

Appendix C

NHS Bedfordshire Dementia Service Mapping for Central Bedfordshire Council

3 key steps;

- 1 Ensure **better knowledge** about dementia and remove **stigma**
- 2 Ensure **early diagnosis**, support and treatment fro people with dementia and their family and carers
- 3 **Develop services** to meeting changing needs better

No	Objectives	Outcomes	Current Services	Gaps In Service	Gold Standard	Rag	Comments
1	Raise awareness of dementia and encourage people to seek help	<p>The public and professionals will be more aware of dementia and will understand dementia better. This will;</p> <ul style="list-style-type: none"> • Help remove the stigma of dementia • Help people understand the benefits of early diagnosis and care • Encourage the prevention of dementia • Reduce other people's fear and 	<ul style="list-style-type: none"> • Alzheimer's Society provide Leaflets/Info • Public Champions have raised awareness e.g. Terry Prachett • POPPS in Luton raised awareness with public & GP's • Internet • Day Care in Luton provide info • Carer Support Groups via Alzheimer's Soc e.g. Music for Memory at Queens Park, Allotment Group at Queens Park - in peer groups • Alzheimer's Society Havens (South Beds) & Carers Rest (Henlow & Bedford) • National Strategy 2009 • Awareness week – Memory Walks • Dignity Champions • Carer's Café 	<ul style="list-style-type: none"> • Awareness within Schools & Further Education • Links needed between publicity of physical & mental wellbeing (regular awareness raising programme) • Training (refreshers for professionals – local workforce plan) • Professionals sharing info/referrals e.g. acute to specialist MH • Articles within 	<ul style="list-style-type: none"> • National campaign e.g. Stroke, Swine Flu • National Champions • Dementia Training (Academic Unit – Competencies Standards) • Champions with CMHT and wider team (Personalisation) 	Red/Amber	

