Gloucestershire National Dementia Strategy

NHS Gloucestershire

Gloucestershire Primary Care Dementia Pathway:

A working document 2010 – 2011

2gether Making life better

Foundation Trust For Gloucestershire NHS

Gloucestershire County Council

CONTENTS

Introduction

The first version of this report was launched at the 2nd Gloucestershire Primary Care Dementia Summit in November 2009. This revised version includes:

- Recent developments in the pathway of care
- Initiatives to support people living with dementia
- Revised range of training options for primary care
- Contact details of agencies supporting people with dementia

This continues to be a working document that requires feedback from health and social care staff.

National Context

The impact of dementia is already hugely challenging to our society, with 800 000 people in the UK currently living with this condition. Dementia mainly affects people over the age of 65 and is set to become an even greater challenge in light of predicted population increases. It is predicted that the older population is growing twice as fast as the population as a whole. By 2031, more than 40% of the population will be aged over 50, with 9.1% being over 85 years.

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

The *Living well with dementia: A National Dementia Strategy* (Department of Health) was published in February 2009. It sets out an ambitious agenda to transform dementia services across the UK over the next three to five years around three key themes:

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

The National Dementia Strategy recommends the use of memory assessment services for early diagnosis and treatment, the introduction of a Dementia Advisor role as well as facilitating peer support through forums such as memory cafes. The National Dementia Strategy challenges commissioners with an expectation that the principles of World Class Commissioning will be used to underpin service redesign, at the same time using resources efficiently.

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 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 aged 65+ in Gloucestershire is expected to have increased by 45%, and for those aged 85+ 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%.

NHS Gloucestershire is committed to the implementation of the National Dementia Strategy and is working with persons with dementia, carers, Gloucestershire County Council, Gloucestershire Hospitals NHS Foundation Trust, Gloucestershire Care Services, [2]gether NHS Foundation Trust, and a number of organisations in the third sector to improve dementia care locally. This document brings together changes in the clinical pathway and service provision to meet these expectations, with a focus on Primary Care.

The themes within this report include:

- Valuing personhood and recognising both the importance of meeting individual needs and respecting the essence of the person
- Recognising dementia as a long term condition rather than a mental illness
- Acknowledging the key role played by carers and making improvements to the support they are offered
- Taking ownership for the care of the person with dementia and carers
- Ensuring that staff have appropriate training with access to those with specialist dementia knowledge and skills
- Introducing early assessment of capacity and active planning of health and social care needs
- Working in partnership with other agencies to improve the standard of care for persons with dementia.

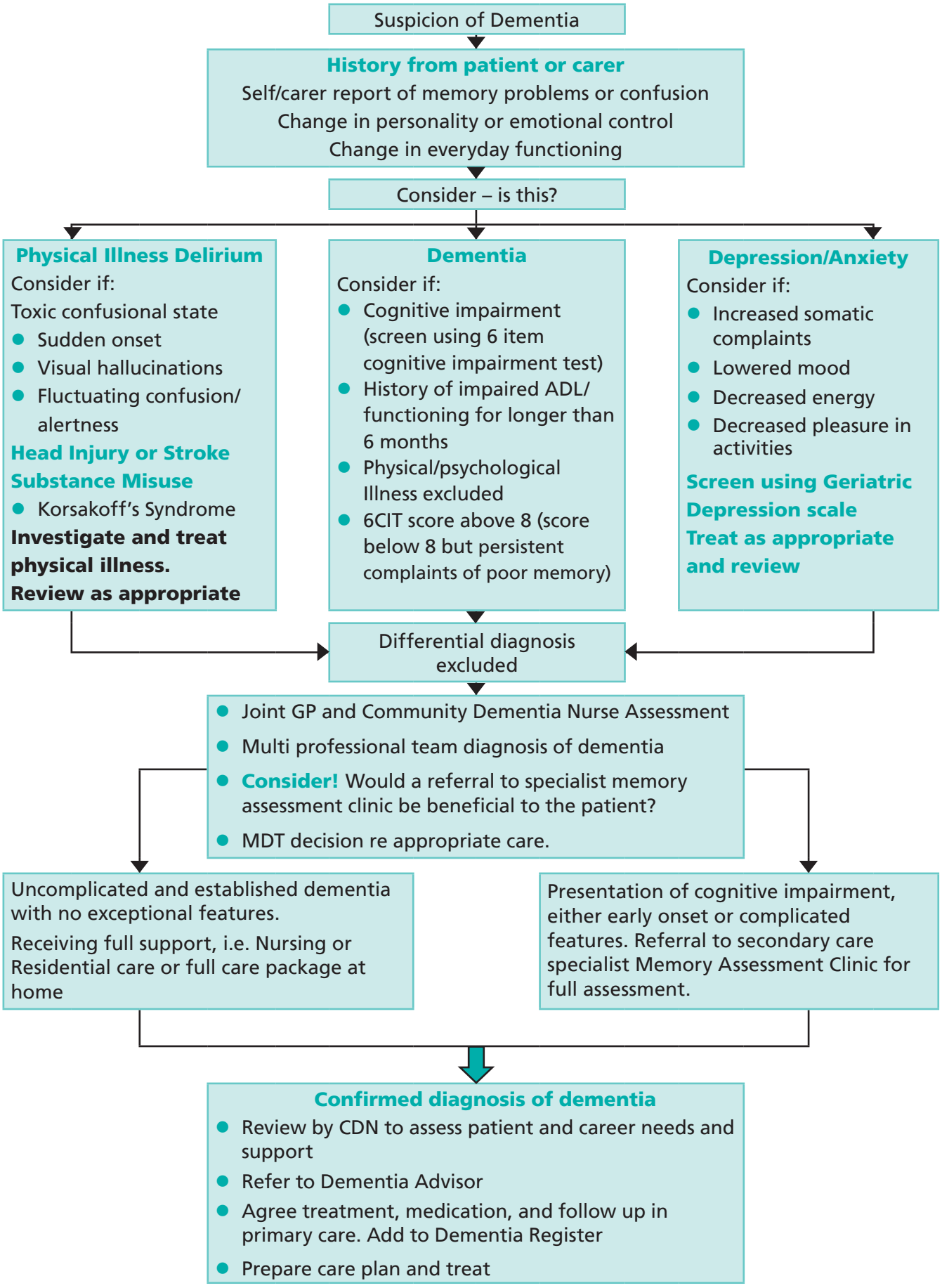
The report includes:

