

DEMENTIA

the view
from
Primary
Care

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A toolbox for use by GPs and practice nurses.

This is intended as an educational tool and not a protocol or a policy. It is for GPs and practice nurses to expand their knowledge and confidence. GPs are critically placed to take a greater role in assessing and treating dementia. Developing a clinical feel for cognitive problems is going to become integral to our care of elderly patients and their families. Most patients who develop dementia have been known to their GPs for years. Dementia rarely travels alone: it travels with multiple and common co-morbidities with which GPs are very familiar.

This booklet does not comprise an instruction for primary care to take over everything; it is hardly likely to make psychiatrists redundant for there is more than enough work for everyone. It is aimed at assessment and treatment and is therefore clinically orientated. Voluntary services and social services are still central. They have been the experts in dementia and its care long before dementia rose up the health agenda. People with dementia, and their families, benefit from advice, knowledge, stimulation, and, above all, companionship. It can be a lonely road, otherwise.

It sometimes seems wrong to refer to people with cognitive problems as 'patients' because of how it places people with this profound, life-changing condition within a medical model. However, it is hard to find an alternative shorthand. Similarly, the term 'carer' seems an inadequate way of describing spouses and families. 'Carers' are co-sufferers and are so often frail and elderly themselves.

Most of what is contained here is the pooled knowledge and experience gained from doing two pilot projects in our practice. The first one was a project on the integrated care of the elderly- now known as the Virtual Ward. I realized, during that project, that my Social Services colleagues knew far more about the elderly, and far more about dementia than I did. The second project aimed to explore what could be learned about commissioning for dementia by attaching a CPN for older adults to the primary care team. I am grateful to those who helped plan and fund these projects and to Phil Smart, our CPN, for patiently teaching me from scratch. Thanks also to Dr Mark Whittingham for his tutorial and corrections, and to Prof Alistair Burns, the National Clinical Director for Dementia, for his approval and additional suggestions. Any mistakes are my own.

I dedicate this booklet to my sister in law, Shirley, and to the Alzheimer's Society who helped her, and her husband Tommy, in ways that medicine alone never could.

Dr E Barrett. Shires Health Care. July 2013

Dementia Commissioning Quality Outcomes.

I was diagnosed early

I understand, so I make good decisions and provide for future decision-making

I get the treatment and support that are best for my dementia and my life

Those around me, and looking after me, are well supported

I am treated with dignity and respect

I know what I can do to help myself, and who else can help me

I can enjoy life

I feel part of the community and I'm inspired to give something back

I am confident my end of life wishes will be respected. I can expect a good death

Dementia and Mild Cognitive Impairment

Dementia

Although most people equate dementia with failing memory, dementia is not just about memory. It is a collection of problems that also includes difficulties with complex tasks, problem solving, and orientation. There is no 'dementia test' – the diagnosis is clinical and is the result of considering a collection of information.

What is 'normal'?

It is normal to have occasional memory lapses and to lose things, and memory does change with age. However, it is normal to retain one's abilities to resolve everyday problems and perform everyday complex tasks. It is normal to retain one's recognition of family, one's attention to personal care and one's orientation in person, time and place.

The specialist (ICD-10) classification) of Dementia is as follows:

- Memory decline. This is most evident in learning new information
- Decline in least one other domain of cognition such as judging and thinking, planning and organizing etc to a degree that interferes with daily functioning
- Some change in one or more aspects of social behaviour e.g. emotional lability, irritability, apathy or coarsening of social behaviour.
- There should be corroborative evidence that the decline has been present for at least 6 months

Cognition should be assessed in the context of a patient who is not severely depressed

or acutely ill (which might indicate depression or delirium as a possible cause of symptoms)

Screening, early diagnosis, and timely diagnosis

There are compelling arguments against population screening for dementia. There is no simple test and the condition does not satisfy the WHO population screening criteria. The AMT (Abbreviated Mental Test) is carried out on all patients >75 who are admitted to hospital and this is a type of screening but the justification is that it is performed on a high-risk population. A low AMT score serves to identify patients at increased risk of developing delirium in hospital, and it also raises awareness of patients and their relatives. The test may open the opportunity for everyone to have important conversations about something they were already concerned about.

There are arguments for early diagnosis but, like any variable condition with an insidious onset and a slow prodrome, the earlier the diagnosis is attempted, the harder it is to be sure about it. It is important to avoid skewing specialist time too far towards early diagnostic conundrums, if that means that their time and skills are not available for more needy and complex patients. There are, however, compelling arguments against delaying or avoiding diagnosis; medication does help many people function better, there is an opportunity for individuals and families to maximize enjoyable activities and to plan to mitigate potential difficulties or crises, and it seems a basic human right for people to know about what is happening to them.

We are moving away from the concept of protecting the patient from the diagnosis ('because nothing can be done'), and towards offering timely diagnosis to patients. We should respect the decision of patients to present themselves at the time that is right for them. We can, gently and sensitively, nudge people towards thinking about their memory, but there is no case for ambushing them. We can raise awareness among the population as a whole and reduce the stigma of dementia and these social trends will tend to bring patients to us a bit earlier. When patients do present, we should be able to offer a pathway of diagnosis and care that is clear and can be done in a reasonable timescale.

