of care will aim to support them in their caring role and support the service user as their needs inevitably increase.
Speech and Language Therapist

Speech and Language Therapists working with individuals with learning disabilities who have developed dementia cover two main areas. These are:

- **Communication**
  
  Individuals with dementia experience decline in their overall skills. This decline is particularly marked in the area of communication. This can cause difficulties for carers when supporting the individual. There may be changes in behaviours due to increased difficulties with understanding and communicating effectively.

  The Speech and Language Therapist’s role is to assess the communication needs of the individual with dementia, identify means for supporting these, and advising carers and support workers regarding improved, or successful communication.

- **Eating and Drinking**
  
  Many individuals with dementia may develop difficulties with eating and drinking as the illness progresses. These difficulties may be due to physical changes and/or changes in behaviours. The role of the speech and language therapist is, in liaison with others, to assess the individual and advise regarding strategies to improve safety of eating, drinking and swallowing or to suggest strategies to support the maintenance of adequate oral intake.

<table>
<thead>
<tr>
<th>Tier 2</th>
<th><strong>Education and support:</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>A range of education, supervision and mentoring activities to enable mainstream services to address the communication and dysphagia needs of people with learning disability and Dementia. The aim is to enable them to make reasonable adjustments and meet the 5 Good Communication standards and safe eating and drinking guidelines.</td>
</tr>
<tr>
<td></td>
<td>Contributing to general dementia awareness training regarding Role of SALT with people diagnosed with dementia.</td>
</tr>
<tr>
<td></td>
<td>Signposting and providing general communication information for people with Dementia.</td>
</tr>
</tbody>
</table>

**Assessment:**

Provide a brief assessment of the specific communication environment in relation to the 5 Good Communication Standards. Provide tools to support services to develop a basic communication passport for an individual.
Skilling staff to recognise communication and eating and drinking issues and make appropriate referrals.

**Intervention:**
Onward referral and signposting.
Provide findings of an individual's communication or eating and drinking assessment to support mainstream services to address their communication or eating and drinking needs.
Provide mentoring and support for staff working in mainstream services to enable them to make reasonable adjustments in relation to communication and Dementia.
Provide general advice, information and resources to support safe eating and drinking.
Provide information and guidelines on best practice. Share resources and tools to support good communication.
Joint working with staff from other services.
Support the development and use of communication passports to inform other staff of the best ways of communicating with individuals.

<table>
<thead>
<tr>
<th>Tier 3</th>
<th><strong>Education and support:</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Specific training to support learning disability environments and community teams working with people with dementia to meet the changing communication needs of people with dementia. This may include specific training in signing, objects of reference, communication passports etc.</td>
</tr>
<tr>
<td></td>
<td>Individualised communication training for staff supporting individuals referred to the service including how to communicate in the best way with the person and how to help the person to understand their diagnosis of dementia when appropriate.</td>
</tr>
<tr>
<td></td>
<td>Contribution to training for other people with LD living with a person with dementia to help them to understand the changes in behaviour of the individual.</td>
</tr>
</tbody>
</table>

**Assessment:**
Formal and/or informal assessment of communication involving both the individual and key communication partners. The aim is to identify areas of communication difficulty experienced by the individual and communication partners including considering whether current behaviour has a communicative function.
Assessment of communication as a diagnostic indicator of dementia.
Contribution of information on premorbid communication abilities to contribute to diagnostic process.
Providing supervision to specialist LD services to ensure that communication impairment is taken into account during administration and interpretation of cognitive assessments.
Contributing to capacity assessments when appropriate.
Completion of formulation providing a framework for describing communication issues and the development of an action plan, underpinned by clinical reasoning, to overcome these difficulties and plan for anticipated changes in communication ability as dementia progresses.

