Gloucestershire Primary Care Dementia

NHS Gloucestershire

Dementia Services in Primary Care for Gloucestershire: a working document requiring feedback from practitioners

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Gloucestershire County Council

Introduction

National Context

The impact of dementia is already hugely challenging to our society, with about 700,000 people in the UK currently living with this condition. Given that dementia most commonly affects people over the age of 65, it is set to become an even greater challenge in light of predicted population increases. It is suggested that the older population is growing twice as fast as the population as a whole. By 2031, it is predicted that more than 40% of the population will be aged over 50, and 9.1% will be over 85 years.

The number of people with dementia is expected to double to 1.4 million in the next 30 years.

The National Dementia Strategy was published in February 2009. It sets an ambitious agenda to transform dementia services across the UK over the next three to five years, based around three key themes:

- Raising awareness and understanding
- Early diagnosis and support
- Living well with dementia

The National Dementia Strategy recommend the use of memory services for early diagnosis and treatment, the introduction of a Dementia Advisor role as well as facilitating peer support through forums such as Memory Cafés. The National Dementia Strategy challenges commissioners with an expectation that the principles of World Class Commissioning will underpin service redesign.[1]

Gloucestershire Context

Within Gloucestershire, there are currently approximately 106,000 people over the age of 65 living in both urban and rural settings, representing a wide socio-demographic range. This is proportionally greater than the over 65 population in England and Wales as a whole.

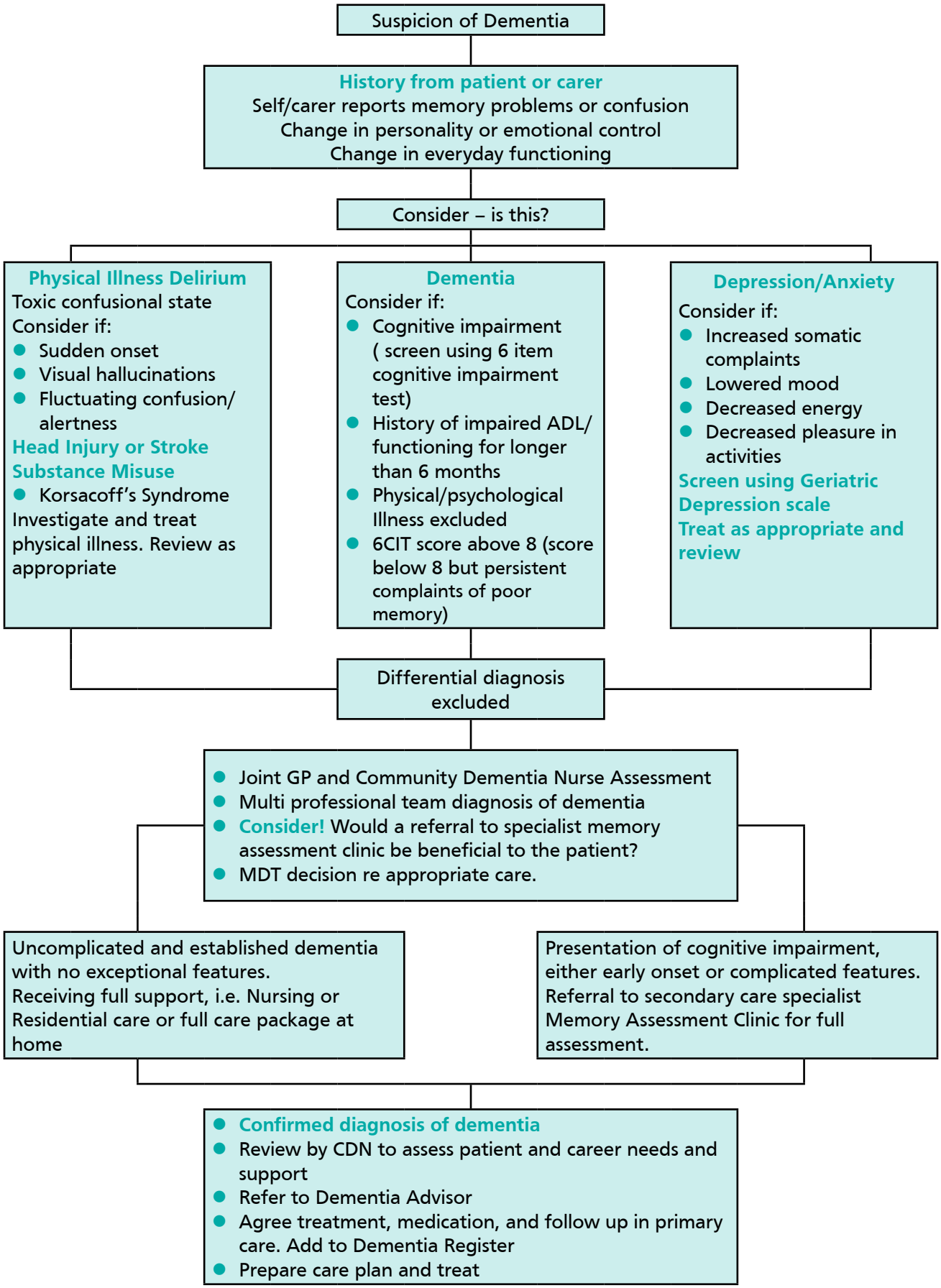
Nationally this group represents 16.1% of the population, but in Gloucestershire this figure is 17.7%. By 2025, the population of over 65 years in Gloucestershire is expected to have increased by 45%, and the over 85s by 75%.

