Somerset NHS Foundation Trust

THE CARE AND TREATMENT OF OLDER PEOPLE WITH DEMENTIA IN A GENERAL HOSPITAL SETTING

Guideline

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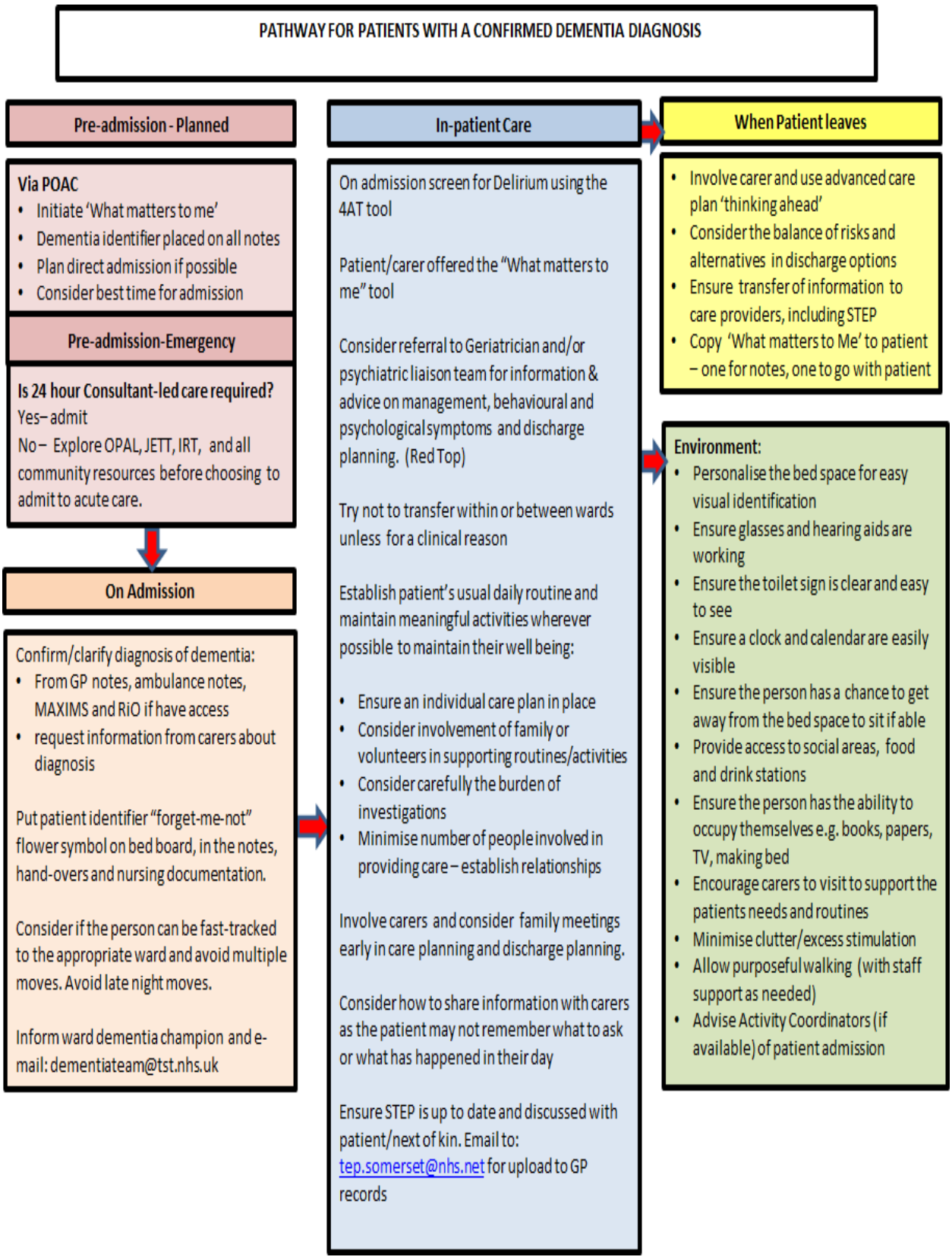
1.0 PATHWAY FOR PATIENTS WITH A CONFIRMED DEMENTIA DIAGNOSIS



2.0 INTRODUCTION AND OBJECTIVES

2.1 This guidance has been produced to assist clinicians in routinely screening older patients for dementia and to develop appropriate plans of care and treatment to manage this condition during their inpatient hospital stay and in preparation for discharge. This guidance is applicable for all older patients with any form of cognitive impairment. Much of this guidance will also be relevant to younger age patients with dementia.

2.2 The overall aim of this guidance is to ensure all patients who have a diagnosis of dementia and cognitive impairment along with their families and carers, receive the best possible care whilst an inpatient and a smooth transition of care on leaving hospital.

2.3 The National Dementia Action Alliance Dementia Friendly Hospital Charter was refreshed in 2018 to include a volunteering element. The Trust is signed up to this charter which provides a framework that forms the basis for a structured improvement plan for dementia care throughout the Trust.