Intervention:
Direct work with an individual to enhance their communication skills including reinforcing simpler methods of communication eg Objects of Reference to be used consistently to prepare for the future deterioration of higher level language skills such as verbal communication.
Direct work with the individual together with other MDT members to support them to understand their dementia diagnosis and the health changes they are experiencing and to express their views and feelings.
To provide supervision to other LD professionals to ensure their interventions are at appropriate communication level e.g. reminiscence work, life story work etc.
Work with key communication partners to develop their communication skills and support them to implement SALT recommendations and consistently follow the Communication Passport. To work with key partners to ensure strategies are in place to meet the changing communication needs of the person with dementia.
Work with key partners to promote maintenance of ongoing interpersonal relationship between individual and carers including introduction of specific communication tools such as Intensive Interaction to improve positive communication as communication abilities decrease.
Working with key partners together with MDT to improve person’s ability to maintain their independent functioning in their environment such as environmental signposting (photo cues on doors etc).
Work with key communication partners to ensure that individual is enabled to be involved as possible in making choices and decisions about their life.
<table>
<thead>
<tr>
<th>Tier 4</th>
<th><strong>Education and support:</strong></th>
<th><strong>Assessment:</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Supporting improvements in the communication environment by enabling services to achieve the 5 Good Communication standards for an individual. To work together with the individual and their carers to enable the person to be fully involved in decisions about their end of life care and preparing for a good death.</td>
<td>Formal and/or informal assessment of communication involving both the individual and key communication partners. The aim is to identify areas of communication difficulty experienced by the individual and communication partners including considering whether current behaviour has a communicative function. Assessment of communication as a diagnostic indicator of dementia. Contribution of information on premorbid communication abilities to contribute to diagnostic process. Providing supervision to specialist LD services to ensure that communication impairment is taken into account during administration and interpretation of cognitive assessments. Contributing to capacity assessments when appropriate. Completion of formulation providing a framework for describing communication issues and the development of an action plan, underpinned by clinical reasoning, to overcome these difficulties and plan for anticipated changes in communication ability as dementia progresses.</td>
</tr>
<tr>
<td></td>
<td>Specific training to support learning disability environments and community teams working with people with dementia to meet the changing communication needs of people with dementia. This may include specific training in signing, objects of reference, communication passports etc. Individualised communication training for staff supporting individuals referred to the service including how to communicate in the best way with the person and how to help the person to understand their diagnosis of dementia when appropriate. Contribution to training for other people with LD living with a person with dementia to help them to understand the changes in behaviour of the individual.</td>
<td></td>
</tr>
</tbody>
</table>
**Intervention:**

Direct work with an individual to enhance their communication skills including reinforcing simpler methods of communication eg Objects of Reference to be used consistently to prepare for the future deterioration of higher level language skills such as verbal communication.

Direct work with the individual together with other MDT members to support them to understand their dementia diagnosis and the health changes they are experiencing and to express their views and feelings.

To provide supervision to other LD professionals to ensure their interventions are at appropriate communication level e.g. reminiscence work, life story work etc.

Work with key communication partners to develop their communication skills and support them to implement SALT recommendations and consistently follow the Communication Passport. To work with key partners to ensure strategies are in place to meet the changing communication needs of the person with dementia.

Work with key partners to promote maintenance of ongoing interpersonal relationship between individual and carers including introduction of specific communication tools such as Intensive Interaction to improve positive communication as communication abilities decrease.

Working with key partners together with MDT to improve person’s ability to maintain their independent functioning in their environment such as environmental signposting (photo cues on doors etc).

Work with key communication partners to ensure that individual is enabled to be involved as possible in making choices and decisions about their life.

Supporting improvements in the communication environment by enabling services to achieve the 5 Good Communication standards for an individual.

To work together with the individual and their carers to enable the person to be fully involved in decisions about their end of life care and preparing for a good death.
Clinical Psychologist

Clinical Psychologists can be involved in diagnosing dementia, often when the person’s difficulties are complex and the diagnosis unclear. We can use a range of different cognitive tests, including memory tests; but would also gather information about the individual’s previous functioning, their environment, behaviour, and mood. We are also asked to do assessments of a person’s capacity to make decisions, particularly in the early stages of dementia.

Once a diagnosis has been made psychologists would intervene where there are problems such as challenging behaviour, depression and anxiety, or where there are issues to do with loss, illness and disability. Therapeutic approaches in dementia care include sensory approaches (Aromatherapy, Music Therapy, and Snoezelen); environmental approaches (Behaviour Management & Problem Solving); and dementia specific approaches (Reality Orientation, Reminiscence Therapy & Validation Therapy). These complement traditional therapeutic approaches.

We often work with carers and staff to support them in looking after the individual.