- Pathways for primary care
- Description of the roles and responsibilities of health and social care professionals
- Links to agencies supporting people with dementia
- Tools for health and social care professionals

The emerging priorities for 2010/11:

- Younger Onset Dementia
- Diagnostic resources
- Improving access to dementia services for minority groups

Early Diagnosis and Support



Dementia Diagnostic Pathway Guidance Notes

Defining Dementia

Dementia is a syndrome which may be caused by a number of illnesses where there is 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, but 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
- Less commonly, dementia can occur in younger persons. In Gloucestershire only 25% of patients predicted to have dementia had been identified and diagnosed.

Benefits of Early Diagnosis

Historically the diagnosis of dementia has often been relatively late in the illness. In Gloucestershire, approximately 40% of patients with dementia have been identified, diagnosed and appropriate support offered (60% have not).

The National Dementia Strategy encourages early diagnosis in order to ensure timely treatment, care and support is offered. Identification and diagnosis of dementia rates of up to 80% have been achieved in some parts of the country.

Research suggests that Hospital Anxiety and Depression (HAD) scores for anxiety and depression can be improved in patients diagnosed with dementia and their carers

if the diagnosis is made and explained to them in a sensitive way. Anxiety about symptoms, without the clarity of a diagnosis and support, is a cause of both anxiety and depression.

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 to benefit from 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). Should be considered 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 subdural 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 of:
  - memory problems or disorientation
  - change in personality or emotional control
  - change in every day functioning
- Alternative diagnoses excluded (see notes on differential 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.

Referral to Memory Assessment Service – what is in the patient's best interest?

A final diagnosis of dementia should be considered as a multi-professional decision and any decision should be based on the best interest of the patient

Two routes for this process exist:

- **A – discussion between GP and Community Nurse with experience of dementia**
- **B – full assessment in Memory Assessment Service**

Route A

A few patients may have symptoms of advanced memory loss, assessment in primary care by GP and Community Mental Health Team 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 Service gives no value to the patient and may cause additional distress. The decision to diagnose and manage within primary care should be based on the best interests of the patient, and discussed with the patient and carers.

Route B

Advantages of referral to the Memory Assessment Service include:

- Early assessment of early symptoms of dementia or MCI
- Support for difficult differential diagnosis issues
- Detailed diagnosis of specific types of dementia to ensure appropriate and safe treatment is 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; best provided through the Memory Assessment Service pathway.

Referral to the Memory Assessment Service can be made through Choose and Book.

The Managing Memory ²gether service can be contacted on 0800 6948800 or managingmemory@glos.nhs.uk

Patients concerned about their memory can self refer by contacting Managing Memory ²gether.

Actions as result of a diagnosis of dementia

All patients diagnosed by either route, will be offered:

- An initial Care Plan within 4 weeks of diagnosis explaining the next steps in support planning, and identifying who will support them
- A named community support from either a Community Dementia Nurse or Dementia Advisor

Living with Dementia

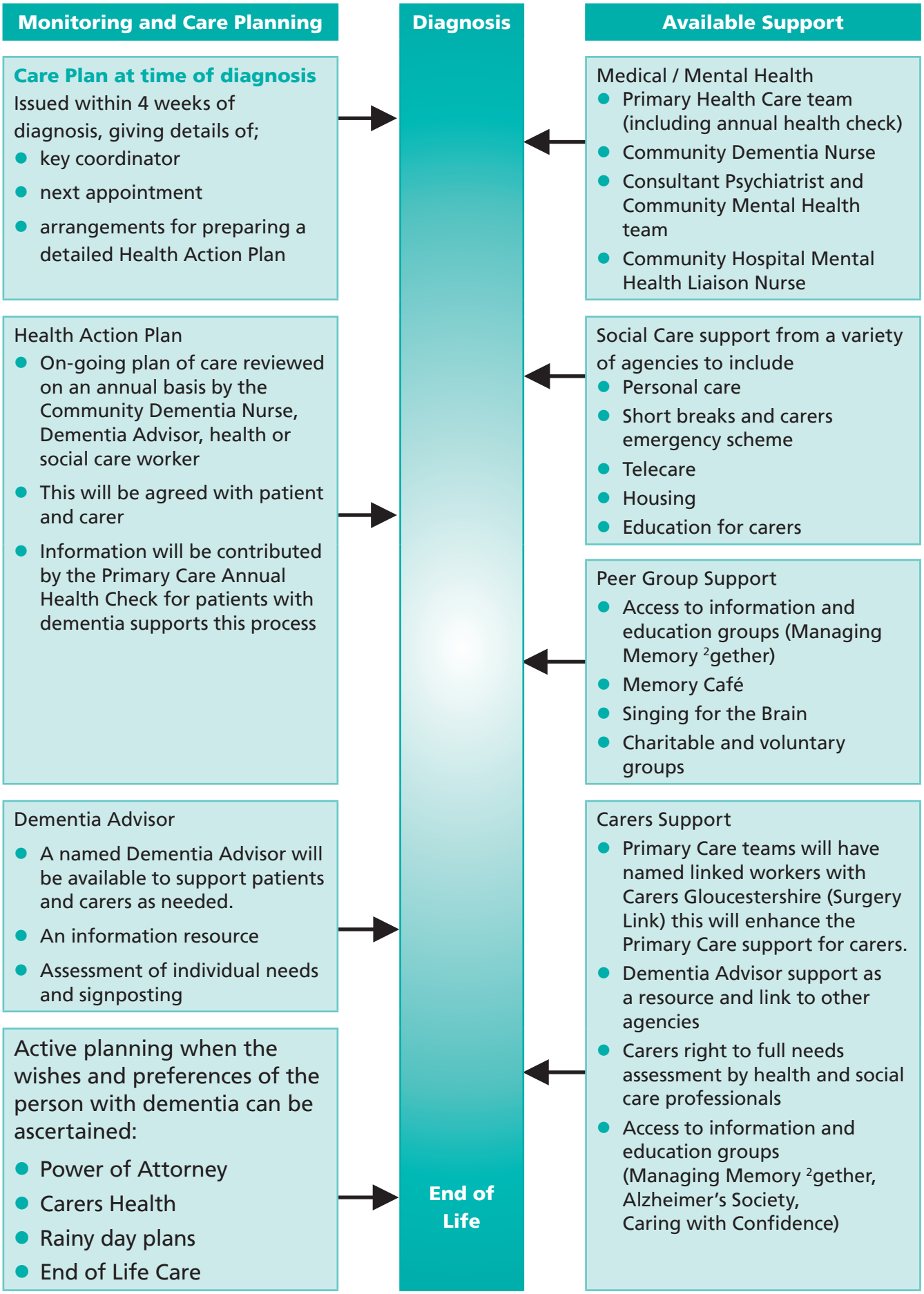
Ensuring good quality of life for persons with dementia involves multi-professional, multi-agency working in close partnership with carers. It is the purpose of this section to consider:

- 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
- Wishes and preferences of the person with dementia.

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



b. New Roles in the Pathway

The care of persons with dementia in the community is the responsibility of all health and social care professionals. Some staff have extended training in the support of persons with dementia.

Within the community:

Dementia Advisor

This service is provided by the Alzheimers Society and jointly funded by NHS Gloucestershire and Gloucestershire County Council. It is currently available to practices in Berkeley Vale and North Cotswolds localities, and named practices in Gloucester City. Discussions are taking place to develop the service county wide.

The Dementia Advisor is an information resource for the person with new or recently diagnosed dementia. They will assess the needs of the person with dementia and provide individually tailored information about access to local services that supports living well with dementia. The Dementia Advisor Information Pack will be added to the Living Well Handbook.

The Dementia Advisor works closely with GP practices and the local community, and can draw on the extensive skills and resource of the Alzheimers Society.

Community Dementia Nurse

This is a service provided by 2gether NHS Foundation Trust nurses with specialist training, knowledge of skills in dementia care.

The Community Dementia Nurse will work closely with the GP to support the person with dementia and their carer during and following diagnosis. There will be a focus on early active multi-agency planning with the individual and carer that seeks to minimize crisis intervention.

They will also work in partnership with the GP to maintain the Dementia Register, review the person centred action plan and the 6 monthly reviews of the ACIs (anti-dementia drugs). Discussions are currently underway with a view to implementing the services across the county for 2011.

Dementia Link Worker

The Dementia Link Worker acts as the dementia champion and expert resource for residents, carers and colleagues within their own work setting. They are supported in continuous development after having received the Dementia Link Worker Award, through specialist workshops run by the Dementia Education Nurses and countywide Dementia Link Worker forums.

Dementia Link Workers have a critical role in improving the environment, promoting person centred care planning and reminiscence work through diaries or memory boxes.

Dementia Link Workers have previously been predominantly working in care homes, but the Joint Dementia Training and Education Strategy has now developed this role in domiciliary care teams, including independent providers and community hospitals.

Diagnosis

At the time of diagnosis each person will have:

- Contact and support with
  - A Primary Health Care Team
  - A named contact for additional support and signposting in respect of the dementia management. This may be :
    - A Community Dementia Nurse
    - A Dementia Advisor
- A care plan will be issued within 4 weeks of diagnosis and a health professional named to lead the person with dementia and their carers through the next stages. This will be either a member of the Memory Assessment Service, or the Community Dementia Nurse based in primary care. Details within the Care Plan will include:
  - Name and contact details of the named Care Plan lead professional
  - Details of the next steps in planning assessment and support
- 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 may be involvement in the Managing Memory ^{2}gether service. For some patients, alternative routes for education and information may be more appropriate
- A Living Well Handbook for personalised information recording
- Their details added to the primary care team register of patients with dementia.

c. Long Term Condition 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:

- An Annual review by a Community Dementia Nurse or Dementia Advisor 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 Community Dementia Nurse or Dementia Advisor will arrange an annual face to face review with the patient and their carer. They will also be available between these checks according to need.

See Appendix 1 – Dementia as a Long Term Condition

d. Data collection and information sharing

Following multi agency consideration of data and information sharing the following is recommended as a co-operative approach. Primary Health Care Teams should liaise with the attached Community Dementia Nurse to finalise working habits, within the following guidelines.

All recommendations regarding the sharing of the information will be subject to discussion with the person with dementia and their consent obtained.

Data collected and place of recording:

- Diagnosis of dementia – Primary Health Care Register of dementia, in line with Quality and Outcome Framework guidelines. It is the responsibility of Primary Health Care teams to keep an up to date register of persons with dementia
- Annual Health Check will be performed according to Quality Outcome Framework within Primary Care. This will involves a Primary Health Care Team assessment of persons with dementia in respect of health, psychological and carer need. Guidelines for data collection are available in template format with associated relevant codes. (Available on the Primary Care Clinical Audit Group (PCCAG) website. Additional advice and support is available from the PCCAG Team)
- A Health Action Plan will be prepared by the Community Dementia Nurse, Dementia Advisor or health care professional. This will be owned by the person with dementia in their Living Well Handbook.

The Living Well Handbook

The Living Well Handbook is owned by the person with dementia and their carer, and can act as a single resource that holds up to date information about the individual and their needs. It allows the person with dementia and their carer the opportunity to share information that health and social care agencies can use to plan person centred care, and for professionals to contribute information that is timely and appropriate.

The Living Well Handbook contains:

- Summary of emergency medical and contact details
- Can be added to by Great Western Ambulance Service alert system
- Person centred care plan
- Advanced care plan that include end of life care
- Dementia advisor information pack
- Details of Health Action Plan
- Appropriate, timely information such as *This is Me*, DisDAT Distress Tool.