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		misunderstanding of people with dementia.		publications 'Stepping Out' & 'News Central' Bedford Borough & Central Bedfordshire literature <ul style="list-style-type: none">• Lack of training or awareness of training around Dementia for the public, spotting early signs			
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2	<p>Good quality early diagnosis, support and treatment for people with dementia and their carers, explained in a sensitive way.</p>	<p>All people with dementia will have access to care that gives them;</p> <ul style="list-style-type: none"> • An early high-quality specialist assessment • An accurate diagnosis which is explained in a sensitive way to the person with dementia and their carers • Treatment, care and support as needed after the diagnosis. <p>Local services must be able to see all new cases of people who may have dementia in their area promptly.</p>	<ul style="list-style-type: none"> • GPs/Neurologists/Community Matrons/Social Workers/Voluntary Services can refer to CMHTs. • Memory Clinic provides Assessment & Diagnosis, Cognitive Enhancers, Cognitive Stimulation Therapy, Specialist Day Care • Voluntary Services – Alzheimer’s Society, Age Concern, Carers in Bedfordshire, Rethink, Beds Advocacy Service • Training & support Exists around Mental Capacity Issues • IMCA Services • Specialist Speech Therapy • Occupational Therapy Exist • Support Groups for SU & Carers in Bedfordshire • Learning Disability Consultant at Twinwoods • MH First Aid Training Package being Developed • Support workers (Age Concern) provide home visits • Lots of information available • Consultant did home visits • Quick diagnosis for some (2weeks) • Carers/spouses felt listened to • Access to specialist centres – Bedford, Addenbrookes • Greeting at Memory Clinic – 	<ul style="list-style-type: none"> • GPs reluctant to refer/identifying an appropriate diagnosis • Education within Primary Care • Multi Agency Working at the referral/diagnostic stage • Specialist MH workers in GP surgery with Dementia focus • Re-design of services to provide memory clinics rather than a fully commissioned service. • Too much info being given in one feedback session • Awareness of Service Directory • Dementia Advisors required (JD already drawn up by Alz Soc) • Sometimes family/Carer understanding 	<ul style="list-style-type: none"> • GP Education • Communication with GPs/Specialist Services • Raising Public Awareness • Dementia Advisor (Contact & Signposting) • Directory of Services • Admiral Nurses • Information Distribution (Vol Sector Responsibility) • Coordinated Service • One stop services funded 24/7 and Open referral system • Royal College of Psychiatry Accreditation of Memory Services • Good Multidisciplinary Working • Liaison nurses in DG Hospitals • Mandatory Training of GPs 	<p style="background-color: #FFD700; color: #FF0000; padding: 2px;">Red/Amber</p>	<p>Comment was made that the pathway could be RAG rated as follows.</p> <p>Before Diagnosis(Memory Clinic) RED</p> <p>During Diagnosis (Memory Clinic) GREEN</p> <p>After Diagnosis RED</p>
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			<p>described as wonderful</p> <ul style="list-style-type: none"> • GP's – some provided prompt referrals and gave good information • Alzheimer's support group is very helpful • Some good experiences at Weller Wing with good information being given • Memory Clinic Carers Assessment 	<p>around the process and their involvement. Provision of accessible info leaflet.</p> <ul style="list-style-type: none"> • Home care service to support enablement assessment/care planning • Meeting culturally diverse needs – especially use of expertise of 3rd sector. • Integrated Service across statutory & 3rd Sector. • Lack of Speech Therapy Input in Memory Clinics • Lack of Ongoing Follow Ups from Memory Clinic • Lack of clear pathway for Assessment & Diagnosis for younger people with Dementia • Lack of one point 	<ul style="list-style-type: none"> • Home Assessments • Sensitive and appropriate forms of Assessment • Continued Follow – up support after assessment • Central Assessment Bureau – one assessment can be updated and accessed by different agencies • Self-Referral • GP provided appropriate training and understanding of Dementia to enable quick referral. 		
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				<p>of contact & ongoing support for carers</p> <ul style="list-style-type: none">• Lack of equality in accessing/funding of drugs• Lack of expertise in meeting the needs of Dementia & Complex Physical problems• More Support Groups Needed• Quantity of specialist Services e.g. Speech & Language, OT.• Dementia Register – GP's• 4-5 Visits to GPs before referral• Wrong Diagnosis - Told it was just 'Ageing process'• Awareness of different types of Dementia• Not told immediately about Alzheimer's			
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				<p>society</p> <ul style="list-style-type: none">• Poor communication between Agencies and Services• Lack of Specialist In-patient service for early on-set Dementia• GP confirmed Dementia with no test• Not aware of CPN's role• Don't see the same psychiatrist• Poor English used by some clinical staff – hard to understand them• Social workers unable to refer to Memory Clinic• GPs not referring to memory clinic until crisis happens• Kept waiting for 2Hours for a 10minute appointment• Follow up			
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				<p>appointments with the same psychiatrist</p> <ul style="list-style-type: none"> • Would prefer Memory Clinic in the community or Bedford Health Village • No clear pathway • Lack of link between Memory Clinic and Acute Wards • Written diagnosis not provided to patient or carer 			
3	<p>Good-quality information for people with dementia and their carers</p>	<p>People with dementia and their carers will be given good-quality information about dementia and services</p> <ul style="list-style-type: none"> • At diagnosis • During their care 	<ul style="list-style-type: none"> • Alzheimer's Society currently produce great literature, leaflets • Self - help books 	<ul style="list-style-type: none"> • Get the balance right between written information & 1:1/group verbal information in relation to people with diverse cultures • Information not always clear on direct payments and Vouchers 	<ul style="list-style-type: none"> • Internet Support 	Red/Amber	
4	<p>Easy access to care, support and advice after diagnosis</p>	<p>People with dementia and their carers will be able to see a dementia adviser who will help them</p>	<ul style="list-style-type: none"> • Emergency Respite for Carers • Carer's Support Bureau through (BRCC) • Link (Alz Society) – Telephone 	<ul style="list-style-type: none"> • Rural Issues geographic isolation/transport to access groups/peer 	<p>Generic Helpline Number (0800),</p> <ul style="list-style-type: none"> • Mobile Memory Clinic 	Red/Amber	