<table>
<thead>
<tr>
<th>Tier 2/3/4</th>
<th>Assessment</th>
</tr>
</thead>
<tbody>
<tr>
<td>2/3/4</td>
<td>Cognitive assessment (reading notes, interpretation and scoring as well as administration of specific assessments)</td>
</tr>
<tr>
<td></td>
<td>Formulation</td>
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<tr>
<td></td>
<td>Guidelines for Carers / Staff (preparation/ teaching)</td>
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<td></td>
<td>Transitions consultation</td>
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<tr>
<td></td>
<td>MCA</td>
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<tr>
<td></td>
<td>Assessment / Consultation</td>
</tr>
<tr>
<td></td>
<td>Best Interests</td>
</tr>
</tbody>
</table>

Return to Flowchart
Outreach Nurses

Behavioural Management
Community Learning Disability Nurses and Psychology have involvement in this. Community Learning Disability Nurses at an early stage and psychology at a complex stage where psychological interventions as required.

Outreach involvement would be at the stage that behaviours have become more intense and could potentially pose a risk to service placement.

Service of criteria:
- Age 19 years or over.
- Diagnosed learning disability. (Referrals of adults with borderline cognitive functioning will be offered an advice/liaison service regarding client’s management, but only following service level discussion and without acceptance of ultimate clinical responsibility).
- Lives within Leicester, Leicestershire and Rutland.
- Challenging behaviour and/or mental health issues that pose an ongoing high risk of serious physical or emotional harm to the individual or others, serious damage to the environment or severely restricted use of ordinary facilities accessed by others. Where assessed as being primarily due to health related issues, i.e. not due to social care issues in isolation: homelessness, service deficits, provision of day care.
- Avoidance of crisis.
- Complexity of care, with a need for intensive specialist input for at least 3 months.
- The normal range of services provided through the community learning disability team cannot meet client’s assessment and treatment.
## USEFUL CONTACTS

<table>
<thead>
<tr>
<th>Organization</th>
<th>Service Type</th>
<th>Phone Number</th>
<th>Address</th>
</tr>
</thead>
<tbody>
<tr>
<td>CLASP</td>
<td>CARERS ADVOCACY SERVICE</td>
<td>0116 2510999</td>
<td>MATRIX HOUSE, UNIT 19 CONSTITUTION HILL, LEICESTER, LE1 1PL</td>
</tr>
<tr>
<td>MENCAP</td>
<td>SERVICE USER ADVOCACY</td>
<td>0116 2422730</td>
<td>KIMBERLY HOUSE, VAUGHAN WAY, LEICESTER</td>
</tr>
<tr>
<td>VAL</td>
<td>VOLUNTARY ACTION LEICESTER</td>
<td>0116 2580666</td>
<td>ACTIVE COMMUNITY CENTRE, 9 NEWARKE STREET, LEICESTER</td>
</tr>
<tr>
<td>MOSAIC</td>
<td>SERVICES FOR DISABLED PEOPLE</td>
<td>0116 2515565</td>
<td>2 RICHARD III ROAD, LEICESTER</td>
</tr>
<tr>
<td>AGE CONCERN</td>
<td>SERVICES FOR OLDER PEOPLE</td>
<td>0116 2220555</td>
<td>CLARENCE HOUSE, 46 HUMBERSTONE GATE, LEICESTER</td>
</tr>
<tr>
<td>ALZHEIMERS SOCIETY</td>
<td>ALZHEIMERS CHARITY SUPPORT</td>
<td>0116 2627933</td>
<td>THE LODGE, 46 HUMBERSTONE GATE, LEICESTER</td>
</tr>
<tr>
<td>Organization</td>
<td>Service</td>
<td>Contact Number</td>
<td>Address</td>
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<tr>
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</tr>
<tr>
<td>LEEAP</td>
<td>LEICESTERSHIRE ETHNIC ELDERLY ADVOCACY PROJECT</td>
<td>0116 2755515</td>
<td>33 CHANDOS STREET; LEICESTER</td>
</tr>
<tr>
<td>CRUSE</td>
<td>BEREAVEMENT CARE</td>
<td>0116 2613516</td>
<td>COMMUNITY HOUSE 133 LOUGHBOROUGH RD LEICESTER, LE4 5LQ</td>
</tr>
</tbody>
</table>
About My Friend

What happens when people get dementia?

Dementia starts slowly. Friends and staff may not know at first that something is wrong.

Later on more changes happen, often at the same time.

People with dementia will forget lots of things. They may forget what they need to do next. They may forget where they’ve put things.