Community Dementia Nurses, subject to agreement with individual practices, will be able to enter relevant clinical data onto the Primary Health Care Team computer record. This will support a single clinical record. Further work will be undertaken to ensure effective record keeping, whilst avoiding the need for unnecessary duplication of work.

The following guidelines are recommended for the sharing of information:

- Subject to agreement with individual Primary Health Care teams the Community Dementia Nurse will be allowed access to the Primary Health Care record, the

Community Dementia Nurse will be asked to enter significant clinical details in the Primary Health care record. This would include:

- Completion of an annual contact for review of dementia care needs
- Completion date of Health Action Plan
- Significant clinical details affecting ongoing patient care.

- Data regarding contract monitoring, activity and administration will continue to be recorded on the [2]gether NHS Foundation Trust information management system
- Information with other Third Sector agencies, including the Dementia Advisor, will be via the person held Living Well Handbook. Further sharing of information will be as a result of consent agreed and recorded by the person with dementia.

e. Medicines Management

The prescribing of anti-dementia drugs will be in accordance with NICE guidelines and are summarised in the new Gloucestershire Shared Protocol for prescribing anti-dementia drugs (see PCT intranet). Initial assessment for suitability of medication will be made by a Consultant Psychiatrist in consultation with the patient and carer. Monitoring will be in accordance with the Shared Care Protocol and will include a Mini-Mental State Examination (MMSE) by the Community Dementia Nurse.
The Community Dementia Nurse and General Practitioner should consider together when it is appropriate to stop the prescribing of anti-dementia drugs.

The prescribing of antipsychotic drugs in persons with dementia has recently been the focus of a report *Antipsychotic medication – time for action* by the Department of Health. This report encourages a reduction in use of antipsychotic drugs for the management of behavioural problems in dementia care. A county guidelines for the management of behavioural problems has been prepared and is attached as a summary.

See Appendix 2 – Managing Behaviour Problems in Patients with Dementia (2010).

f. 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. In Primary Health Care Teams may refer as needed to:

- Community Mental Health Teams and Consultant Psychiatrist
- Consultant Psychiatrist for Older People
- Other agencies as appropriate.

Support to patients with dementia admitted to District General Hospital and Community Hospitals will be given by Mental Health Liaison Nurses attached to these hospitals.

The Alzheimer's Society's *Counting the Cost: caring for people with dementia on hospital wards* (2009) report drew attention to the negative effects often experienced when persons with dementia are admitted to acute hospitals on both their physical and cognitive symptoms.

The following issues are recommended for consideration when persons with dementia require admission to a District General or Community Hospital:

- Could additional support be provided at home rather than admission?
- Advance planning with view to reducing need for unscheduled care may involve:
  - Carers education programmes www.gloucestershire.gov.uk/caringwithconfidence
  - Registration in advance with Emergency Care Scheme
  - Discussion at Annual Health Check and Health Action plan of potential problems, and recording of active planning decisions on Adastra
  - Consideration of End of Life Care needs are reviewed and documented accordingly
- Informing ward staff of diagnosis by means of practice summary
- Encourage the recording of issues relating to the individual person in the Living Well Handbook.

g. Active planning

Persons with dementia will experience gradual reduction in their memory and reasoning during the course of their illness. This gradual change may have a significant impact on their capacity to weigh up choices and make decisions.

It is essential to discuss the individual's wishes regarding their future care and welfare with professionals and carers so that options are considered at an early stage in the disease journey.

The following points consider steps of active planning that need to be considered:

- Lasting Powers of Attorney (LPA). Two separate powers exist:
  - Lasting Powers of Attorney for finance
  - Lasting Powers of Attorney for health and welfare decisions
- Carers health and well-being
  - Carers education programme from ²gether NHS Foundation Trust and Gloucestershire County Council or Third Sector
  - Registration with Emergency Carers Scheme
- Living Well Handbook
  - Rainy day plans: how and where the person wants to be cared for if changes occur
  - End of life planning using the Advanced Care Plan
- Acute physical illness
  - Consider in advance possible risks and discuss treatment options. Will an acute hospital admission lead to a benefit to a patient, or could increased support in a home environment be more appropriate.
  - Record on ADASTRA out of hours record keeping system active care plans and guidelines.

h. Social Care

Following assessment of need by the Community and Adult Care Services, packages of support will be considered and planned. A support plan will be developed which will identify how those needs will be met – individuals and their carer will be fully involved in the development of this support plan. Details will be listed within the Care Plan. This may include:

- Personal care
- Intermediate care/Reablement
- Housing support
- Telecare
- Short breaks and support for carers
- Emergency Carer Scheme registration
- Care Homes
- Domiciliary Care

These services may be provided by a number of different agencies.

i. Peer Group Support and maintaining personhood

NHS Gloucestershire has allocated funding to Local Planning Teams (District Councils) to increase county wide access to peer support for persons with dementia, which will include memory cafés. Funding has been allocated to the third sector organizations that provide:

- Mindsong groups in care homes through Three Choirs
- Singing for the Brain by funding the training of additional facilitators provided by the Alzheimers Society
- Expert Patient Programme

Additional projects, such as reminiscence therapy, poetry and theatre exist throughout the county and may be accessible. Details of these additional services will be known to Dementia Advisors and recommended accordingly. Those projects providing high quality care may be considered for county provision in an effort to ensure equitable access to high quality services throughout the county.

j. Carer Support

The following support to carers will be available:

- Carers Gloucestershire supports primary care to improve the information and service they offer to carers. Carers Gloucestershire's Surgery Link will provide a named link to work with practices to support carers. www.carersgloucestershire.org.uk or 01452 386283
- All Carers have the right to their own Carers assessment which can be initiated by any health and social care professional, or by self referral to the GCC Helpdesk on 01452 426868

- Gloucestershire County Council provide a range of services in partnership with Carers Gloucestershire and other third sector providers:
  - Advocacy Trust Gloucestershire (ATGlos) 08454 0511203
  - Carers Emergency Scheme via GCC Helpdesk 01452 426868
  - Caring with Confidence – carers education on 01452 500885
- Managing Memory [2]gether; a carer and patient education programme offering advice, information and support is accessible by self referral or via primary care on 0800 6948800
- Ongoing support through contact with the
  - Dementia Advisor
  - Community Dementia Nurse

Voluntary organisations, e.g. Alzheimer's Society, Age UK.

k. 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 about how dementia affects the ability to communicate pain, for example. Integrating end of life care into diagnosis and review processes will enable care to reflect the person's needs more accurately. From mid October 2009, five Stroud locality care homes successfully piloted the Advanced Care Plan, and this will be rolled out county wide in January 2011.

l. Quality of Care

It is 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 Primary Care Clinical Audit Group (PCCAG) is providing advice on data collection and codes for data collection in Primary Care.