Estimates suggest that in 2008, there were just under 8,000 people aged 65 and over living in Gloucestershire with dementia: it is projected that this is likely to rise to nearly 12,000 by 2025, an increase of nearly 50%. [2]

NHS Gloucestershire is committed to the implementation of the National Dementia Strategy. In early 2009 it participated in patient and carer consultation. The Strategic Health Authority (SHA) conducted a review of dementia services in the region. The review recognized early successes in working towards the key targets of the National Dementia Strategy, as well as emphasising the direction of travel. The Local Improvement Programme (Action Plan) was submitted to the NHS Gloucestershire Professional Executive Committee (PEC) in July 2009.

1. DoH (2009) Living well with dementia: a National Dementia Strategy. London: DH
2. Gloucestershire Joint Strategic Needs Assessment Version 2

Early Diagnosis and Support



Dementia Diagnostic Pathway Guidance Notes

Defining Dementia

- Dementia is a syndrome which may be caused by a number of illnesses in which there is a progressive decline in multiple areas of function, including decline in memory, reasoning, communication skills and the ability to carry out daily activities There may be impairment of emotional control, social behaviour and motivation
- There is no clouding of consciousness

Types of Dementia

- **Alzheimer's disease** 60%
  Characterised by gradual onset and continuing cognitive decline
- **Vascular dementia** 20%
  Associated with cerebrovascular disease. Typically more abrupt onset, often stepwise, fluctuating decline in function
- **Lewy Body dementia** 15%
  A similar regressive decline as in Alzheimer's but with parkinsonian features, frequent psychotic symptoms (visual hallucinations, delusions) and a history of falls
- **Front-temporal dementia** 5%
  Personality and behaviour may be affected before memory

Many patients may have a mixed cause (Alzheimers and Vascular dementia)

Prevalence and Incidence

- Incidence (the number of new cases per year) and the prevalence (the number of cases at any time) rise exponentially with age.
- Approximately 6% of the population over 65years of age, rising to 30% over 90 years of age may be affected
- This equates to approximately 20 patients per GP list of 2,000 patients

Benefits of Early Diagnosis

Historically diagnosis of dementia has often been relatively late in the illness. Currently approximately 30% of patients with dementia have been identified, diagnosed and appropriate support offered (70% have not). The National Dementia Strategy encourages early diagnosis in order to ensure that timely treatment, care and support is offered.

Advantages of early diagnosis may include:

- Treatment with dementia modifying drugs
- Advice and care from :
  - Primary Health Care Team (including annual health check and health care needs related to dementia)
  - A named specialist mental health nurse (Community Dementia Nurse)

    A named Dementia Advisor to support and signpost to additional support services
- Opportunities for peer group support
- Support and education opportunities for carers
- Opportunity for the individual to make informed advanced welfare decisions

All patients with a diagnosis of dementia will be offered the support as listed above

Differential diagnosis

Important considerations include:

- Physical illness:
  - Toxic confusional state (delirium). Consider if sudden onset, visual hallucinations and fluctuating confusion/alertness. Investigation and treatment of physical illness is indicated
  - Endocrine or metabolic disturbance
  - Head injury, malignancy or sub dural haematoma
  - Stroke
  - Substance misuse / Korsakoff
- Psychological illness:
  - Consider if increased somatic symptoms, lowered mood, decreased energy, decreased pleasure in activities
  - Depression
- Mild Cognitive Impairment (MCI). There is subjective cognitive deficiency with no decrease in function. However 60% of those diagnosed with MCI progress to dementia within 5 years and will need to be regularly reviewed

Diagnosis of Dementia

Dementia can be considered a likely diagnosis if:

- History from patient and carer describes:
  - memory problems or disorientation
  - change in personality or emotional control
  - change in every day functioning
- Alternative diagnoses excluded (see notes re diagnosis as above)

- Cognitive impairment demonstrated on testing (6 item Cognitive Impairment Test). Scores above 8 are strongly suggestive of dementia. Scores below 8 but with definite history may be indicative of dementia and such patients should be considered for further assessment.
- Final diagnosis of dementia should be considered as a multi-professional decision and based on the best interests of the patient. Two routes for this process exist:
  - **A – discussion between GP and Community Nurse** with experience of dementia
  - **B – full assessment in specialist memory clinic**

  For consideration of these routes see below.

Referral to Specialist Memory Clinic – what is in the patient's best interest?

Advantages of referral to a specialist memory assessment clinic (Route B) include:

- Early assessment of early symptoms of dementia or MCI
- Difficult differential diagnosis issues
- Detailed diagnosis of specific types of dementia which may influence treatment offered
- Assessment of suitability for anti-dementia drug treatment (NICE guidelines)
- Patient and carer preference

Patients presenting with early, suspected symptoms of dementia, or complex symptoms and problems in differential diagnosis, will need the full assessment of their memory. This is best provided through the Memory Assessment Clinic pathway .

A few patients however, may have symptoms of advanced memory loss and assessment in Primary Care by a GP and a Community Dementia Nurse may be more appropriate. A multi-professional group within Gloucestershire has considered this option and believes that for this group of patients, referral to the Memory Assessment Clinic gives no value to the patient. The decision to diagnose and manage within primary care should be based on what is in the best interests of the patient, and will be considered with the patient and carers.

A diagnosis by either route will result in the same package of support.

Actions as Result of a Diagnosis of Dementia

All patients diagnosed by whatever route, will be offered:

- An initial Care Plan within 4 weeks of diagnosis explaining the next steps in support planning support
- A named Community Dementia Nurse
- A named Dementia Advisor