They will get muddled up. They will do things that are odd, like putting things in the wrong place.

Do these changes mean the person has dementia?

Often changes are not caused by dementia. Many problems can be sorted out.

A person may need glasses for the first time, or new glasses.

They may need a hearing aid or to have their hearing aid looked at.

Some people get other illnesses. Doctors can make them better.

They may feel sad or worried. Something difficult may have happened to them. Talking to someone may help.
Later on you may see more changes in your friend.

Your friend may do things more slowly. They may need more help with stairs. They may need more help getting onto buses or down kerbs.

Your friend may need more help to do lots of things they could do, like dressing, washing and doing things they enjoy.

They may need changes in their home, like rails in the bathroom and toilet.
Dementia Questionnaire for People with Learning Disabilities (DLD)

Evenhuis et al., 2007

- It is a screening tool for the early detection of dementia in adults with learning disabilities, completed by carers, consisting of 50 items.

- **Sub-scales**: short term memory, long term memory, orientation (making up Sum of Cognitive Scores), speech, practical skills, mood, activity and interest and behavioural disturbance (making up Sum of Social Scores).

- **Scoring**: The questionnaire is provided with a simple linear score system in which the items have three response categories: 0 = no deficit, 1 point = moderate deficit, 2 points = severe deficit.
  - **Sum of Cognitive Scores (SCS)**: Combined scores on the first three subscales (Short-term memory, Long-term memory and Orientation).
  - **Sum of Social Scores (SOS)**: Combined scores on subscales 4 through to 8 (Speech, Practical skills, Mood, Activity and Interest, and Behavioural disturbance).

- **Interpreting the results**: Longitudinal judgment of DLD scores provides the most reliable diagnosis and therefore at least two DLD assessments would be required. DLD assessment is best undertaken when the individual does not have acute physical health problems or other significant changes in environment.

**Baseline**  
DLD to be carried out during the first assessment to aid with the diagnosis of dementia.

Initial subsequent DLDs could be completed at 3, 6, 12 months following the advice of the Psychiatrist.

**Community Nurses** are to carry out initial DLD to obtain a baseline (along with Ok Health Check and a basic sensory screening) and up to two subsequent DLDs.

**Ongoing monitoring** of Dementia  
DLDs to be carried out at a minimum of 12 monthly, 3 to 6 monthly if the patient is taking anti dementia medication.

**Psychiatrists** are to carry out the DLD for patients who are stable and attending OPA by working with the Carer where possible. If this is not possible ie there is a need for wider consultation to complete the DLD or there are additional health needs it may be appropriate to ask for support from the Community Nurse. If the patient is open to community nursing this can then be part of their intervention if not the nurse will have to open the case.

Return to Flowchart
## MEMORY CLINIC

<table>
<thead>
<tr>
<th>Name:</th>
<th>Date:</th>
</tr>
</thead>
<tbody>
<tr>
<td>DOB:</td>
<td>Venue:</td>
</tr>
<tr>
<td>Main Carers:</td>
<td>Baseline: Yes / No</td>
</tr>
<tr>
<td>Co-ordinator:</td>
<td></td>
</tr>
</tbody>
</table>

Consider changes during the visit, include difficulties and improvements.