- The domains of the charter are:
  - Staffing
  - Partnership
  - Assessment
  - Care
  - Environment
  - Governance
  - Volunteering

3.0 DEMENTIA-FRIENDLY HOSPITAL CHARTER

3.1 The following is a summary of key objectives in line with the dementia friendly hospital charter.

3.1.1 Staffing

- Dementia training is an integral part of the organisation's training and development strategy.
- Training is provided for all staff and volunteers to enable them to provide a proactive approach to caring for people with dementia and they are knowledgeable and skilled in identifying and addressing needs.
- All staff and dedicated volunteers undertake Tier 1 dementia awareness training and some undertake more in-depth training appropriate to their role i.e. Tiers 2 or 3 of the Dementia Training Standards Framework.
- Staff understand that because of the cognitive and physical issues experienced by patients with a dementia or delirium, being in hospital can be very frightening and unsettling for patients. Therefore a greater understanding of patients' needs is required and often extra time to care for patients.
- Additional staff support is available through volunteers, activity co-ordinators and cognitive support workers.

3.1.2 Partnership

- People with dementia and their families/carers are recognised as partners in their care. This includes:
  - Choice and control in decisions affecting their care

- Support whilst in hospital and on discharge

- The Trust should work with carers to facilitate e.g. flexible visiting, carer assistance at mealtimes and provide clear communication around discharge.
- The discharge summary should clearly document the patient's cognitive and functional status (on admission and discharge), their diagnosis, their treatment plan and their community support and follow-up plan. This information will also be available for carers.

3.1.3 Assessment

- There is routine use of assessment and screening by skilled staff to ensure any symptoms of dementia or delirium are identified promptly, care adapted and risk reduction measures put in place. This should meet the needs of the patient and also include an assessment of carers needs.
- All patients aged 65 and over with an emergency admission to MPH will be screened for cognitive impairment on admission to hospital.
- Younger patients identified as having cognitive impairment or dementia, will be screened for delirium on admission.
- All patients aged 75 and older with an emergency admission and a stay > 72 hours will be 'screened' for possible dementia prior to discharge.
- In-patients > 65y and those with a dementia diagnosis will have regular review of their cognitive state to identify changes in their condition that may indicate delirium and treatment and management plans adapted accordingly.
- Patients presenting with dementia symptoms should be investigated in order to identify any treatable or reversible cause for their cognitive decline, in order to both support the diagnosis and to provide appropriate care and treatment.
- Pre-operative assessment of patients over the age of 65y should include a cognitive screen to identify patients who have dementia and who will be at high risk of delirium post-operatively.

3.1.4 Care

- All patients with dementia and/or delirium will be treated with the same care, respect and dignity as other patients in the Trust
- All patients with dementia and cognitive impairment will have multidisciplinary care plans that reflect their individual needs and circumstances and take into account the needs of their carers.
- Information about patient preferences such as the 'What matters to me' document is clearly displayed.
- Encouragement and support is provided for people to remain as independent as possible and remain mobile, where appropriate. Support is provided for people to stay involved in activities that support their health and wellbeing.
- Staff should be supported to enable flexibility in carrying out observations on patients who have dementia and/or delirium. Any intervention can cause distress and worsen sleep disruption significantly. For example, routine blood pressure monitoring overnight should try to be avoided unless patients are unwell.

3.1.5 Environment

- We provide an environment that is dementia-friendly and safe by encouraging the personalisation of bed spaces, dementia-friendly ward design and clear signage throughout the hospital.
- Reasonable adjustments need to be made to enable staff and volunteers to support cognitive and physical rehabilitation through activities to encourage orientation and stimulation.
- The environment promotes safety by adhering to key design principles.
- Policies are in place to minimise patient moves, particularly at night.

3.1.6 Governance

- There is a system for routinely gathering meaningful feedback on how people with dementia and their carers experience the hospital's services.
- The Trust is signed up to the Dementia Friendly Hospital Charter and adheres to these principles.
- There is a local dementia strategy group that will expand across both Trusts.
- There is regular feedback at board level.

3.1.7 Volunteering

- All volunteers undertake Tier 1 training and have a support structure with clearly defined roles.
- The role volunteers can have in supporting patients with dementia should not just be considered on care of the older peoples' wards, or non-medical wards, but where patients access other services e.g. Outpatients, Emergency Departments, Discharge Teams, across the hospital environment.

4.0 PROCESS DESCRIPTION

4.1 Scope of the guidance

- This guidance applies to all Trust staff who are directly or indirectly involved in the care of people with dementia or cognitive impairment, their carer's and families.
- It is primarily for older patients (aged 65 years+) but may be relevant to younger patients with dementia. Delirium (a sudden change in mental state including confusion and personality change) can present in a similar manner and can co-exist with dementia. Patients who have dementia are at extremely high risk of developing delirium. Delirium should be actively considered in all patients presenting with confusion and/or behaviour change and assessed using appropriate tools.
- This guidance can be found on the Intranet: Policy portfolio (acute services), search for Dementia
- Further information and signposting can be found on the intranet - Look up under Hospital Systems A-Z : D – Dementia and C - Care of Older People (Dementia) for further information.

4.2 Background:

4.2.1 Dementia

- Dementia is a term used to describe a clinical syndrome that may present in a number of different ways and may be caused by a number of distinct pathological processes. It results in a progressive decline in a person's memory, reasoning, communication skills

and the ability to carry out daily activities. Its progression varies from person to person and each person will experience dementia in a different way. Behavioural and psychological symptoms of dementia such as agitation, anxiety and restlessness can sometimes occur especially during a period of illness requiring a stay in hospital.