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		<p>throughout their care to find the right;</p> <ul style="list-style-type: none"> • Information • Care • Support • Advice 	<p>Service</p> <ul style="list-style-type: none"> • Alzheimer's society helps direct you to different agencies and services • Age concern helped with information and form filling • Inconsistent service at Memory Clinic when providing information on Dementia and Support Groups 	<p>support</p> <ul style="list-style-type: none"> • Support to make self-directed support work, presently very process driven. • Self – funding people on their – no support to find Carers/ care homes/Respite • Once diagnosed, no obvious links on where to go next • Would like information about Dementia, benefits and support groups as early as possible 	<ul style="list-style-type: none"> • Self directed support, direct payments • To ensure Service Users and Carers are made aware of support available after diagnosis • Advice and support around power of attorney • More activity groups e.g. Gardening, Fitness, Golf • Simple overview of services • To ensure services are set-up by Health and Social Care to enable Service Users and Carers to Commission their own services 		
5	Develop structured peer support and learning networks	<p>People with dementia and their carers will be able to;</p> <ul style="list-style-type: none"> • Get support from local people with 	<ul style="list-style-type: none"> • Using Existing resources e.g. Day centres for partnership working between statutory/3rd sector 	<ul style="list-style-type: none"> • Clarification over the remit of 'peer support' • 3 haven groups in S.Beds become more 	<ul style="list-style-type: none"> • Increase numbers of Cafes & Drop In Centres 	<p>Red(South of County)</p> <p>Green (North of County)</p>	

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		<p>experience of dementia</p> <ul style="list-style-type: none"> • Take an active role in developing local services 		<p>social in focus rather than peer support</p>			
6	<p>Improve community personal support services for people living at home</p>	<p>There will be a range of flexible services to support people with dementia living at home and their carers.</p> <p>Services will consider the needs and wishes of people with dementia and their carers.</p>	<ul style="list-style-type: none"> • Voluntary sector support groups • Assessment and treatment team • Specialist Learning Disabilities assessment • Commissioned personal care at home • Alzheimer's society provide home care not personal care • Carers rest run by Alzheimer's society/Henlow/Barton/Dunstable/LB • Carers Café run by NHS • Drop-in Café in Biggleswade & Houghton Regis • "Dega Project" in Aspley Guise run by age concern, Transport included • Social Services, Dementia Units providing respite for carers in Biggleswade and LB 5days a week • Home support specifically for LD Patients with dementia • Communication assessment with carer – speech and language, eating and drinking 	<ul style="list-style-type: none"> • No specialist team to assess for personal care • Crisis teams over 65 • Counselling • GP Knowledge • Training for carers and family • Lack of carers rests and cafes in Ampthill and Flitwick • Transport is Limited in Rural Areas • Day care- very restrictive depending on where you live, mid-beds very restrictive • Social care is means tested • Self-funding issues • Only one speech and language 	<ul style="list-style-type: none"> • Respite needed • Flexible to individual needs • Specialist Dementia workers across all settings • GPs working alongside specialist services • One system pathway, measurable quality outcomes in all settings • Specialist training and development • Community Hub • Person Centred planning is a good model • Comprehensive list of services available or flowchart of pathway 	Red	