SCI, MCI and Dementia

Subjective Cognitive Impairment

Alzheimer's Disease has a very long prodrome. There are some patients who have a strong subjective sense that something is wrong with their memory but they perform well on objective tests. Many of these patients suffer from chronic depression that, itself, is a significant risk factor for the development of dementia. Offering sensible health advice, periodic cognitive testing and access to memory support services may be a help to them.

Mild Cognitive Impairment (MCI)

MCI has become more commonly diagnosed as people present earlier with concerns

about their memory.

In patients with MCI, there is objective cognitive impairment but the impact on daily activities is relatively minor and there is little discernible progression. As with dementia, MCI can affect one or more domains of cognition. MCI does not always progress to dementia. In any year, 10% of patients with MCI will develop diagnosable dementia.

Types of dementia

These are the main types of dementia with their QOF readcodes

- Alzheimer's Disease [Eu00.]
- Vascular Dementia [Eu01z]
- Mixed Alz/vascular [Eu002]
- Dementia unspecified [Eu002.]
(use for Lewy Body Dementia, Dementia in Parkinson's disease and Frontotemporal lobar degeneration)

Sub-typing may seem superfluous but it does help to guide prescribing decisions both at the time of diagnosis and later on.

Dementia sub-types

- *Alzheimer's Disease*: insidious onset of memory loss and other executive functions with gradual deterioration
- *Vascular Dementia*: step-wise presentation, sometimes noticeable after a small CVA or an operation. Vascular dementia can remain static for long periods. It can also progress suddenly.
- *Mixed Alzheimers/Vascular dementia*: it is not always possible to distinguish clearly between AD and vascular dementia and people can obviously have both.
- *Lewy Body Dementia*: often associated with Parkinson's Disease. Key features are arousal at night, fluctuating levels of cognition and consciousness and vivid hallucinations.
- *Frontal lobe dementia*: more accurately called 'front-temporal lobe degeneration'. There is often early loss of insight and a loss of sensitivity in relationships and social situations, which may create great distress for relatives. Memory can be quite well preserved. There are two language sub-variants – one in which speech is fluent but impoverished in content, with loss of the store of information and facts (semantic knowledge), and the other in which word meaning and knowledge is preserved but fluency is impaired.

Assessing Cognition

Cognitive testing forms part of an assessment for dementia and needs to be taken in context with history and overall functioning.

Although some of these tests are relatively simple and can be done quite quickly, they shouldn't be rushed and are generally better done as a separate appointment by someone who can become experienced with using a range of tests.

Cognition testing includes assessment of recall, reasoning, abstract thinking, visuo-spatial and verbal skills.

Useful cognitive tests are detailed in the Alzheimer's Society publication; 'A practical toolkit for clinicians'.

Common cognitive tests are the

- MOCA, GPCOG
- MMSE (subject to copyright issues)
- ACE III (modified Addenbrooke's, which has the MMSE taken out)

MMSE and MOCA are useful for initial assessment and for follow up. MOCA is well validated and is free to download from the internet. The MMSE is used as a monitoring tool in memory clinics, and it is important to compare like with like, but avoid using and scanning the published format so as not to fall foul of copyright law.

The following scores indicate cognition difficulties:

A MOCA score of below 26/30

An MMSE score 20-26; mild cognitive impairment.

10-20: moderate impairment. <10 severe

An ACEIII score of 82/100 indicates likely dementia. Severity can be gauged by scoring and balance over the domains

The ACEIII has good diagnostic value and gives good detail on domains of function.

Attention: marked out of 18

Memory: marked out of 26

Fluency: marked out of 14

Language: marked out of 26

Visuospatial: marked out of 16

Some people develop marked deficits in some domains, but function relatively well in others. In general, it is common to see global reduction over all domains. Unusually skewed scores might indicate the need for a specialist opinion and this is where building experience helps.

Care needs to be taken in interpreting any score. Literacy, educational attainment and learning difficulties will all affect scores, as one might expect. There are some specially formulated tools for people with visual impairment (the ACEIII requires usable vision). Inappropriately low scores may also be the result of poor engagement or high levels of anxiety and they may need to be repeated. It can be helpful to do them at home with a relative present.

ECGs and Scans

An ECG is mainly useful in assessing heart rhythm and rate prior to starting AChE inhibitors, but ischaemic changes need to be noted. Bradycardia of <60, and heart block are contraindications to commencing AChE inhibitors and LBBB is an indicator of ischaemic damage and risk.