- The term dementia is not in itself a diagnosis. It covers a range of degenerative brain diseases such as Alzheimer's disease, vascular dementia, Lewy Body dementia. Dementia is acquired rather than congenital and its course is usually chronic and progressive Cognitive decline can also be caused by a long list of secondary conditions (e.g. hypothyroidism, space occupying lesions).
- The dementia syndrome comprises three core features:
  - A progressive neuropsychological deficit
  - Neuro-psychiatric features and
  - Disabilities in activities of normal daily function
- There are approximately 850,000 people in the UK with dementia. This represents 1 in 14 of the total population aged over 65 years, rising to over 1 in 7 of those aged 80 and over. It is estimated that by the year 2040 there will be 1,600,000 people with dementia. Dementia is devastating for the sufferer but also has a major impact on carers, family and friends. Over 2 million people in the UK have some caring role for a dementia sufferer and this can take a significant toll on them and their health.

4.2.2 Delirium

- Delirium is a sudden change in mental state which may include confusion, agitation, personality change, difficulties with understanding and memory loss. Delirium is often referred to as acute confusion**.** Conscious level is altered - either reduced (more drowsy) or over-active (restless and hyperactive).
- Common causes of delirium are: pain, infection, constipation, dehydration, certain medications and a change in environment.
- Delirium affects 1 in 8 hospital patients. It is usually, but not always, reversible if detected and treated promptly. Delirium is more common in patients who have dementia and may also be a marker for the later development of dementia. It is important to recognise delirium and differentiate it from dementia as the treatment of delirium will improve the patient's prognosis. An untreated delirium is associated with a poorer prognosis. Delay in the diagnosis of delirium may adversely affect clinical outcomes and increase length of hospital stay.
- Cognitive impairment (delirium and dementia) is present in approximately 30% of the general hospital population at any one time. Delirium particularly, and often dementia, frequently goes unrecognised in hospital. Screening reduces the number of cases where diagnosis is missed; screening can therefore have a significant positive impact on the patient's stay and their clinical outcome.

The common forms of dementia are:

- **Alzheimer's Dementia (Alzheimer's disease, Dementia of Alzheimer's type):** This is the commonest form of dementia. It may be the cause of up to 60% of cases of all dementias. It begins with mild impairment of cognition and communication, is insidiously progressive leading to global deterioration of mental functioning and full dependency. There is extensive neuronal loss with neuritic plaques, neuro-fibrillary tangles and extensive neurotransmitter loss. There is neither a single diagnostic biochemical marker nor neuro-imaging technique to diagnose it and a definitive diagnosis is only possible at autopsy.

- **Vascular Dementia:** Up to 20% have a more varied presentation commonly seen in patients with significant vascular risks (hypertension, diabetes, stroke disease, ischaemic heart disease). They may have a fluctuating or stepwise progression. Imaging shows evidence of vascular damage to various areas of the brain which can be diffuse, multifocal or single vascular lesions.
- **Mixed:** Many cases have a mixed disease pathology - both Alzheimer's and vascular so they are called mixed dementia. Vascular pathology can also be mixed with other types of dementia for example Lewy Body Dementia.
- **Lewy Body Dementia** Up to 20% of patients present with fluctuating cognitive impairment, physical features of Parkinsonism and visual hallucinations. These patients are prone to falls and commonly have an abnormally sensitive response to anti-psychotic medications. An example of a medication that must be avoided is haloperidol.
- **Frontotemporal dementia (Pick's disease, frontotemporal lobar degeneration**) This is less common overall but a commoner type in younger patients (<65y). Patients first notice problems with language and significant changes in their personality and behaviour.

- **Other forms include:**

  Parkinson's disease dementia, Wernicke-Korsakoff syndrome (including alcohol-related dementia) and dementia associated with rarer conditions such as Huntington's Disease.. There are also many other conditions associated with chronic cognitive impairment for example, normal pressure hydrocephalus.

  People with dementia often have co-existing physical conditions (co-morbidities) that necessitate an admission to hospital. Physical illness, change of environment and many medical interventions are known to exacerbate the symptoms of dementia and can cause delirium. Patients with dementia are also known to be more prone to depression and can have significant anxiety when out of their normal routine.

  Therefore older people with dementia are particularly vulnerable in hospital. They are highly susceptible to environmental change, suffer loss of functional ability and independence quickly and are at high risk of developing delirium. This in turn leads to longer lengths of stay and poorer outcomes for patients.

4.3 Identifying a new diagnosis of dementia and confirming a diagnosis:

4.3.1 **Screening** (See Appendix C for a pathway summary)

- All patients over the age of 65y admitted to hospital should be screened for cognitive impairment. Screening for possible dementia should be carried out on all patients over 75y if admitted for longer than three days, at an appropriate time pre-discharge. (This screening is mandated with compliance formally reported nationally). A collateral history is key on admission to establish whether cognitive changes are new or whether a patient is known to have a diagnosis of dementia. There are a number of screening tools available.