### Physical Health

### Eating, Drinking and Swallowing

### Continence

### Mobility (safety, independence, vulnerability)

### Falls / Transfers (safety, independence, vulnerability)

### Epilepsy

### Sleep

### Hearing

### Vision

[Return to Flowchart]
<table>
<thead>
<tr>
<th>Memory, Thinking Processes. Orientation and Mental Health</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neurological</td>
</tr>
<tr>
<td>e.g.</td>
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<tr>
<td></td>
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<tr>
<td>Cognitive Change</td>
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<tr>
<td>e.g.</td>
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<tr>
<td></td>
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<tr>
<td>Hallucinations</td>
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<tr>
<td>e.g.</td>
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<td></td>
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<tr>
<td>Mood</td>
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<tr>
<td>e.g.</td>
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<tr>
<td></td>
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<tr>
<td>Short term</td>
</tr>
<tr>
<td>e.g. can remember or have problems remembering something which has happened recently?</td>
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<tr>
<td></td>
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<tr>
<td>Long term</td>
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<tr>
<td>e.g.</td>
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<tr>
<td>Visuo-Spatial</td>
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<tr>
<td>e.g.</td>
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<td></td>
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<tr>
<td>Attention</td>
</tr>
<tr>
<td>e.g. is able or not to concentrate.</td>
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<td></td>
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<tr>
<td>Problem Solving</td>
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<tr>
<td>e.g.</td>
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<tr>
<td>Sensory</td>
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<tr>
<td>e.g.</td>
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<tr>
<td>Category</td>
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<td>--------------------------------</td>
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<tr>
<td>Dressing / Washing</td>
</tr>
<tr>
<td>Domestic Activity</td>
</tr>
<tr>
<td>Behavioural Issues / Changes</td>
</tr>
<tr>
<td>Environment (Capable)</td>
</tr>
<tr>
<td>Communication</td>
</tr>
<tr>
<td>Daytime Activities</td>
</tr>
<tr>
<td>Social Interaction / Interests</td>
</tr>
<tr>
<td>Equipment</td>
</tr>
<tr>
<td>Placement Issues</td>
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<tr>
<td>Carers Issues</td>
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<tr>
<td>Medication</td>
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</table>

If on Dementia Medications fill out Cholinesterase checklist  YES / NO

**CHECKLIST ASSESSMENTS**

<table>
<thead>
<tr>
<th>Checklist</th>
<th>Is assessment or re-assessment required?</th>
<th>Completed Date</th>
<th>Review Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>DLD (Dementia ques for people with LD)</td>
<td></td>
<td></td>
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<tr>
<td>Direct Instrument (tool being developed)</td>
<td></td>
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<tr>
<td>Nutritional Screening (MUST)</td>
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<tr>
<td>Waterlow (Pressure area risk assessment)</td>
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<tr>
<td>Carers Assessment</td>
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<td></td>
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</tr>
</tbody>
</table>

The above assessments are required to be completed for everyone.

<table>
<thead>
<tr>
<th>Checklist</th>
<th>Dose</th>
<th>Freq</th>
<th>Prep</th>
<th>Reason prescribed</th>
<th>Side effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cholinesterase Inhib.(Dementia medication)</td>
<td></td>
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<tr>
<td>Falls</td>
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<tr>
<td>Dysphagia (Difficulty swallowing)</td>
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<tr>
<td>Eating &amp; Drinking Pathway</td>
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<tr>
<td>Continence Assessment</td>
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<tr>
<td>Epilepsy Pathway</td>
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<tr>
<td>Behaviour Assessment</td>
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<tr>
<td>Mental Capacity Assessment</td>
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<tr>
<td>Metabolic Parameters (Side effects from medication)</td>
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<tr>
<td>Dementia Care Mapping (Quality of Life Assessment)</td>
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<tr>
<td>Best Interests decision</td>
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<tr>
<td>Deprivation of Liberty</td>
<td></td>
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</table>

*Return to Flowchart*
### MEMORY CLINIC INFORMATION GIVEN

<table>
<thead>
<tr>
<th>Information</th>
<th>Date given</th>
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</thead>
<tbody>
<tr>
<td>Carer's Booklet</td>
<td></td>
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<tr>
<td>Dementia Pathway and End of Life Package</td>
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</tr>
<tr>
<td>FALLS Information</td>
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<tr>
<td>Medication Information</td>
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<tr>
<td>LD Service Information</td>
<td></td>
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<tr>
<td>Support Agency Information</td>
<td></td>
</tr>
<tr>
<td>Carer's Training in Dementia</td>
<td></td>
</tr>
<tr>
<td>PEERS Training</td>
<td></td>
</tr>
<tr>
<td>Eating and Drinking Tips</td>
<td></td>
</tr>
<tr>
<td>Other</td>
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### APPOINTMENTS

**Future GP / Hospital appointments**

<table>
<thead>
<tr>
<th>Date</th>
<th>Appointment</th>
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**Date for next visits**

<table>
<thead>
<tr>
<th>Date</th>
<th>Who</th>
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**Review Dates (include CPA)**

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**Return to Flowchart**
<table>
<thead>
<tr>
<th>Need</th>
<th>Action</th>
<th>By Who</th>
<th>Evaluation / Outcomes</th>
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<tbody>
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</table>