Living with Dementia

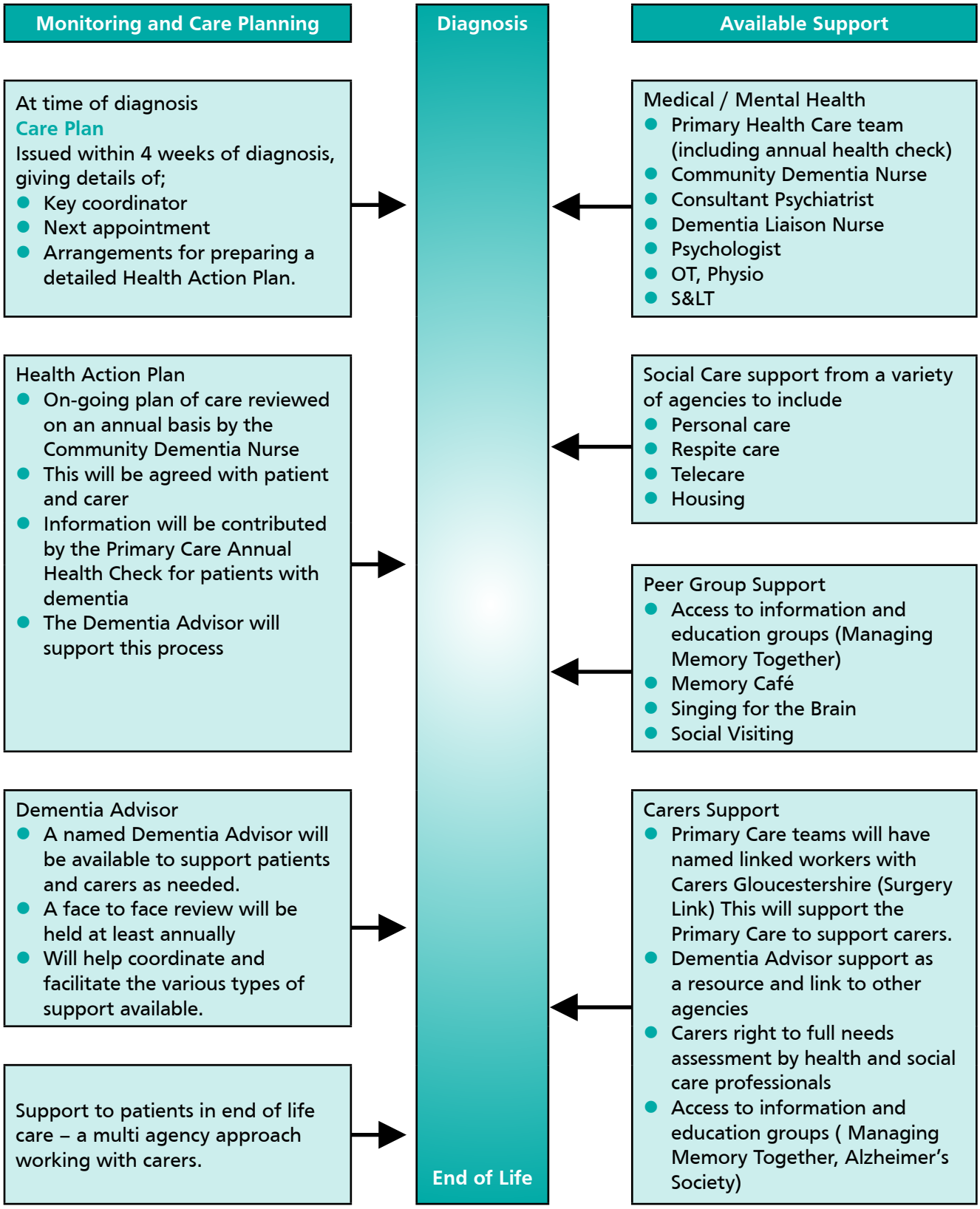
Ensuring good quality of life for persons with dementia involves multi-professional, multi-agency working in close partnership with carers. It is the purpose of this section to consider:

- A pathway of care from diagnosis to end of life
- The medical management of dementia as a long term condition
- The role and responsibilities of professionals and agencies in providing care to the individual and their families
- The services available to support persons with dementia and their carers
- Information and education support for persons with dementia and their carers

Enabling the person with dementia to live well with dementia following diagnosis, would also consider:

- Social inclusion
- Empowerment
- Utilising and supporting family and community structures
- Promoting independence for as long as possible

a. Pathway of Care – dementia diagnosis to end of life



Diagnosis

At the time of diagnosis each person will have:

- Contact with
  - A Primary Health Care Team
  - A named Community Dementia Nurse (²gether Trust) who will be a Community Mental Health Nurse with expertise in the management of dementia
  - A named Dementia Advisor who will support the person with dementia and their carer. The Dementia Advisor will have knowledge of local health, social care and voluntary sector support services and will also be able to coordinate and signpost to other agencies, to provide the support to meet the needs of the individual and carer
- A Care Plan will be issued within 4 weeks of diagnosis and give details of the next steps in arranging assessment and the planning of support. A lead person will be named and contact details given. This person will help lead both the person with dementia and carers through this initial period.
- An agreed medication treatment plan (if indicated). For some patients specific medicines aimed at treating the dementia may be appropriate.
- An offer of information and education opportunities for both the person with dementia and their carer. This could be as a referral to the Managing Memory Together project. For some patients, alternative routes for education and information may be more appropriate.

b. Chronic Disease Monitoring

Each Primary Health Care Team will hold a Register of patients with dementia in order to ensure ongoing support and review is routinely offered to patients with dementia and their carers.

Regular monitoring and review will be offered:

- Annual review by Community Dementia Nurse with preparation of a Health Action Plan. Information will be given to the person and their carers of the support that may be appropriate to their needs
- An Annual Health Check by a member of the Primary Health Care Team. This information will help to inform the Health Action Plan and, subject to patient agreement, this information will be shared with the Community Dementia Nurse.
- The Dementia Advisor will arrange an annual face to face review with the patient and their carer. The Dementia Advisor will be available between these checks according to need. The Dementia Advisor will liaise with the Community Dementia Nurse in both the planning and the implementation of the Health Action Plan.