At Musgrove Park Hospital:

- For initial cognitive screening we recommend the use of the AMT4 or AMT10.
- Delirium screening should be completed within 24 hours of an emergency admission for all patients over 65y.
- For delirium screening use the AMT4 and the SQiD (Single Question in Delirium). (See pathway Appendix). If answer 'yes' to the SQiD and/or AMT4 less than 4, complete the 4AT delirium assessment tool. ITU use the CAM-ICU to screen for delirium.
- A personalised care plan should then be initiated for patients who are assessed as having delirium and/or dementia or any form of cognitive impairment.
- Cognitive assessment should be repeated pre-discharge. If the AMT4 has shown a result less than 4 OR patients have a diagnosis of delirium and/or dementia OR you have some concerns re: cognitive ability OR the patient reports new concerns, then complete the AMT10.

- N.B. The Test your Memory (TYM) should not be used in the hospital setting as it distorts community memory assessments.
- All patients being routinely screened for memory issues may be given the patient information leaflet: 'Testing for Memory Problems'. On discharge, the AMT should be recorded on the patients EPRO discharge summary, even if normal. If abnormal (<8) or there are concerns reported about cognition, it should be documented what the follow up plan is and whether a referral to memory services is warranted (if appropriate for that patient and as per patient's wishes).
- A collateral history from a carer, relative or friend of the onset, duration, and progression of cognitive impairment is essential to enable a diagnosis of delirium, establish whether there is a confirmed diagnosis of dementia or a possible new diagnosis of dementia and enable an understanding of the patient's preferences in order to target supportive intervention. Having key information about what we can do to personalise the environment for the patient reduces anxiety and complications such as falls whilst in hospital.

4.4 Diagnosis

4.4.1 The ICD-10 criteria define dementia as:

- A syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is impairment of multiple higher cortical functions, including memory, thinking, planning, orientation, comprehension, calculation, learning capacity, language and judgement. Consciousness is not clouded. The cognitive impairments are commonly accompanied or sometimes preceded by, deterioration in emotional control, social behaviour or motivation.
- Assessment is important in helping to decide if a person has dementia, the cause, whether there are reversible elements, the individual problem areas and helps to form a focus for the management plan. It is particularly important to exclude delirium and depression.
- It is also important to identify and treat any co-existing physical or psychiatric conditions. Physical examination (including full neurological assessment) and a full assessment of cognitive function should be carried out.
- **In the normal course of events, the diagnostic process for dementia would occur outside of an acute hospital admission** (as it is very unreliable to assess background cognitive ability in an unfamiliar location OR when someone is medically unwell or has delirium). When appropriate we can refer to specialist memory services directly or,

through the discharge letter we can refer to the memory service via the relevant General Practitioner. In a small number of cases, it is possible to make a new diagnosis of dementia during an acute hospital episode – involving input from the care of the older person and old age psychiatry services.

- If the Dementia team (ext. 3935) have previously confirmed that the patient has a diagnosis of dementia, there will be an alert for dementia on MAXIMS. The Alert is used to identify a confirmed dementia diagnosis only, not a suspected diagnosis. This alert is linked to the electronic whiteboard on the wards.

4.4.2 Routine Investigations

- The following investigations should be routinely performed in all patients with cognitive impairment to look for a reversible cause and a cause of delirium if suspected.
  - Full blood count
  - Urea and electrolytes, CRP
  - Blood glucose
  - Thyroid, renal and liver function, calcium
  - Folate and Vitamin B12 levels
  - Urine analysis (if symptoms suggestive of infection), +/- bladder scan
  - ECG
  - Chest X-ray
- A CT brain scan should be performed if a space-occupying lesion is suspected, there are focal neurological signs or there is an unexplained reduced conscious level, persistent symptoms of delirium, the patient is on an anticoagulant or has had a fall with a head injury. It should also be performed if the history is unclear, especially in the context of head injury. Patients with cognitive impairment may not be able to give a comprehensive history or next of kin may not be available. Further neuroimaging may be appropriate for selected cases e.g. atypical cases; young onset (onset below age of 65); rapidly progressive cases.
- Further investigations may be indicated such as lumbar puncture in rapidly progressive cases or, in atypical cases e.g. young onset cases; Syphilis serology, HIV status, autoimmune profile. This should be after discussion with specialists.
- Once treatable causes of cognitive impairment have been ruled out and a new diagnosis of dementia is being considered, it is important to try to determine the type of dementia (e.g. Alzheimer's disease, Vascular, Lewy Body Dementia) as this will have implications for the management of the patient and medications prescribed / therapy options.

4.4.3 History

As well as the usual information the following should be specifically sought:

- Full drug history – any recently started or discontinued medication, over the counter (OTC) medicines, including night sedation/antihistamines. Ask 'Does the patient remember to take their medications?'
- Alcohol history
- Co-morbid illness
- Type of cognitive problems and onset and course e.g. memory problems, word-finding problems, do they fluctuate?
- Previous episodes of confusion

- Sensory deficits and any aids used
- Functional capabilities - physical and cognitive- ‘what can they not do now that they used to be able to do?’
- Pre-admission social set up and support - including finances and driving status
- Any power of attorney arrangements
- Information about the patient's previous occupation

Collateral history is essential; any source may be used - family, carers, friends, GP, care home staff. Good communication between staff is essential in obtaining the information and in avoiding unnecessary repetition of information gathering.