NICE guidance currently recommends a brain scan as part of investigation, but you can use your judgement, especially if a patient refuses or it is going to be very difficult for the family to get them to a scan appointment. A scan may support the diagnosis but normal scans do not exclude dementia. CT scanning is available on open access. CT machines and reporting vary. Essentially, they exclude brain tumours, can show up areas of vascular damage and lobar atrophy and can demonstrate normal pressure hydrocephalus. (Normal hydrocephalus should be suspected if cognitive deterioration is associated with specific neurological symptoms or signs)

MRI scanning is more sensitive than CT scanning at showing the atrophy that is associated with Alzheimer's Disease but cannot be routinely done. Atrophy around the hippocampus is particularly relevant. As scanning becomes more detailed, more is learned about the sites of degeneration and their effects. This is fascinating but not of practical value to GPs at the moment.

Blood tests

Routine blood tests include FBC, ESR, TSH, LFTs, RBS, Vit B12 and Folate. These need to be done within 6 months of adding a dementia readcode to the patient's record (QOF requirement). It is not necessary to do routine syphilis serology.

Blood tests rarely help with diagnosis. They may unearth pathology that is contributing to deteriorating health, which needs to be dealt with as well.

Who to refer?

GPs are very skilled in judging which patients they should treat and which they should refer. Referral decisions may be influenced by many factors, including views of patients, local and national guidance, clinical knowledge and experience and the availability of clinical support. As experience grows, referral practices may change, but the following are likely to remain the situations in which a specialist opinion is advisable. This is not a protocol and the list may not be complete. Referral will remain a judgement call.

- PD and suspected LBD. Dementia in PD is an extremely challenging clinical problem.
- Working age dementia.
- Non-typical presentation or course
- High risk situations at presentation, such as challenging behaviour, wandering, psychosis or other risks.
- Safeguarding

- Potentially contentious legal issues
- Associated psychiatric morbidity
- Patients with Learning Disability or significant previous head injury, who may be very difficult to assess.
- Suspected alcohol related dementia

When to start treatment?

Patients are tending to present earlier because they are aware of drug treatment. The decision to treat with Acetylcholinesterase inhibitors is based, firstly, on whether a diagnosis of dementia can reasonably be made. The patient should hit the threshold for dementia on cognitive testing and also satisfy other criteria – especially global deterioration in function with insidious course, corroborated by a relative or carer. Dementia caused solely by vascular disease will generally not respond to AChE inhibitors but it is often difficult to be sure and patients can have both. Even if vascular dementia is suspected, a corroborated history of insidious decline over months may swing the balance towards a trial of medication.

Follow up

Systematic follow up of patients with dementia, whether on or off treatment, presents a logistical challenge for general practice. Follow up needs to be initiated by the practice and patients who cannot or do not attend should be visited at home. The patient should have a simple care plan that includes the diagnosis, a treatment plan, review plans, sources of information and a specific person to contact if there are problems.

Follow up should include assessment of cognition, functioning, well-being and carer views, as well as medication. Offering information is important and Alzheimer's Society is an excellent resource. Having good links with local memory support workers and social care colleagues is essential. Follow up is well within the remit of a practice nurse who has a knowledge of dementia and its problems, and is trained in cognition testing, but there needs to be a regular MDT with the lead GP. Patients whose risk is causing concern need to be referred to the CPN, social services, or the Virtual Ward

When to stop treatment

Stopping AChE inhibitors needs to be considered in any patient in whom dementia has progressed to the point where the drug may no longer be useful, or if side-effects or interactions outweigh benefits.

Original guidance was to stop Donepezil when the MMSE dropped to 10/30.

Experience has grown over the decade of use and some clinicians have been reluctant to withdraw AChE inhibitors if they seem to be well tolerated. In advanced dementia, it can be helpful to stop AChE inhibitors if the patient is agitated or anxious, as AChE inhibitors have a stimulating effect. The result may be more apathy but less agitation. Side effects such as bradycardia, syncope or nausea and weight loss should also lead to consideration of cessation of treatment.

Drugs used for Alzheimer's Disease:

AChE inhibitors:

Donepezil: AChE inhibitor. Now off patent. Generic cost per month = **£1.73 for 28**. Licensed for mild and moderate dementia

Rivastigmine: AChE inhibitor. Licensed for mild and moderate dementia, and dementia in Parkinson's Disease. Price is falling and may fall further if other generics come on the market.

Current drug tariff per month = **£39.04** for 56 x 6mg **£77.97** for 28 patches of both strengths

Galantamine: AChE with nicotinic acid action. Also off patent but cost yet to come down.

Cost per month = **£64.90** (for 28 x16mg)

Others:

Memantine; Glutamine receptor antagonist. Licensed for severe dementia. Also off patent but cost is yet to come down

Cost per month = **£69.01** for 28 x 20mg.

Dosage regimes and pharmacology

General information

Important AChE inhibitor side effects are:

Nausea and sickness. Increase in acid production

Bradycardia (should not be given if HR <60, sick sinus syndrome or 2nd or 3rd degree heart block)

AChE inhibitors can cause loose bowels, muscle cramps and headaches.

Prescribers should review the patient's anticholinergic burden before starting pro-cholinergics. If they can't be stopped, it may be possible to reduce doses. Some common drugs have anticholinergic action. The list includes Amitriptyline and medication for bladder instability. There is a list of others in the appendix at the back.