The following actions are being taken to monitor the quality of care given:

- Primary Care contract – issues relating to the dementia register, annual health check of persons with dementia and carer registers and support is monitored through the Primary Care Contract Framework
- County wide audit of dementia care by PCCAG being considered for 2012
- Monitoring performance through contractual agreements with providers
- National and regional benchmarking of dementia services
- All acute hospitals participating in national audit of care of persons with dementia in acute hospital settings.

m. Education in Primary Care

Education Options for Dementia Training Awareness for GPs and Practice Staff, gives details of the training options that have been developed for primary care teams. Additional elements for GPs are being finalised with Gloucestershire GP Education Trust (GCPET).

See Appendix 4. Information and support in raising awareness of the issues relating to dementia is available to all members of the Primary Health Team.

For further information contact:

Helen Vaughan on 08454 221947 or helen.vaughan@ glos.nhs.uk

n. Further information

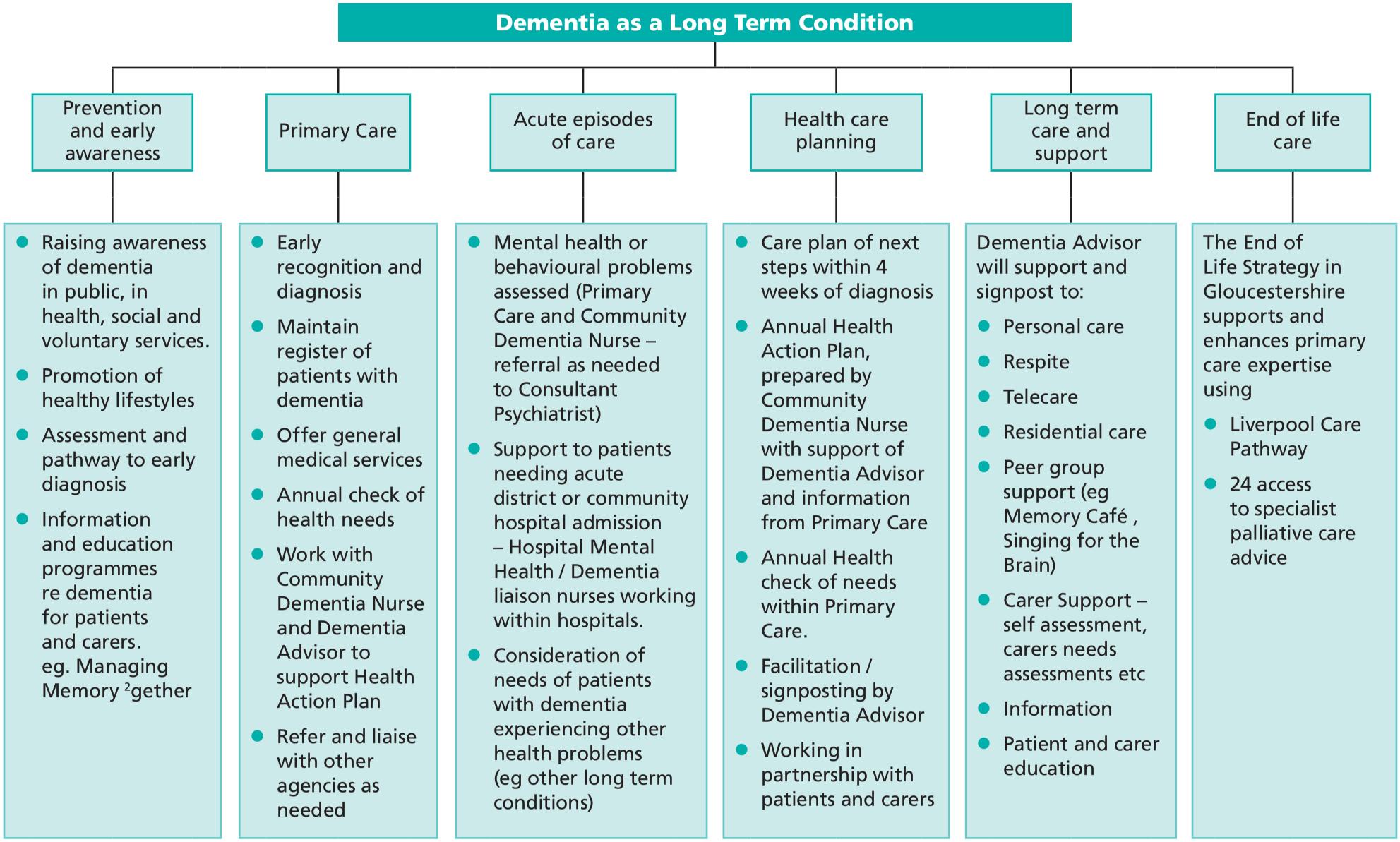
For further information on dementia services in Gloucestershire:

- NHS Gloucestershire intranet
  http://nww.glospct.nhs.uk/C15/C3/Dementia/default.aspx
  The Living Well Handbook – Section 4 and 5
  See Appendix 5

National and Regional information is available:

- South West Dementia Partnership
  www.southwestdementiapartnership.org.uk
- Department of Health Care Networks
  www.dcarenetworks.org.uk
- Social Care Institute for Excellence
  www.scie.org.uk