Sharing of Information

The individual and their carer will be informed of the need to share information with health, social care and voluntary agencies. Subject to agreement by the patient it is intended that information will be shared in order to maximize communication and ensure that the implementation of the Health Action Plan is closely linked to the needs of the individual.

Further work is needed on the governance and IT implications of information storage and sharing. In principle it is expected that:

- Primary Care will receive advice from the Primary Care Clinical Audit Group on relevant templates and codes for information storage in order to support later audit.
- Primary Care data should be shared with Community Dementia Nurses who will be based within the Community.
- The implications and practical aspects of sharing information between Primary Care, the Community Dementia Nurse, and the Dementia Advisor needs to be fully explored.
- Patient held records, using a health facilitation model will be explored in more detail as a means of both sharing information and empowering the patient and carer in the planning of their health and social care.
- Methods for the electronic sharing of important data between multiple agencies involved in caring for patients with dementia will be explored.

c. Medicines Management

Initial assessment for suitability of medication will be made by a Consultant Psychiatrist and involve consultation with patient and carers. Monitoring of dementia drugs will be according to NICE guidelines. This will involve a 6 monthly review including an MMSE score by the Community Dementia Nurse.

A Shared Care procedure is being updated to reflect current NICE guidelines. This will also include guidelines for GPs and Community Dementia Nurses when considering circumstances in which it is appropriate to discontinue medication.

d. Problem Management

Mental health and behaviour problems relating to dementia will be assessed and managed by Primary Health Care Teams, under their usual General Medical Services (GMS) or Personal Medical Service (PMS) contracts. PHCTs may refer as needed to:

- Community Dementia Nurses
- Consultant Psychiatrist for Older People
- Other agencies as appropriate

Support to patients with dementia during admissions to District General Hospitals and Community Hospitals will be given by Dementia Liaison Nurses attached to these hospitals.

e. Social Care

Following assessment of need by the Community and Adult Care Services, packages of support will be considered and planned. Details will be listed within the Care Plan.
This may include:

- Personal care
- Intermediate care
- Housing support
- Telecare
- Respite Care (short term and holiday)
- Care Homes
- Domiciliary Care

These services may be provided by a number of different agencies

f. Peer Group Support and Maintaining Personhood

Available for all persons with dementia:

- Memory Café
- Singing for the Brain
- Expert Patient Programme

Additional projects, such as reminiscence therapy, poetry and theatre exist throughout the county and may be accessible to the individual. Details of these additional services will be known to Dementia Advisors and recommended accordingly. These resources are not currently centrally funded or commissioned, but projects providing high quality care may be considered for County provision in an effort to ensure equitable access to high quality services.

g. Carer Support

The following support to carers will be available:

- Managing Memory Together (currently being tested in ten practices) - carer and patient education programme offering advice, information and support. Accessible by self referral or via primary care.
- Primary Care Teams will be supported to develop the services they offer to carers. Carers Gloucestershire will provide a named link to work with practices to support the service they offer to carers
- All Carers have the right to a Carers assessment which can be initiated by any health and social care professional, or by self referral to the GCC Helpdesk
- Ongoing support through contact with the
    - Dementia Advisor
    - Community Dementia Nurse
    - Voluntary organisations, e.g. Alzheimer's Society

h. End of Life Care

Whilst persons living with dementia and their carers can be well supported by general end of life care planning, there are specific issues that need to be considered. The effect of dementia on mental capacity means that end of life decisions, choices, and advanced decisions must be considered at an earlier stage than other long term conditions. There is understandable concern about addressing this at the same time of the diagnosis. Both the Dementia and End of Life strategies seek to widen public awareness with training and education.

Whilst symptom management is addressed by tools such as the Liverpool Care Pathway, there is debate how dementia affects ability to communicate pain, for example. Integrating end of life considerations into diagnosis and review processes will enable care to reflect the persons needs more accurately. From mid October 2009, five Stroud locality care homes will be piloting Advanced Care Planning.

Carers will be able to access support through Carers Gloucestershire and the Alzheimer's Society.