Metabolism: 2D6 is a metabolizing liver enzyme involved in breaking down psychiatric drugs. Rivastigmine is not metabolized by 2D6 and Donepezil is only weakly metabolized by 2D6, so both drugs can be used with other psychiatric drugs if necessary.

Donepezil alters the relationship between dopamine and acetylcholine, so treating dementia in PD presents huge therapeutic dilemmas in balancing movement against cognition, and judging BPSD against the side-effects of PD drugs. This is definitely a specialist area.

It is reasonable to trial a second AChE inhibitor if Donepezil is not tolerated, but if two are not tolerated, there is no indication for embarking on a trial of a third.

Specifics

Donepezil is usually started as a night time dose to minimize GI side-effects. However, it has a long half-life of 70 hours and therefore it can be taken at any time of the day, which is useful if a patient needs medication given by a relative or carer.

Many patients will have good benefit on 5mg. Increasing the dose may not increase efficacy but is likely to increase the side-effects. Maximum dose is 10mg daily.

Potential drug interactions: Anticholinergics, Anti-fungals, Anticonvulsants, Betablockers, Benzodiazepines, NSAIDs, SSRIs

Rivastigmine: It has pro-cholinergic effects but may be better tolerated than Donepezil in some patients, so it is second choice if Donepezil cannot be tolerated. It has a licence for dementia in Parkinson's Disease. Consider as a first choice for dementia if visual hallucinations are a strong feature.

Rivastigmine has a short half-life and needs to be taken twice a day.

Dosage commences at 1.5mg bd with food for 4 weeks.

Increase in steps of 1.5mg bd at intervals of 4 weeks

Usual maintenance dose 3-6mg twice daily with a maximum of 6mg bd

Patches are significantly more expensive than tablets. They come as 4.6mg and 9.5mg and are changed daily. There needs to be a strong case for choosing them.

Memantine: is licensed for moderate and severe dementia

It may be useful in improving behavioural symptoms in a patient with advanced dementia (see BPSD below).

It can also be considered if there are concerns about bradycardia or cardiac conduction.

It is metabolized by 2D6 so it competes for metabolism with other psychiatric drugs.

Specialist advice may be needed.

It comes with a ready-made starter pack with fixed titration.

5mg once a day for 7 days, 10mg daily for 7 days, 15mg for 7 days, then 20mg daily

Maximum dose is 20mg daily, or 10mg daily in renal impairment.

Galantamine XL:

Galantamine may be used by some specialists, so you may come across it, but it is not likely to be initiated in primary care. For information, the titration is as follows:

Commence 8mg daily with food

After 4 weeks increase to 16mg

Usual maintenance dose is 16-24mg daily

Maximum dose is 24 mg daily

Behavioural and Psychological Symptoms of Dementia

Drugs in BPSD : see *JAPC guidelines*

Patients with dementia can be placid and lovely. Apathy may cause concern but the major problems arise when patients show behaviours like persistent screaming, agitation, aggression, or disinhibition. In small residential care units, unremitting screaming can create an intolerably stressful environment for other residents, let

alone staff. Patients who are aggressive can injure staff and other residents and sometimes the care home may need to involve the police if an injury has occurred.

There are many possible aggravating reasons for a patient's deteriorating mental state: the stage of the disease, infections, constipation, pain and depression are all common causes of increased disturbance.

Correcting obvious medical problems, and using behavioural techniques to calm behaviour are obvious first steps. Consider pain as a possible cause. Carers will become familiar with daily patterns and behaviour charts may show up aggravating factors, such as misidentification, hallucinations and tiredness. Carers are often in need help, advice and reassurance.

Hallucinations are commonly visual, especially in PD and LBD. They tend to become worse in the evening (a phenomenon known as sundowning). Patients can retain insight and they are not always frightened and it is important to talk in a matter-of-fact way about hallucinations to discover how the patient feels. If they are very vivid and frightening, reacting to hallucinations may provoke a social crisis. It may be helpful to remove 'hallucinogenic props' such as coats hanging up or curtains that create shadows, and to cover mirrors, especially on wardrobes, or to address anything that might be misinterpreted

There is not a wide range of effective drug choices for BPSD problems. Often, the pressure is to manage symptoms as an emergency, but longer term strategies also need to be considered.

Depression is common in dementia but can be hard to diagnose. If depression is suspected as a cause of additional misery in a patient with dementia, anti-depressants may sometimes improve behavioural problems like agitation by lifting mood.

Sertraline is the preferred anti-depressant in the elderly, generally, because it is less cardio-toxic than other SSRIs. Start with 25mg or 50mg initially. Trial for at least a month, if tolerated. SSRIs can be used alongside AChE inhibitors

Citalopram lengthens the QT interval and is increasingly avoided in the elderly. Max 20mg in the elderly.