Appendix 1


Dementia as a Long Term Condition
Prevention and early awareness
Primary Care
Acute episodes of care
Health care planning
Long term care and support
End of life care
Raising awareness of dementia in public, in health, social and voluntary services.
Promotion of healthy lifestyles
Assessment and pathway to early diagnosis
Information and education programmes re dementia for patients and carers. eg. Managing Memory 2gether
Early recognition and diagnosis
Maintain register of patients with dementia
Offer general medical services
Annual check of health needs
Work with Community Dementia Nurse and Dementia Advisor to support Health Action Plan
Refer and liaise with other agencies as needed
Mental health or behavioural problems assessed (Primary Care and Community Dementia Nurse – referral as needed to Consultant Psychiatrist)
Support to patients needing acute district or community hospital admission – Hospital Mental Health / Dementia liaison nurses working within hospitals.
Consideration of needs of patients with dementia experiencing other health problems (eg other long term conditions)
Care plan of next steps within 4 weeks of diagnosis
Annual Health Action Plan, prepared by Community Dementia Nurse with support of Dementia Advisor and information from Primary Care
Annual Health check of needs within Primary Care.
Facilitation / signposting by Dementia Advisor
Working in partnership with patients and carers
Dementia Advisor will support and signpost to:
Personal care
Respite
Telecare
Residential care
Peer group support (eg Memory Café , Singing for the Brain)
Carer Support – self assessment, carers needs assessments etc
Information
Patient and carer education
The End of Life Strategy in Gloucestershire supports and enhances primary care expertise using
Liverpool Care Pathway
24 access to specialist palliative care advice

Appendix 2

Managing behaviour problems in patients with dementia

(Does not cover rapid tranquillisation of acutely disturbed)

Patient has behavioural and psychological symptoms in dementia (BPSD) (delusions, hallucinations, agitation, aggression, irritability etc with steady decline in cognition over 6/12)

Yes → Does patient have a Delirium? (Short history <1 week confusion, hallucination, delusions with fluctuating cognition)

Yes → Treat underlying acute medical problems e.g. UTI, chest infection, side effects of drugs, alcohol and drug withdrawal etc.

No ↓

Apply "**PAIN**" approach and manage or treat:
P = Physical problems, e.g. infection, pain
A = Activity-related e.g. dressing, washing
I = Latrogenic e.g. side effects of drugs e.g. anticholinergics
N = Noise and other environmental factors e.g. lighting

→ Behavioural problems unresolved

Identify the dominant target symptom group – see chart below
Consider risk – benefit of drug treatment vs other options such as tolerating the symptom or altering care environment.

Consider non-pharmacological approaches; distraction, leave and return, activity, one-to-one care, music, aromatherapy, carer support may improve coping ability of carer

Could this be Dementia with Lewy bodies or Parkinsons disease dementia?
Key Features: long term (> 6 months) history of vivid visual hallucinations or Parkinsonism or fluctuating cognition.
If unsure, get specialist advice

Delirium
- After a delirium resolves, an underlying dementia is often apparent.
- Antipsychotic drugs may be used short-term for delirium but note problems with antipsychotic drugs can cause in dementia (see below)
- Keep number of doses to a minimum (eg 3 doses of haloperidol or risperidone in absence of a dementia history)

In the event of continuing problems, advice can be obtained from CMHT's

If pharmacological treatment is needed:
Document that discussion to initiate drugs has taken place with carer, and where possible the patient.
Antidepressants: much safer than antipsychotics, often worth a trial of Mirtazepine.
Benzodiazepines/hypnotics: Diazepam used regularly is often troublesome. Lorazepam is powerful, short acting, with little hangover effect but tolerance can develop quickly
Antipsychotic drugs in dementia: have a high rate of adverse effects. For example:
- Increased risk of CVA's (~3x) and Increased mortality rate (~2x)
- Reduced cognitive function
- Risk of falls and Parkinsonian effects
- Risks even higher in Parkinson's related dementia / dementia with Lewy bodies
- Risks rise with length of course and higher doses.

If antipsychotics are necessary:
Only prescribe initially as a time-limited course
- If longer term use considered, ensure the decision is based on consultation with individual, carers, secondary care and the outcome is documented
- Prescribe at lowest effective dose.
- Try withdrawing drug at intervals – see guidance below.
- Use one drug rather than two if possible.

Withdrawal from Antipsychotic Drugs
Ensure that drug is not being prescribed for other psychiatric illness: If unsure, ask psychiatric services to check this before reducing doses.
- Try withdrawal at intervals – this is generally successful.
- Is the drug still needed? If unsure, try tapering doses off gradually over 2-3 month period.
- If behavioural symptoms re-emerge, consider using intermittent 6 week courses, recommencing only if needed.

Acetylcholinesterase inhibitors (ACIs) Donepezil, Rivastigmine, Galantamine
* To be initiated by secondary care and patient monitored while treatment continued.
Memantine
* Use only by specialist services: only if placement at risk and other alternatives tried.

Treatments for Behavioural and Psychological Symptoms in Alzheimer's Disease, Dementia with Lewy Bodies or Parkinsons Disease Dementia

Key Symptom	First Line	Second Line	Third Line
Depression / anxiety Apathy	SSRI or Mirtazepine, reassess at 4 weeks	*ACI drug, Eg Donepezil	Risperidone Rarely for anxiety in AD
Psychosis – **if urgent** effect needed Reduce antiparkinsonian drugs first	2 week course of Risperidone 0.5mg daily increasing to bd (*extreme caution in Lewy Body / Parkinson's)*	* ACI drug, Eg Donepezil	
Psychosis – if can wait a week for effect	* ACI drug, Eg Donepezil	2 week course, Risperidone (*extreme caution in Lewy Body/ Parkinson's)*	* Memantine
Aggression – consider behavioural triggers first	Trazodone 50mg daily, increasing to twice daily, reassess 4 weeks	2 week course, Risperidone	
Agitation / restlessness	Trazodone – doses as above	2 week Risperidone as above, Mirtazepine Memantine	Carbamazepine
Poor sleep	Increase daytime light levels	Temazepam or Zopiclone Trazodone 50-100 mg	(Melatonin in LD)

Vascular Dementia or Stroke Related Dementia

Broadly, similar treatments can be used as in the table above for Alzheimer's, except that ACI drugs are much less likely to be effective and the evidence base for Memantine is much weaker.