4.4.4 Differential Diagnosis

The differential diagnosis of dementia includes delirium and depression. In order to distinguish between dementia and delirium the most helpful action is taking a good history, which includes the patient’s pre-admission state, from a carer or relative. Dementia and delirium may co-exist. If unsure treat as delirium. Depression may be picked up by use of depression screening tools such as the Hospital Anxiety and Depression Scale (HAD), and the Geriatric Depression Scale. Depression and dementia may co-exist and this should always be considered in the differential.

4.4.5 Making a New Diagnosis of Dementia

- Any clinician who has the appropriate skills can recognise and make a diagnosis of dementia. Specialist advice may be needed in the very early stages and in particular clinical situations such as when the presentation or course is atypical, where significant risks are identified and in groups such as people with learning disabilities.
- Specialist advice may also be needed to establish the exact cause of the dementia. This may have clinical implications for the prescription of medication such as drugs for Alzheimer’s disease, treatment of vascular risk factors in vascular dementia or avoidance of antipsychotics in Lewy body dementia.
- In terms of brain scanning, the NICE Dementia Guideline states “Imaging may not always be needed in those presenting with moderate to severe dementia, if the diagnosis is already clear”. This may particularly apply to older and frailer patients with an established history of cognitive impairment.
- It is important that post diagnostic support, which should be person-centred, goes hand in hand with the diagnosis (which does not necessarily have to result in the prescription of medication). This support needs to be independent of the cause of the dementia[1] and provided when a diagnosis of dementia is made.
- In choosing to make a formal diagnosis of dementia in hospital please, refer to a patient’s history especially that in RiO, as it may be the case that the patient has either declined to have such a diagnosis made in the past or has requested that relatives not be informed of such a diagnosis. Contact the dementia team or psychiatric liaison team if further information from RiO is required.

4.4.6 When making a diagnosis it is best practice to:

[1]Alistair Burns, National Clinical Director for dementia, NHS England, October 2014

- Explain the diagnosis to the patient and any carers and giving relevant information about sources of help and support.[1] This may require exploration of the patient's ability and/ or willingness to engage in the process.
- Give information about the likely prognosis and progression.
- Provide The Alzheimer's society 'The Dementia Guide: Living Well after diagnosis', available from the Dementia Team, along with a support after diagnosis pack.
- Make appropriate referrals to Memory Clinic or Dementia Advisor Service, details available from the Dementia Team.
- Inform the Dementia Team to enable patient alerts to be updated.
- Follow the Principles of Dementia Care set out in the next section.

4.5 Principles of dementia care

People living with dementia have many needs and therefore it is useful to think of some overall guiding principles. For further information link with the ward/department Dementia Champion or contact the Dementia team or see the Dementia Intranet site.

- People living with dementia have the same human value as anyone else, irrespective of the degree of disability or dependence. This means recognising the worth of people with dementia. They should always be listened to, not be abused verbally, psychologically, physically or socially.
- People living with dementia are often in hospital with a condition unrelated to their dementia but the manifestations in dementia can make them extremely vulnerable to emotional distress. This requires a sensitive approach.
- People living with dementia have the same varied needs as everyone else. This means services need to respond to the full range of their needs. Patients should have the same access to health resources, have the right to be in a safe environment and have the right to relaxation and recreation and a good diet that optimises their health.
- People living with dementia have the same rights as all other citizens. They should be able to express their views about services, be able to make choices, expect first class care that aims to meet the needs of the person living with dementia.
- Every person living with dementia is an individual. This means providing person-centred care. They have the right to express their individuality, the right to make choices about their clothes, their food and their belongings.
- People living with dementia have the right to forms of support that do not exploit their family and friends. This means we proactively safeguard the quality of life of carers. They should receive information about support and services available and receive appropriate professional support in their role.
- The rights of people living with a dementia are protected under the specific and documented framework of the Mental Capacity Act including Deprivation of liberty (DoLs).

4.5.1 Management of confusion and behaviour change in hospital:

The following guidance emphasises the use of non-pharmacological management and is applicable to patients with behavioural and psychological symptoms of dementia, acute changes and distress with delirium or behaviour change with any form of cognitive impairment.

Management should be directed at reducing the impact of cognitive problems and importantly reducing distress, as well as identifying the underlying causes and

exacerbating conditions. Confusion, patients' perceptions, orientation, functional abilities and behavioural changes are exacerbated by: changes in environment, changes in routine, pain, dehydration, constipation, poor nutrition and alterations to medication. The patient should be nursed in an environment that supports orientation and with involvement of the multidisciplinary team, activity co-ordinators and carers where possible.