Trazodone is a very useful drug; it is helpfully sedating with a useful dose range. Check with the pharmacist for manufacturing supply problems as these can occur. Liquid formulations are expensive and awkward. Unfortunately, there is no exact equivalent if you do have to do a drug swap. **A starting dose of 50mg once or twice a day.**

Mirtazapine is sedating. Note that Mirtazapine has agonist and antagonist action **and sedation DECREASES as dose increases. The 30mg dose is LESS sedating than the 15mg and the 45mg dose CAN CAUSE AGITATION.**

Lorazepam. Benzodiazepines tend to be unhelpful in dementia as they may increase confusion. Lorazepam, however, can be useful for agitation but should be used on a PRN basis and not routinely. Start with 0.5mg PRN.

Temazepam and Zopiclone are often used for chronic insomnia but they increase the incidence of falls.

Memantine

See above. Memantine may improve cognition in severe dementia, sufficiently to help with disturbed behaviour.

It should not be used with Amantadine.

Rivastigmine (AChE inhibitor) may help with hallucinations associated with LBD and PD. It takes a while (several weeks) to build up the dose and a small dose of Quetiapine may be necessary to reduce hallucinations while Rivastigmine is taking effect. **See Anti-psychotic drugs below.**

Alcohol and Thiamine.

Alcohol misuse is probably under-recognised in older people. Generally, people tend to reduce alcohol intake as they become older, but some do not. Previously social drinkers may start drinking regularly to alleviate anxiety or loneliness. They may forget how much they have drunk and this puts them at risk of falls and malnutrition.

It can be difficult to separate dementia from alcohol as a cause of deteriorating cognition and self-neglect. Tolerance to alcohol diminishes with age and body weight, and a poor diet will contribute to thiamine deficiency in someone who is drinking too much. An assessment in care may be needed .

Alcohol misuse may lead to alcohol dementia (Korsakoff's syndrome). It often presents in a slightly younger age group. Patients have short-term memory loss, lack of insight and blunting of behaviour – often apathy. High doses of thiamine and abstinence from alcohol may halt progress but some patients may already be stuck in a miserable life situation by that time, institutionalized in a care home intended for much older people.

Anti-psychotic drugs

There is a national drive to reduce anti-psychotic prescribing in dementia because these drugs increase the incidence of stroke. Nevertheless, sometimes there is no other option especially in a patient showing aggression or having difficult hallucinations or other psychotic symptoms. Anti-psychotics should only be used when all other ways of dealing with the situation have failed and CPN or consultant psychiatrist help should be sought. If these drugs are initiated in general practice, they should be started in very low doses and reviewed in order to avoid the risk of embarking on a lifelong repeat prescription. Patients who become settled may remain settled on withdrawal of anti-psychotics.

Quetiapine is the anti-psychotic that is least likely to cause major side-effects. It has the advantage of a wide dose range with a very low starting dose. Start with tiny doses, especially in PD and LBD. Primary care physicians should seek specialist advice if doses need to be increased beyond 25mg bd.

Risperidone is the only anti-psychotic drug licensed for aggression in Alzheimer's Disease. Anti-psychotics (except low doses of Quetiapine) are absolutely contraindicated in PD and LBD because they can cause major severe reactions and can make a patient very flat with a high mortality risk. This is why it is so important to identify LBD as a sub-type.

Risperidone, if needed, should be started at a low dose of 250mcg od or bd. Max dose 1mg bd. Review with a view to stopping at 6 weeks.

Delirium, dementia and anti-cholinergics.

As GPs, we need to increase our awareness of anti-cholinergic drugs and their potential effect on cognition, delirium and falls.

Patients with cognitive impairment are at risk of delirium on admission to hospital, whether for elective or emergency care.

Delirium is a potentially serious condition. It carries a high mortality and seriously delays recovery and discharge from hospital. Many patients who have had delirium do not fully recover their pre-admission cognitive status and prolonged admission can make it very difficult for them to resume their normal self-care.

Vivid hallucinations may be remembered long after the patient is better, and disturb important and previously trusting relationships. The delirious patient is at risk of falls.

Patients who have experienced delirium often remain puzzled and shaken about what has happened to them. Cognitive recovery can take six weeks or more. Between 40% and 70% of patients with delirium have not made a full recovery at the time of discharge. 60% of ward referrals for patients >65 to the in-hospital psychiatric team are for delirium.

Minimising the anticholinergic burden in the elderly is an important GP role, especially in those with cognition problems. (see list below)

Cognition and driving

Patients with Mild Cognitive Impairment and Dementia must inform the DVLA. The GP or practice nurse has a duty to inform patients of this. The DVLA may continue to issue a driving licence – usually for a year at a time and the diagnosing doctor will need to fill in a medical enquiry form. Patients whose attention, judgement or orientation, are affected should not drive. If a patient has lost insight and will not accept advice not to drive, a clinician or relative may have to inform the DVLA in the interests of the patient and other road users. Specialist advice may need to be sought. Sometimes relatives get around the problem by disabling the car, or the patient may forget to renew a licence.