Frontal-Temporal Lobe Dementia

Trazodone 50-150mg per day can be helpful; otherwise SSRI drugs

For advice and help:

Non-pharmacological management in care homes: Care Home Support Team 08454 598107

Other issues: Local CMHT & Old Page Psychiatrist

This guidance and future revisions can be found on the Clinical Information section of the NHS Gloucestershire intranet site

nww.glospct.nhs.uk/C1/ClinicalInformation/default.aspx

Review Date: November 2011

Appendix 3

Gloucestershire Health Community
Antipsychotic Medications Prescribed for a Patient with Dementia

Information for Patients, Families and Carers

Antipsychotic medications are a group of drugs which have several different uses.

This information sheet is for situations where a prescriber is thinking of prescribing one of these in order to treat a symptom caused by a dementia. The commonest situations where these drugs are prescribed is where the dementia is causing someone to become agitated, or to experience hallucinations which are causing upset and when alternatives approaches have either been unsuccessful or are not appropriate.
There are also some patients who have been taking one of these medications for some time, where a decision is needed on whether or not to continue the medication. To help make this decision a prescriber may reduced the dose of the antipsychotic medication or stop it in order to assess the benefit of continuing to prescribe the antipsychotic.

There are situations where these medications can be the most effective way of treating the above symptoms and can reduce distress and sometimes allow someone to be more independent. However, there is also evidence that, particularly if used for longer than 2 months, they can have adverse effects for many patients, including:

- Drowsiness
- Falls
- Stooped posture, tremor and stiffness
- Increased risk of strokes
- Increased rate of progression of the dementia
- Constipation
- Some newer medications are less likely to cause falls or tremor, but may cause weight gain, raised cholesterol and sometimes diabetes.

The risks are significantly reduced if doses are kept as low as possible and if the length of time that they are used is kept as short as possible.

Patients taking these medications for prolonged periods (eg. for more than 3 months) should be reviewed at regular intervals so that there can be decisions on whether to continue them.

Appendix 4

The Dementia Training & Education Strategy for Gloucestershire

Education Options for Dementia Training Awareness for GPs and Practice Staff

The following optional menus are available for all Practice staff and are divided into two sections:

Section 1 "Essential Dementia Awareness"
Section 2 "Further Knowledge in Dementia"

The training is offered in a variety of formats; e-learning and small group face to face learning sessions. The e-learning programmes will help you establish your current knowledge level.

Section 1: The options in Section 1 'Essential Dementia Awareness' lead to knowledge in the following areas:

Describing dementia, symptoms of dementia, types of dementia, differences between dementia, delirium and depression, person-centred approaches and behaviours that challenge and importance of a good diagnosis.

Menu A: (available for all Practice staff)

KWANGO dementia e-learning. Follow the links on the Dementia Training Strategy for Gloucestershire website: www.gloucestershire.gov.uk/dementiatraining
Printed certificate available upon completion. User name: GPd Password: Glos DEM05

Menu B: (available for GPs only)

BMJ e-learning

'Just in time: Alzheimer's disease: diagnosis & management' http://learning.bmj.com

Menu C: (available for all Practice staff)

SCIE e-learning: The Open Dementia Programme (7 modules), Follow the links on the Dementia Training Strategy for Gloucestershire website:

www.gloucestershire.gov.uk/dementiatraining Includes a Record of Learning Log

Menu D: (available for all Practice staff) Delivered by Cathie Bambra, PMHDT Facilitator for Older People

Bite-sized small group multi-disciplinary learning sessions each of approximately 30-60 minutes duration:

- Introduction to Dementia
- Differences between Dementia, Delirium & Depression
- Importance of a Good Diagnosis
- Person-centred Approaches
- Behaviours That Challenge

Certificates are available upon completion.

Working together in partnership

The Dementia Training and Education Strategy for Gloucestershire

Education Options for Dementia Training Awareness for GPs and Practice Staff

Section 2: The options in Section 2 '**Further Knowledge in Dementia**' will lead to knowledge in the following areas:

Person-centred Care: Communication, Mental Capacity Act, Safeguarding Adults, Black & Minority Ethnic Issues, Working with Services and Support Networks, Working with Families and Carers, Approaches in Communication and Life History Work.

Menu F: (available for all staff)

Attendance at Dementia Day 1 & Day 2 Training Workshops:

Day 1: 'Essential Dementia Awareness' (Dementia / Depression / Delirium)

Day 2: 'Person Centred Care & Emotional Distress' (Behaviours That Challenge Us)

Contact: GCC People Organisational Dev. & Workforce Planning Admin Team
Tel: 01452 425519 or follow the links on the Dementia Training Strategy for Gloucestershire website: visit: www.gloucestershire.gov.uk/dementiatraining

Certificate of Attendance presented upon completion.

Menu G: (available for GPs & members of Primary Care Teams):

Attendance at Annual Gloucestershire Primary Care Dementia Summit:

- Full day's protected learning time
- Accredited for CPD – Learning credits 5hrs 45mins

Programme of sessions delivered by professional experts followed by facilitated workshops. Accrediting body: GGPET (Gloucestershire General Practice Education Trust)

These menus have been mapped to:

- The NHS Knowledge & Skills Framework (KSF - 2004)
- Qualification & Credit Framework, Qualifications and Curriculum Development Agency (QCF - 2010)
- Common Induction Standards, Skills for Care (CIS - 2010)

Cathie Bambra – PMHDT, Facilitator for Older People
cathie.bambra@glos.nhs.uk

Dr. Martin Freeman – G.P Clinical Lead for Dementia
martin.freeman@GP-L84019.nhs.uk

Jan Ellis – Dementia Training & Education Strategy Implementation Lead
jan.ellis@gloucestershire.gov.uk