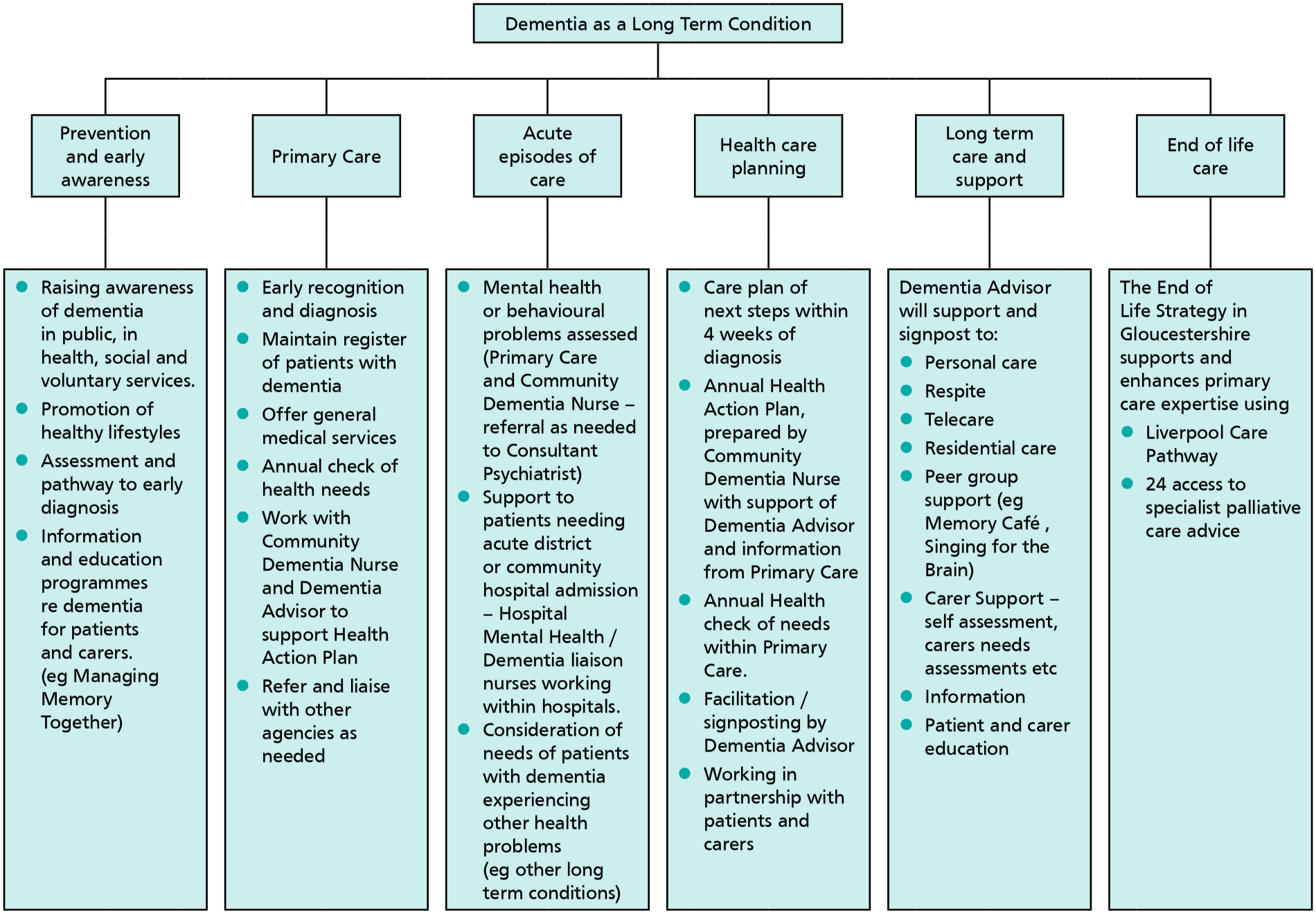
i. Quality of Care

It will be essential for provision of services and standards of care to be monitored in order to ensure learning and the subsequent planning of improved services. Audit of care given needs to be considered across the whole range of services, and throughout the patient's journey in dealing with dementia.

The following points summarise the work to be done:

- Monitoring of commissioning outcomes
- Incident reporting and analysis
- Common data sets for audit
- Agreement on information access / sharing between agencies
- Consideration of data codes within each service and suitability for future audit.
- Multi-agency approach to audit and learning

j. Long Term Condition Map



Feedback

Please return by **18th December 2009** to

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