If the patient insists they are able to drive, an independent arbiter may be needed. Patients can be referred, on the NHS, to the Kingsway Hospital in Derby for a driving assessment. The DVLA may also request independent assessment but the patient will be charged (around £130)

Falls

Patients with cognitive impairment or dementia have an increased risk of falls. There are many reasons; they may not be managing their medication properly, they may have poor attention or reduced visuo-spatial awareness. Falls prevention assessment is necessary if a patient has had unexplained falls. Some local authorities provide a Falls Recovery Service and notify GPs if they have been called out to a fall that has not required medical attention. These notifications should be logged on GP risk data. Where wandering and falls are a very high risk, sensor pads can be fitted beside beds and in doorways. These trigger an alarm and prompt a warden visit or a call to a relative. Patients should be encouraged to hire and wear pendant alarms.

Benefits Advice

Patients and carers can be referred to Derbyshire Carers for carers and benefits assessments. The County Council has a welfare rights department. All services are reached through Call Derbyshire.

Social Services

Home care and day services

The development of the Virtual Ward model may allow a care coordinator to have read-only access to Framework 1 ('eye', not 'one'). This is enormously helpful because it allows the team to access information about whether a patient has been assessed and offered services and, if they have services, what level they receive and who their care manager is. This access, and regular MDT meetings, helps both health and social care to coordinate around the care of the patient and avoid misunderstandings and unnecessary delays.

Social care sits within the County Council. Social services commission services to help look after people in their homes and also commission or provide day services and residential care. It is best not to promise particular services to patients as they need to meet the eligibility criteria and these will differ slightly across local authorities. People also have to contribute, depending on their income and will have to have a financial assessment. As local authority cuts bite, eligibility criteria have been forced up. Problems may occur when there are differences in opinion with regard to eligibility criteria and this can happen, particularly, when a patient with dementia requires social routine and stimulation, but their day to day personal care requirements are below the threshold for services.

Many people choose not to pay for services that they are assessed as needing. Some patients lack insight into their needs and their refusal to accept services can cause concern. Those who wish to pay for day services, but do not satisfy the criteria, cannot buy them through Social Services. As criteria are pushed up, there is a risk of under-utilisation of good, local day services.

Care homes

To satisfy the eligibility criteria for residential care, patients need to be assessed as having needs that cannot be met through care in their own home. This usually means that maximum home care support has been tried and found to be inadequate. In the case of dementia, risks are taken into account, as well as practical care needs. Residential care is expensive and patients need to contribute. A financial assessment will be done, which includes all sources of income as well as the value of assets, such as a house, if the person lives alone and owns their own house.

If a care situation is becoming difficult, social services should be asked to assess or reassess, and some contingency planning is advisable. Respite can be arranged if appropriate. It is extremely difficult, and time-consuming, to obtain respite in an emergency and it may not always be local.

Unfortunately, one of the common routes to residential care is via hospital admission, when the default response to an unaddressed crisis has become a 999 call. This can result in protracted and enormously expensive stays in hospital while an appropriate care placement is found and details negotiated.

Safeguarding vulnerable adults and complaints about care.

Adult safeguarding sits within social services. It is not uncommon to have concerns about financial abuse of people who are vulnerable as a result of cognitive problems and, if it is suspected it must be investigated. Other abuses include verbal abuse, neglect and cruelty – physical or mental.

Relatives sometimes approach GPs with complaints about care home standards. Relatives should report concerns to the local authority responsible for commissioning the care home or report directly to the Care Quality Commission. If the concern is about nursing care, they should report concerns to the Nursing Director of their CCG.

If GPs or visiting nurses have concerns about nursing standards in a care home, these must be discussed with managers. The community nursing team should report to DCHS and GPs should report to their Director of Nursing or discuss the matter directly with Jim Connolly, Director of Nursing for Hardwick CCG.

NHS Continuing Care.

NHS Continuing Care can be used to fund nursing care in a patient's own home or, more commonly, in a care home with nursing facilities. If a patient is assessed as needing Funded Nursing Care or NHS Continuing Care, either part of (in FNC) or the full (NHS Continuing Care) care costs will be paid by the NHS through the CCG. Relatives sometimes explore this funding because protracted care costs are so expensive. A relevant nurse completes the initial Decision Support Tool (DST) checklist. This may be a DN or a CPN, depending on the main needs. If the patient's needs hit the DST threshold, a full assessment will be done by an NHS Continuing Care assessor. The threshold for NHS Continuing care is high and relatives need to be aware of this

in order to avoid unrealistic expectations. Patients require expertise beyond routine care in order to qualify. This may be specialist behaviour management or support. Occasionally, a family will put in a retrospective claim. The family occasionally want to involve the GP in this. A patient who is discharged to a care home under the Mental Health Act will have their care costs paid for by the NHS.

Mental Capacity Act, Power of Attorney and Advance Directives.

Lasting Power of Attorney sits within the Mental Capacity Act 2005. It is a legal arrangement to allow someone to appoint another person to make decisions on their behalf in the event of them losing relevant capacity. It is therefore a form of advance planning and it needs to be done while the person is still able to understand who they want to act for them, and what they want them to do. A GP may be asked for an opinion as to whether someone has capacity to appoint Lasting Power of Attorney. Once a patient loses capacity, it is too late, and a deputy needs to be appointed through the Court of Protection. This is much a much more expensive option. LPOA can cover financial affairs or matters about care, or both. It is quite easy to do and a lawyer does not necessarily have to be involved. Forms are available from the internet and Alzheimer's Society gives good information.