Principles include:

- Knowing the patient from their perspective. This is helped by the use of the documents ‘What matters to me’ - put up by a patient's name board or 'This is me' which the patient may bring with them to hospital. These documents enable you to establish preferences such as what the person likes to be called, their likes and dislikes, routines and things which are important to them which can help calm them if they are distressed or upset.
- Reassurance and explanation are given to the patient about interventions and personal care using clear, understandable language.
- That we understand that behaviour we can find challenging, is a communication. That if we can understand the message, (e.g. I am in pain, I am scared by.., I need my partner, the toilet etc., I am bored) then we can meet a patient's needs more easily and creatively.
- Provision of some continuity in care e.g. limited number of different staff
- Avoidance of physical restraint
- Inter and intra ward transfers and ward moves at night should be avoided unless a clinical necessity
- The environment feels safe and welcoming: Good lighting levels, regular and repeated cues to orientation e.g. clocks, calendars, personalisation of bed space, noise levels minimised.
- Meaningful activity is provided to help breakup the day. This may be through the intervention of an activity coordinator (if available) or through chatting to a patient or enabling them to take a walk off the ward.
- Encourage regular contact with visitors; they can be a valuable support mechanism for patients. Explain clearly to visitors how and why they can help. Volunteers may be able to assist if family members are not available.
- Ensure sensory aids are working and used e.g. glasses, hearing aids.
- Maintenance of normal sleep and eating patterns as much as possible and allowing flexibility to enable patients to keep close to their usual routine.
- Ensure adequate fluid and nutrition, encourage socialising at meal times on the ward, and families helping at mealtimes.
- Assess regularly for pain and manage appropriately including regular pain relief. Patients with dementia may not ask for prn pain medications. If a patient is unable to communicate clearly, assess for pain using the Abbey pain scale (Appendix B).
- Staff use a reassuring and understanding manner when administering medications.
- Attend to bladder and bowel care needs, enabling as much independence with normal function as possible.

4.5.2 Prevention of Delirium

The NICE guidelines on Delirium CG103 2010, updated 2019 and the SIGN guideline 2019, SIGN 157 emphasise the need for risk reduction to prevent delirium. This is particularly important for those with a dementia who are more vulnerable to developing delirium whilst in hospital. The principles outlined above are the same for patients who have delirium. In addition in delirium it is important to:

- Look for and treat the cause
- Avoid unnecessary catheterisation and investigations
- Encourage mobility after surgery
- Use active range of motion exercise
- Review medications, avoid anticholinergics

4.5.3 Communication

Clarity of communication is important; these are some tips (also available on the Alzheimer's Society website):

- Approach the person from the front and identify yourself
- Gain eye contact before speaking
- Make sure you are face to face with the patient
- Ask one question at a time.
- Ask yes or no questions. For example, "Would you like some coffee?" rather than "What would you like to drink?
- Be clear about your question before speaking
- Give plenty of time for the patient to process your question and answer
- Don't interrupt their answers, however slow
- If needed try different ways to ask the question.
- Avoid arguing. If the person says something you don't agree with, let it be.
- Offer clear, step-by-step instructions for tasks. Lengthy requests may be overwhelming.
- Give visual cues. Demonstrate a task to encourage participation.
- The patient may not remember the conversation well but they will remember how they felt during the interaction.

Patients with dementia may exhibit confused speech; it is usually preferable not to agree with confused speech but to adopt one of the following strategies:

- **V**alidate the behaviour expressed: To a distressed patient looking for their Mum. - "I can see you really need to see your Mum, I am sorry that your mum is not here. How can I help you?" or "tell me a little about your mum. All these responses assume, as does the patient, that her Mum is still around. (Don't contradict them – i.e. by explaining that their Mum has died)
- **E**mpathise about the underlying **E**motion: "This is very upsetting for you, is there anything I can do to help?" "It must be frightening when you don't know where your Mum is" "We are not a prison here, but I understand hospitals do sometimes feel like that".
- **R**eassure: (You will help them to find a solution to the problem they are experiencing – not the one you observe) "my name is XXXX - I am here to help you" ("As soon as your

Mum arrives I will let you know where you are". "Is there anything we can do to make you feel better?"

- **A**ctivity (Only after the above stages): distract and look at what the person can do "you are asking to catch the bus, but I am not sure about the buses, but I was going to wait here and have a drink. Would you like a drink with me?"

4.5.4 Behaviours that challenge us:

- Patients with dementia may exhibit communication non-verbally and in ways which can appear challenging; (e.g. scream or try to grab if they feel they will fall off the bed when turned on their side, even if it is clear to you they are safe). In this situation use of the one of the strategies listed above (validated for dementia care) is often helpful.
- For further strategies, please discuss with your local dementia champion, the dementia team or psychiatric liaison teams.

4.5.5 Special considerations – psychological and behavioural disturbances:

People living with dementia are likely to present with a wide range of psychological and behavioural problems and sometimes psychiatric problems. These can be a significant challenge to carers in all settings. Within hospitals, this can also present challenges to other patients. They include:

- Hallucinations - visual, auditory (these can be distressing for patients)
- Delusions- often paranoid in nature or related to personal belongings
- Anxiety
- Emotional lability
- Aggressive behaviour
- Activity disturbance- wandering, agitation, apathy
- Eating disturbance- refusal to eat, eating inedible materials
- Diurnal rhythm disturbance
- Sexual acting out

The management of these symptoms requires careful assessment to identify the triggers and causes and there are a variety of non -pharmacological strategies that can be used. (See Our Enhanced Care Policy). Consider referral via red top to the psychiatric liaison or care of the older person teams.