Appendix 5

Section 5

Useful Contacts

Advocacy

Care Quality Commission Independent regulator of health and social care in England	03000 616161
Advocacy Trust Gloucestershire (ATGlos) Provides independent volunteer advocates to help vulnerable people to protect their rights	Stroud, Cheltenham **0845 0511203** Cotswolds, Gloucester Forest of Dean **01594 821121**
Gloucestershire Older Persons' Assembly Independent organisation providing a voice for those aged over 50 years.	**01452 313999**
GUiDE and PALS GUiDE is an information data base. The Patient Advice and Liaison Service is a confidential service providing information, advice and support for patients, their family and carers.	**0845 658 3888** **0800 0151548 (Freephone)** **www.guide-information.org.uk** **www.palsglos.org.uk**

Charitable and Voluntary Agencies

Age UK (National) (Between 8.00am - 19.00pm)	**0800 169 6565** **www.ageuk.org.uk**
Age UK Gloucestershire	**01452 422660**
Alzheimer's Society	National Telephone **0845 300 0336** **www.alzheimers.org.uk** Gloucestershire **01452 525222** Alzheimer's Society Gloucestershire, Agriculture House, Greville Close, Sandhurst Lane, Gloucestershire GL2 0RG
Alzheimer Cafe UK	**01452 525222**
Barnwood Trust Gloucestershire-based charity dedicated to improving the quality of life for those with complex needs	**01452 614429 / 0845 5040670** **www.barnwoodtrust.org**
Brunel Care Provides care and services to older people	**Gloucester** **01452 550066**
Carers Direct	**08088 020202** **www.nhs.uk/carersdirect**
Carers Gloucestershire	**01452 386283** **www.carersgloucestershire.org.uk**

Citizens Advice Bureau	Gloucester and District **01452 527202** Cheltenham, Cirencester and Tewkesbury **01242 522491** Stroud and District **01453 762084** Forest of Dean **01594 823937**
Cruse Bereavement Care	National **0844 477 9400** **www.cruse.org.uk** Gloucestershire **01242 252518**
Independence Trust Mental Health Services	**0845 863 8323** www.independencetrust.co.uk
Parkinson's UK **Local branch**	**020 7931 8080** Helpline **0808 800 0303** **hello@parkinsons.org.uk** Gloucestershire, Swindon and North Wiltshire **0844 225 9821** **lsw.gloucs@parkinsons.org.uk**
Samaritans	Gloucester **01452 306333** Cheltenham **01242 515777** **www.samaritans.org.uk**
SPECAL (Specialised Care for Alzheimer's)	Burford **01993 822129** **www.specal.co.uk**
Stroke Association	National Helpline **0845 3033 100** **www.stroke.org.uk** Gloucester **01285 821666** Cirencester **01285 821481** Stroud **01453 825574** Forest of Dean **01594 835816**
Gloucestershire Young Carers	**01452 733060** **www.glosyoungcarers.org.uk**

Secondhand Equipment (household furniture etc)

For specialist items/mobility aids contact **GUiDE** and **PALS**

Emmaus	**01452 551146**
Furniture Recycling Project	**01452 302303**
Reclaim	**01242 228823**

Statutory Services

Benefits Advice Line (Department of Work and Pensions)	**0800 0556688** New claimants **0800 882200** Disability and carers
Gloucestershire Adult Helpdesk (Social Services)	**01452 426868** Telecare – Assistive Technology

Gloucestershire Community Alarm Service	Gloucester Lifelink Forest Linkline Tewkesbury Helpline Cheltenham Lifeline Careline in the Cotswolds Stroud Careline	**01452 396505** **01594 812505** **01684 272745** **01242 264393** **01453 825473** or **01594 812505** **01594 812506** **01453 754149**
Gloucestershire County Council	**01452 425000**	
Gloucestershire Energy Efficiency Advice Centre	**01452 835086**	
Gloucestershire Fire and Rescue Service	**Freephone** **www.glosfire.gov.uk**	**0800 1804140**
Gloucestershire Out of Hours GP	**08454 220220**	
Gloucestershire Police	**0845 0901234**	
Hospitals	Gloucestershire Royal Cheltenham General Berkeley Cirencester Dilke Lydney Moreton in Marsh Moore Cottage Hospital Stroud General Tewkesbury	**08454 222222** **08454 222222** **01453 562006** **01285 655711** **01594 598100** **01594 598220** **01608 650456** **01451 820228** **01453 562200** **01684 293303**
HM Revenue and Customs (VAT)	**0845 0109000** **www.hmrc.gov.uk**	
Managing Memory ²gether Carers education	**0800 6948800** **managingmemory@glos.nhs.uk** **www.2gether.nhs.uk**	
NHS Direct	**0845 4647**	
Pension Service	**0845 6060265** **www.thepensionservice.gov.uk**	
Primary Mental Health Service	**01452 504329** **www.pmhsglos.org.uk**	

Registration Service (Births, Marriages and Deaths)	Gloucester Cheltenham Stroud Forest of Dean Cirencester	**01452 425275** **01242 532455** **01453 766049** **01594 822113** **01285 650453**
Telecare	Enquiries	**01452 583743**
Wheelchair Assessment Centre	**01242 713900**	

Training

Gloucestershire County Council (Information about training for professionals and carers)	**01452 425519** **www.gloucestershire.gov.uk/dementiatraining**

Transport

Blue Badge Parking Scheme	**01242 532302**	
Dial-a-ride/Community Transport Scheme/Volunteer Car Service	Cheltenham Cinderford Cirencester Coleford Gloucester Lydney Newent Tetbury Tewkesbury Bream Wotton under Edge Dursley (Elderly & Disabled) North Cotswold Moreton in Marsh	**01242 515388** **01594 844558** **01285 658802** **01594 844558** **01452 627851** **01594 843809** **01531 821227** **01666 502514** **01684 297209** **01594 560257** **01453 542091** **01453 545386** **01608 651115** **01608 651199**
Shopmobility	Gloucester Gloucester Quays Cheltenham	**01452 302871** **01452 501839** **01242 255333**
Lydcare	**01594 860143**	

Feedback

Please return to

Helen Vaughan, NHS Gloucestershire, Unit 5220 Valiant Court, Gloucester Business Park, Brockworth, Gloucester GL3 4FE

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