Advance Directives (previously 'living Wills')

Under the Mental Capacity Act, any patient can write an advanced directive. In order to be used, this needs to be kept in a place where it can be found in the event of need. It is best for patients to send copies to relatives and for the existence of the document to be on the patient records. As long as the patient retains capacity, they can rescind the directive at any point. A patient can only dictate what medical care is NOT to be done, in the event of them losing capacity. They cannot dictate what medical care should be done. Common requests are not to be resuscitated, ventilated or artificially fed. CQC has standard forms. Information can also be obtained from the Alzheimer's Society website and from patient.co.uk.

Some misconceptions about the MCA

While the Mental Capacity Act is admirably simple, there are two common misconceptions about capacity assessment. The first is that it has to be done by a professional and the other one is that patients can be deemed to have 'lost capacity' generally. Capacity is issue specific and should be done by the person who needs the answer to the question. A lawyer who is drawing up a will, for instance, is the right person to assess the patient's capacity, although they may ask for corroborative medical information. Court of Protection documents must be done by a professional, and generally this is a doctor. One of the more common requests is to assess capacity so that a local authority can appoint an administrator to ensure that care home fees are paid.

Advocacy

Advocacy: Advocates are sometimes needed when there is conflict within families and a disinterested third party is needed. Conflict within families is common and can be very difficult to deal with. Seek advice if you need it.

IMCA; In situations where deprivation of liberty safeguards need to be put in place, and the patient does not have any family or friends to advocate for their interests, patients can be referred to the IMCA service (independent mental capacity advocate)

DoLS. Deprivation of Liberty Safeguards are legally binding and can only be put in place for hospitals or care homes, and police can return the patient if they leave. Decision makers are always professional but there is legal duty to take the views of the patient and their relatives into account. DoLS can be applied for urgently, but an independent best interest assessment needs to be done if it is to be continued.

End of Life

Advanced dementia is a terminal condition and end of life plans should be put in place to support palliative care. These should be individualized and discussed with relatives.

Nutrition can become a serious concern at end of life and nutritional neglect is a common cause of complaint from relatives. Occasionally, there is a Coroner's investigation and legal action. Care home staff are understandably very nervous of this scenario. Patients with end stage dementia do lose weight because they may lose interest in food. They may have difficulties with the coordination of chewing and swallowing. Dietician and SALT assessments should be sought where someone is losing weight or choking. Relatives sometimes ask about PEG feeding. PEG feeding is not readily tolerated by patients with dementia as the process of insertion and feeding requires considerable cooperation. Sudden deterioration, as a result of a CVA, might be an indication and would require a specialist decision.

'Dementia', as the sole cause of death, will not be accepted on a Cause of Death Certificate. You need to specify severity. The registrar will accept 'Severe Dementia' for 1a.

Place of death

Hospitals are highly detrimental and deliriogenic environments and always involve changes of wards and frequent changes of staff. The risks of hospital admission require careful conversations with relatives and a discussion on the balance of risks and benefits, and realism about what can be achieved by hospitalization. Many will proactively ask that their relative is kept comfortable at home. EMAS and Rightcare forms should be filled in (or relevant OOH provider forms). Relatives must be made aware of these forms and their views sought, though it is important to emphasise to them that CPR is futile when someone has reached the end of life, and they are not agreeing to shortening their relative's life in any way.

Role of Alzheimer's Society and Making Spaces

The Alzheimer's Society has a national role as well as a local one. It acts as a huge resource for patients and carers. Alzheimer's Society also has the contract for Dementia support cafés and support workers in Derbyshire County (Making Spaces has the contract for Derby City). Support workers can offer help to anyone with a memory problem, no matter whether it is diagnosed or not. Support organisations run information sessions, cognitive stimulation sessions and Singing for the Brain and a host of other activities that help sufferers and their families. They run rolling training programmes for relatives and carers.

On the whole, these charitable organizations play a far greater role in enhancing the lives of patients and carers than the medical profession does. Patients should be encouraged to make good use of them.

Patients and carers should also be encouraged to attend Living Well programmes which are education programmes. They run for 6-7 weeks and cover all aspects of cognition and dementia, behaviour management, self-help and social support.

Appx i

Common Anticholinergic drugs used in the elderly:

Strong anti-cholinergic burden:

Drugs for bladder instability: Oxybutinin, Solifenacin, Tolterodine etc
Amitriptyline
Hydroxyzine

Weaker anti-cholinergic burden

Beta blockers
Digoxin
Fentanyl
Codeine
Cimetidine
Ranitidine
Loperamide
Prednisolone
Warfarin
Colchicine

This list is not exhaustive.

Appendix ii

MDT DEMENTIA CHECKLIST. First assessment.