Specific guidance is available on managing Parkinson's disease symptoms in people with Parkinson's disease dementia or dementia with Lewy bodies and the Care of the Older Person team or psychiatric liaison teams should be contacted.

4.5.6 Wandering and agitation

Patients who wander require close observation within a safe and reasonably closed environment. It is always preferable to try to distract and facilitate a patient to walk around where possible. There is no pharmacological treatment for wandering. Patients who are more mobile are less likely to develop the complications of the sedentary patient (pressure sores, respiratory infections, muscle wasting and deconditioning.) Relatives, carers and volunteers can be used to help in his situation. It is often a sign of an unmet need. An attempt to identify the reason for the behaviour should be made – are they looking for the toilet? thirsty? in pain? constipated? and addressed where possible. If extra support is needed, refer to the Enhanced Care Policy. For a patient that is at high risk leaving of the ward unnoticed, ask medical photography to photograph the patient. Ensure Deprivation of

Liberty Safeguards (DoLS) are in place for patients who lack capacity to consent to admission.

4.5.7 Sedation

Occasionally a patient's behaviour may be so disturbing that it is a danger to themselves or staff. Equally they may be so distraught that their suffering becomes unbearable to themselves and their distress spirals out of control. It is at times like these that sedation is thought of. However **sedation MUST be a last resort**.

The cause of the distress, whether pain, constipation, fear etc. should be actively sought and addressed.

Non-pharmacological, supportive interventions must always be tried first and for an appropriate length of time.

- Enhanced Care (1 to 1 or specialling) will need to be considered to manage severe challenging behaviour in patients with delirium or dementia
- The use of the VERA approach (above) being used
- The patient having sufficient activity including walking and fresh air where possible.

All sedatives can cause delirium in patients with dementia, especially drugs with anticholinergic activity. The use of sedatives and antipsychotics should be kept to a minimum to reduce the risks of delirium, falls, altered sleep patterns and effects on nutrition.

Pharmacological sedation *may* be required in the following circumstances:

- In order to carry out essential investigations or treatment
- To prevent patients endangering themselves or others
- To relieve distress in a highly agitated or hallucinating patient.

Prior to the prescription of sedation, a clinical review should be carried out. This review should be discussed with one of the following: a senior member of your team, a Geriatrician, a member of the Psychiatric Liaison Team or a Parkinson's specialist if appropriate.

If a patient has previously received a drug for sedation its effect should be sought- if one drug has been previously safely tolerated it may be preferable to consider using the same drug again. Always use care in drug naive patients. It is preferable to use sedation in a proactive planned manner rather than a reactive one. Identification of at risk patients on admission can facilitate this process.

Lorazepam 0.5mg to up to four times daily can be effective in reducing severe acute distress in the above circumstances in the short term (72 hours). There is an associated increased risk of falls, but agitation and restlessness from delirium also carry this risk. Higher doses may be needed. Seek specialist advice.

Contact the Psychiatry liaison team if uncertain about medication management or if the above is ineffective. The team would be happy to advise before using antipsychotics. There is an evidence base for benefit from some antipsychotics in dementia where there are psychotic symptoms or aggression.

Please also contact the Psychiatry liaison team for advice on prescribing antipsychotics in Lewy body dementia. Patients with Lewy body dementia are very sensitive to antipsychotics particularly. There is evidence of a small but significant increase in stroke in elderly patients with dementia treated with antipsychotics. This is not confined to risperidone and olanzapine, and includes other antipsychotics and probably extends to antidepressants and benzodiazepines.

If a patient with dementia is admitted already taking antipsychotics it would be advisable to ask for a review from the psychiatry liaison team.

Sedatives if used should be regularly reviewed and the patient closely monitored; the patient should be assessed to identify and treat any comorbid conditions, the lowest dose possible used and they should be discontinued as soon as possible. Specialist advice may be required in difficult cases. All patients given sedation must have a regular review and regular observations (NEWS2, or non-contact observations if NEWS2 not possible) to ensure they are clinically safe.

N.B. the reason for sedation must always be clearly documented, communicated to families / carers during admission with explanation of risk and the G.P. informed on discharge.

Please also see guidelines specific to pharmacological management of delirium and discuss this with Geriatricians/Old Age Psychiatry.

4.5.8 Medication issues in dementia

Patients with dementia are often not taking their pills at home and if this is not known on arrival in hospital, it can mean a sudden tidal wave of medication hitting their systems

- Patients with dementia are at increased risk of adverse drug reactions.
- Worsened cognition and delirium may be seen related to drug changes - starting or stopping medications or dose changes.
- Certain classes of drugs are particularly prone to causing confusion and should be used with caution. These include: sedative drugs, opiate analgesics, drugs with anticholinergic activity, anti-parkinsonian medication.
- Hospital admission therefore, provides an opportunity to review medication usage to minimise the risk of adverse events and interactions. It is often an opportunity to cut down on medication rather than increase it. It is worth noting that most drug trials exclude people with dementia. There is no clear evidence for example, that treating hypertension or high cholesterol is useful in patients with advanced dementia.
- General rules are to avoid drugs with significant anticholinergic activity, start on a low dose and titrate doses slowly, avoid starting /stopping multiple drugs at one time.
- Evidence demonstrates an increased mortality in people with dementia with increased numbers of medication taken.