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			<ul style="list-style-type: none"> • Community Dietetic support for LD Patients with Dementia • LD services are not split for under/over 65s • Limited OT Support • Families providing respite care • Respite breaks provided by Kilorian & winged fellowship holidays 	<p>therapist across the county</p> <ul style="list-style-type: none"> • Patients feel in the middle of social and Health Care • Crisis Support Team • Respite care – emergency break, plan in place now before I need it • Someone to come into our own home, could be family – if paid (Respite) • Residential care – over night in a familiar care home • Bed & Breakfast rooms purchased by the PCT for respite • Holiday Initiatives and provision for Service User and Carer • More Vouchers for Service Users & Carers – three hours a week 	<ul style="list-style-type: none"> • Admiral Nurses Scheme – more chance of staying at home • Educated Staff, GPs, Nurses, Reception Staff etc • Good signposting by front line staff • Nurse Training covers both Physical and Mental needs • Home Carers who are highly qualified and skilled • More time per care slot • Flexibility in Care • Opportunities to socialise for person with Dementia and Carers • Keeping familiar structures for the day • Good support in a crisis • Ongoing practical advice and support 		
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				<p>instead of eight hours a month</p> <ul style="list-style-type: none"> • Turn one of the Bupa homes into a resource centre where all services are under one roof • More publicity about benefits and financial help that may be available • Access to Occupational Therapist • Not aware of how to access care at home • Poor Quality Home Care, in-experienced Care staff • Carers for Individual staff, rather than alternating (seeing different Carers each time) • Task orientated and not Holistic Home Care • Regular monitoring of 	<ul style="list-style-type: none"> • Specialist help with daily tasks • One point of call for all services – e.g. Specialist Link nurse to help co-ordinate social and Health Issues • Live – in Carers where appropriate 		
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				<p>people without family</p> <ul style="list-style-type: none"> • Confusion and fear of Accessing social services 			
7	<p>Implement the New Deal for Carers</p>	<p>Carers will:</p> <ul style="list-style-type: none"> • Have an assessment of their needs • Get better support • Be able to have good-quality short breaks from caring. 			<ul style="list-style-type: none"> • Carers Strategy • Personalisation • Carers Assessment • Choice 	Red/Amber	
8	<p>Improve the quality of care for people with dementia in general hospitals</p>	<p>This way people with dementia will get better care in hospital:</p> <ul style="list-style-type: none"> • It will be clear who is responsible for dementia in general hospitals and what their responsibilities are • They will work closely with specialist 	<ul style="list-style-type: none"> • Ambulance, A&E, Paramedic service – Excellent • Older persons team liaison 	<ul style="list-style-type: none"> • Support for challenging behaviour • Learning Disability Liaison in general Hospitals • Lack of dignity on the ward, level of training is patchy • Focus on beds rather than patients • Lack of information stating if dementia 	<ul style="list-style-type: none"> • Dementia Liaison in General Hospital and community-specific role, not add-on • Hospital and Clinical Environments that are easy to access • Facilities for person with Dementia in hospitals while carer sees hospital consultant 	Red	

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		older people's mental health teams.		assessment have been made, triggers, preferences <ul style="list-style-type: none">• Nutrition issues on ward-staffing commitments to assist eating• Night Cover – Staffing issues• Mental Capacity assessment – not clear• No Liaison with memory clinic and general acute ward• No provision for relatives to stay• Poor In-patient care and Discharge information• Confusion over appointment times• Hospital Transport – Unreliable• Car-Parking difficult at hospital• Lack of basic care i.e. Food and Drink			
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				<ul style="list-style-type: none">• Lack of Dementia Training & Information available for nurses on ward – Cultural shift needed• Inappropriate discharges home – without social work assessment• Poor communication of patient needs• Not in specialist ward because admitted with Physical problems• Better link between Addenbrookes and NHS Bedfordshire• General wards not picking up on symptoms when un-diagnosed patients are in hospital• Social workers sometimes have to insist on a diagnosis if client			
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				in Hospital showing signs of Memory loss			
9	Improve intermediate care for people with dementia	There will be more care for people with dementia who need help to stay at home.	<ul style="list-style-type: none"> • Learning Disabilities pathway • Intermediate beds and care homes 	<ul style="list-style-type: none"> • Specialist Training for all front line staff, with further updates • Rehab • Register of Support Workers 	<ul style="list-style-type: none"> • Intermediate care service tailored to Individual needs • County-wide definition of what good quality Dementia Care is • One statutory organisation providing dementia support • One point of access 	Red	
10	Consider how housing support, housing-related services, technology and telecare can help support people with dementia and their carers	Services will: <ul style="list-style-type: none"> • Consider the needs of people with dementia and their carers when planning housing and housing services • Try to help people to live in their own homes 	<ul style="list-style-type: none"> • “Projects” Aarogan Housing-Clophill Shillington • Telecare care line • Smart Flat Technology 	<ul style="list-style-type: none"> • Knowledge of SMART facilities • Availability of SMART facilities • Awareness of Telecare • Web Based Support • Making adaptations to the homes – very difficult & very costly 	<ul style="list-style-type: none"> • Assistive technology for all – adaptations and equipment • Information about panic alarms, and assisted technology 	Red	