Name and Role of Member of Team: ____________________________________________

Signed: ____________________________________________

Date: ____________________________________________

Return to Flowchart
<table>
<thead>
<tr>
<th><strong>Please use these prompts to guide you when filling out the following chart:</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Memory</strong></td>
</tr>
<tr>
<td><strong>Orientation</strong></td>
</tr>
<tr>
<td><strong>Mood</strong></td>
</tr>
<tr>
<td><strong>Behaviour</strong></td>
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<tr>
<td><strong>Practical Skills</strong></td>
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<tr>
<td><strong>Communication</strong></td>
</tr>
<tr>
<td><strong>Hallucinations</strong></td>
</tr>
<tr>
<td><strong>Activities</strong></td>
</tr>
<tr>
<td><strong>Sleep</strong></td>
</tr>
<tr>
<td><strong>Mobility / Safety</strong></td>
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<tr>
<td><strong>Any other comments</strong></td>
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</tbody>
</table>
**Virtual Memory Clinic**

<table>
<thead>
<tr>
<th>Help Notes:</th>
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<tbody>
<tr>
<td>Memory Clinic form discussed and some further changes made – see form.</td>
</tr>
<tr>
<td>Home record sheet discussed – see form.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Ideas for using the form:-</th>
</tr>
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<tbody>
<tr>
<td>The main form to be used by different members of the MDT and completed / updated for each visit.</td>
</tr>
<tr>
<td>To appoint a co-ordinator from the MDT who will hold the form? Copy for client / carers/.</td>
</tr>
<tr>
<td>The Home record sheet is for carers / clients to complete.</td>
</tr>
<tr>
<td>Would be useful to link the completion of the forms to Psychiatric Out patients’ appointments.</td>
</tr>
<tr>
<td>It is suggested that the ‘Required’ assessments are carried out at planned intervals, a minimum of 6 monthly. The other assessments when necessary.</td>
</tr>
<tr>
<td>It may be possible to see the last page (appointments and agreed actions) as a summary of contact and this could form the basis of sharing of information between client / carer and MDT.</td>
</tr>
<tr>
<td>5 checklist assessments required for everyone – remember to set dates to re-assess.</td>
</tr>
<tr>
<td>The direct assessment instrument will be developed. The idea is that you identify a skill / task that the person can do well to use as a gauge to measure changes in ability for the person.</td>
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</table>
GOOD PRACTICE STANDARDS For People With Learning Disabilities and Dementia

People who develop, or are at risk of developing dementia have access to assessments and interventions that are delivered within current legislation and national guidance.

1. Each area has a register/database of people with learning disabilities, which identifies people with Down’s syndrome that can be used to plan and deliver effective services.

2. Each geographical area has an agreed multi-agency learning disabilities and dementia strategy for people with learning disabilities with an agreed action plan that addresses the standards outlined in this document.

3. People who develop, or are at risk of developing dementia have assessment, diagnosis, treatment and support delivered according to an agreed multi-agency care pathway which includes access to other services beyond the specialist learning disability areas (e.g. Older People’s Mental Health Services, neurology, and advocacy).

4. People who develop, or are at risk of developing dementia are offered assessments, diagnosis and specialist support from the full range of dedicated and skilled professionals within learning disabilities services. They have easy access to specialist assessments within the general health services (e.g. neurology).

5. People who develop, or are at risk of developing dementia have easy access to comprehensive assessment and diagnostic services according to an agreed protocol.

6. People who develop, or are at risk of developing dementia have their care provided according to person centred principles and this is individualised to meet the needs of the person.

7. People who develop, or are at risk of developing dementia have their care purchased, monitored and reviewed by an effective care management system, whether in the geographical area or in an out of area placement.

8. People who develop dementia have prompt access to the full range of medical, psychological, therapeutic and social interventions as required.

9. People who develop, or are at risk of developing dementia, have accommodation and day and leisure activities which are dementia friendly and are commissioned to meet their changing needs.

10. People who develop dementia are supported to ‘die in place’, with additional supports provided in a timely manner.

11. The wishes, choices and rights of the person with learning disabilities who develops, or is at risk of developing dementia are respected, and this is evidenced in the care provided.
12. Family carers are assisted to understand and support their relative who has dementia. Their needs as carers are met.

13. People who develop, or are at risk of developing dementia, and their families, receive support, advice and care from a capable workforce that is appropriately skilled.

14. People with learning disabilities and dementia have End of Life care delivered in line with the national strategy.

Dementia and People with Learning Disabilities 2009