History: Abrupt, gradual, fluctuating	
Behavioural/mood/risk	
Social situation incl NOK/carers	
Other medical history	
Formal memory testing	
Blood tests/ECG	
CT scan	
Diagnosis	
Support referral/information	
Plan	
Prescribing	
Follow up	
Who the patient should contact	

Information sources:

Alzheimer's Society: *A practical toolkit* – available to download from website www.alzheimers.org.uk

JAPC Guidelines for *Managing Behaviour Problems in patients with behavioral and psychiatric symptoms of dementia*. On Medicines Management site

Guide to the Psychiatry of Old Age. Ames, Chui, Lindesay and Shulman. Cambridge University Press ISBN 9780521681919

Cognitive Assessment for Clinicians. John Hodges Oxford University Press ISBN 978-0-19-262976-0

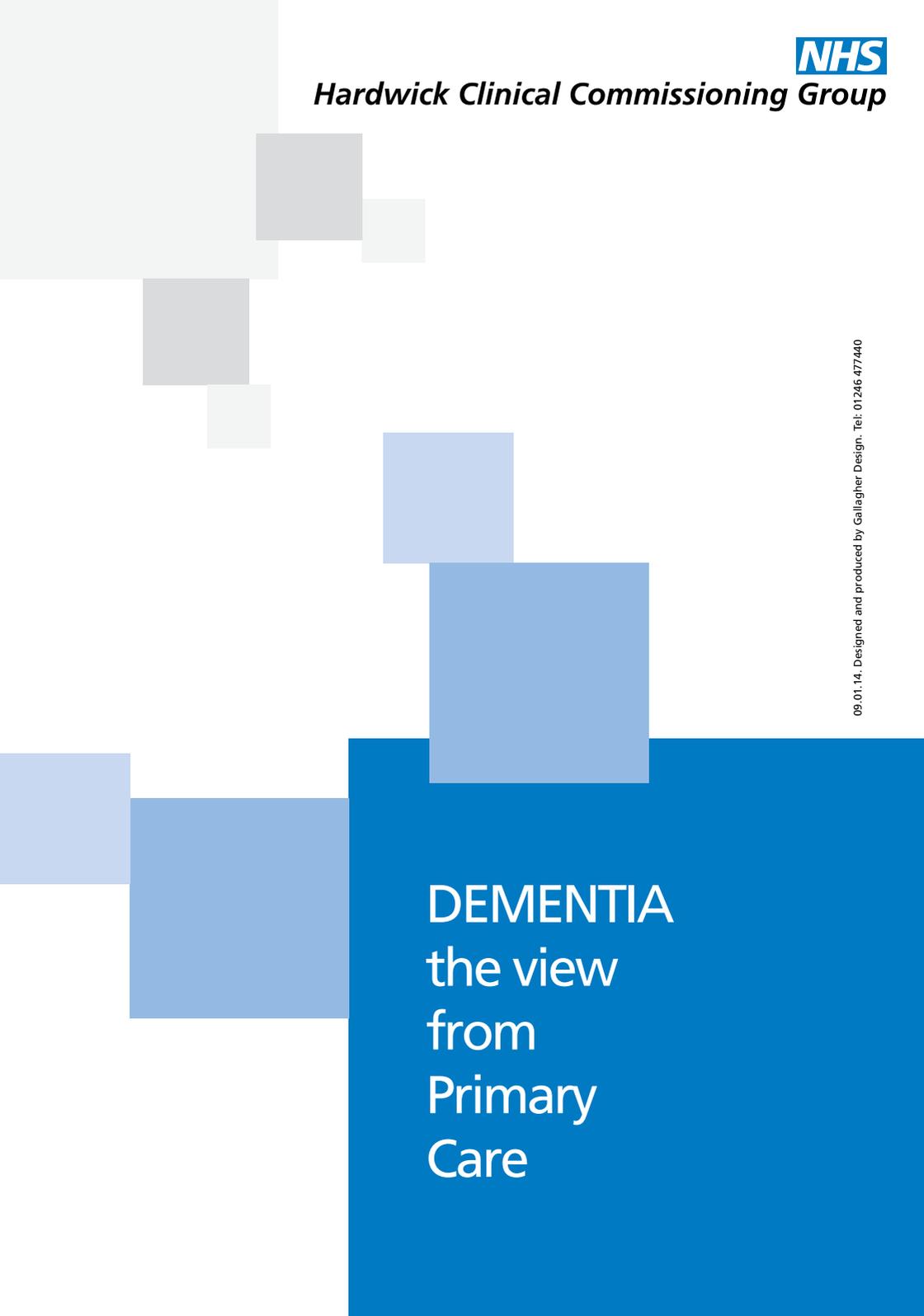
Alzheimer's Society Memory Cafés; information and individual support to anyone concerned about memory either in themselves or in a relative or friend.

The society provides memory support irrespective of diagnosis or sub-type

Telephone number 01246 223366
www.derbyshire@alzheimers.org.uk

elizabeth.barrett@nhs.net for details or copies.

Feedback welcome

A graphic of a staircase with steps of varying heights and widths, colored in shades of blue and grey, ascending from the bottom left towards the top right.

DEMENTIA
the view
from
Primary
Care