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11	<p>Improve the quality of care for people with dementia in care homes</p>	<p>for longer Services will work to ensure;</p> <ul style="list-style-type: none"> • Better care for people with dementia in care homes • Clear responsibility for dementia in care homes • A clear description of how people will be cared for • Visits from specialist mental health teams • Better checking of care homes 	<ul style="list-style-type: none"> • Learning Disabilities homes – personalisation agenda, April 2010 • Some good care homes/day care/dom care • Some training available via Alzheimer’s society • Some specialist training (AMHP- Approved Mental Health Practitioner), BIA (Best interest Assessors) • Family needed for support • New care homes for couples to stay together 	<ul style="list-style-type: none"> • There is not enough care homes in Bedford • Some Care home rates are above the funding ceiling • Some care homes not specialist in Dementia even though they state they are • Sexual/Intimacy support • Valuing of Care Home staff • Not enough care homes for younger people in Mid-Beds • Registration Criteria can lead to inappropriate placements • GP Assessments do not happen at all homes • Funding is an issue • Lack of Activities stimulation/therapy/no music 	<ul style="list-style-type: none"> • Care home support, networks/forums 	<p>Red</p>	
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				<ul style="list-style-type: none"> • Unclean • Not being prompted to walk by Care Staff 			
12	Improve end of life care for people with dementia	<p>People with dementia and their carers will be involved in planning end of life care.</p> <p>Services will consider people with dementia when planning local end of life services.</p>	<ul style="list-style-type: none"> • Bereavement services offered 	<ul style="list-style-type: none"> • Provision for families staying at hospitals • Liaison with continuing health care • Clear discussions with family on expectation of end of life • Dignity Choices 	<ul style="list-style-type: none"> • Admiral nurses for end of life • Palliative care 	Red	
13	An informed and effective workforce for people with dementia	<p>All health and social care staff who work with people with dementia will;</p> <ul style="list-style-type: none"> • Have the right skills to give the best care • Get the right training • Get support to keep leaning more about dementia. 	<ul style="list-style-type: none"> • Bedford college run NVQ style distance learning • Dementia Care planning in some homes and hospitals • Learning Disabilities, Multi Disciplinary Teams • EoE 1-2day training course 	<ul style="list-style-type: none"> • No mandatory awareness training • In depth Quality Training 	<ul style="list-style-type: none"> • Harmonise training for health/ social/independent sector • Statutory training • Continue on professional development • Clear standards of quality and assurance 	Red	
14	A joint commissioning	Health and social care services will	<ul style="list-style-type: none"> • Move away from Silo working has improved] 	<ul style="list-style-type: none"> • Duplication of work 	<ul style="list-style-type: none"> • World Class Commissioning 		

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	strategy for dementia	<p>work together to develop systems to:</p> <ul style="list-style-type: none"> • Identify the needs of people with dementia and their carers • Best meet these needs <p>There is guidance in the Strategy to help services to do this.</p>	<ul style="list-style-type: none"> • The work on joint strategy should lead to joint working • NHS Bedfordshire taking the lead on the strategy 	<ul style="list-style-type: none"> • Criteria of the social services and NHS • Access to direct payments & personalised budgets • Lack of presence of world class commissioning • Framework for implementation – action plan to continue to drive forward • Ring fenced funding for dementia 			
15	Improve assessment and regulation of health and care services and of how systems are working	There will be better checks on care homes and other services to make sure people with dementia get the best possible care.	<ul style="list-style-type: none"> • Safeguarding Adult procedures 			Red	
16	Provide a clear picture of research about the causes and possible future treatments of dementia	<p>People will be able to get information from research about dementia.</p> <p>We will do lots of things to identify gaps in the research information and do</p>	<ul style="list-style-type: none"> • Information from Alzheimer's society • Cognitive stimulation therapy • Dendron – Research network, Luton registering and creating database 	<ul style="list-style-type: none"> • Dementia Champions at Clinical/Consultant Level • Sharing of research outcomes 	<ul style="list-style-type: none"> • Research outcomes disseminated • Reduce anti-psychotic meds and focus on behavioural 	Red	

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		more research to full the gaps.					
17	Effective national and regional support for local services to help them develop and carry out the Strategy	<p>The Government will give advice and support to local services to help them carry out the Strategy.</p> <p>There will be more good-quality information to help develop better services for people with dementia.</p>	<ul style="list-style-type: none"> • Consultation/ Forums to capture all sectors demographically e.g. Young Persons, LD etc • Darzi review looking at uniform memory clinic model and education unit for service providers 	<ul style="list-style-type: none"> • Uncertainty of take-up for service users – adapting existing services • Regional lead for dementia 	<ul style="list-style-type: none"> • Local Implementation Network (LIN Group) • Memory Clinic accreditation (Aspire to obtain excellent status within two years) 	Red	