4.5.9 Complications

The main complications of dementia are:

- Psychiatric and behavioural disturbance
- Delirium
- Depression
- Physical consequences-falls, pressure sores, poor nutrition

Psychiatric and behavioural disturbance is discussed in previous sections.

Note that any change of environment, routines, disrupted sleep and late night ward moves will cause these disturbances to worsen. This also applies when a patient is discharged from hospital - they will take time to settle back in to their own environment.

4.5.10 Delirium

Patients with dementia are particularly prone to develop acute episodes of confusion superimposed on their dementia. There is a risk of clinicians failing to identify and treat this, which can adversely affect the outcome. Delirium may present as a hyperactive state, hypoactive state or a combination of both. The use of appropriate assessment tools for delirium is to be encouraged 4AT (appendix one) and is proven to increase the accurate recognition and diagnosis of delirium. New confusion is also scored in the NEWS2 (see appendix).

4.5.11 Depression

Depression is common in elderly patients in hospital and in those with dementia. It is potentially treatable and its presence may be overlooked in a patient in the context of a dementia .

If depression is identified or considered to be an important factor then referral to Mental Health Services, involvement of Mental Health Liaison nurse service or appropriate medication should be considered as part of the management plan.

4.5.12 Pain

Patients with dementia may suffer pain and be unable to communicate this clearly to staff. It is important to consider pain as a possible contributor to behavioural disturbance. Patients should be asked if they are in pain. If it is not clear, behavioural and physiological scales are available to help identify pain in dementia patients e.g. Abbey Pain Scale (see Appendix 3). Involving carers who know the patients well can also help to identify altered behaviour that may be an indicator of underlying pain.

Do not rely on a patient with dementia to ask for pain relief. If they can communicate clearly, they should be routinely asked about pain. If they are unable to communicate clearly then a regular assessment for possible pain should be part of their ongoing care.

4.5.13 Falls

- Falls risk in people with dementia is often higher than in people without. Use of the falls risk assessment tool is essential to develop an individualise falls prevention strategy for the patient whilst in hospital.
- Risk assessment should include a lying and standing blood pressure where possible (see falls section of the intranet for how to do this properly).
- Supportive strategies need to include environment, delirium prevention, minimising ward moves and maintaining daily orientation and activities.

4.5.14 Advance care planning

Advance Care Planning for patients who have dementia should be considered at each contact with hospital services. Many patients from local care homes will have a Somerset Treatment Escalation Plan (STEP) already in place. This form does not need to be re-done in hospital. We have a duty, where it is not in place, to start conversations about treatment escalation and planning ahead. Patients and their families living with dementia should be given opportunity to discuss their wishes and preferences regarding future care. This includes appropriateness of re-admission to hospital. GP's should be informed that conversations have started in hospital where appropriate.

4.5.15 Referral to Older Person's Mental Health

Most patients with dementia can be managed safely within the general hospital setting. However, some may present particular difficulties and require assessment or input from the mental health team.

- Diagnosis remains uncertain
- Advice on some aspects of pharmacological management
- Severe agitation or behavioural disturbance
- Severe depression
- In the context of complex discharge planning- including residential placement –where mental health issues will require follow up or further assessment

Within Musgrove Park Hospital, there is access to support and information from the Psychiatric Liaison team via a red top referral. They can assist in management of patients and the discharge and follow up of patients with dementia, amongst other mental health issues.

5.0 TRANSFERS AND DISCHARGE

5.1 Ward Transfers

- People with dementia can experience disturbance in their orientation as a result of unexpected changes in their environment. In the hospital setting this can exacerbate all of their cognitive problems and cause delirium. It is important to keep environmental changes to a minimum to assist in orientation strategies.
- Clinical site often have to make difficult choices about transferring patients, often out of hours. Ensure that there are 2 patients listed who are appropriate for transfer on the ward bed board at all times. If no patients are appropriate, it is better to list 2 patients for whom a transfer will have the least detrimental effect.
- People with dementia should be admitted to an appropriate ward that meets their clinical needs.
- They should not transfer ward unless there is a clear clinical reason and that the transfer benefits the patient. Do not transfer a patient if it will clearly adversely affect their overall management and care.
- Patients who are wandering are not appropriate in most circumstances to be transferred
- There should be clear and simple communication with the patient explaining a transfer.
- There should be timely and clear communication with family and friends and whenever possible they accompany the transfer to support orientation.
- It is important that all personal belongings are transferred and that the patient is aware of this - particular focus on hearing aids, glasses and dentures.
- Try and choose a ward that has a similar physical layout to the present ward
- Plan the time of the day to avoid disturbing important daily events that assist in reality orientation - avoid meal times, medication times
- **People with dementia should not be transferred at night**—many patients are better orientated earlier in the day
- There must be a clear, effective handover from the initial to receiving ward identifying the medical, nursing and functional problems with the patient as well as any cognitive or behavioural aspects.

- On arrival to a new ward, the patient should be settled in and orientated. Key personnel should identify themselves to the patient. They should be shown their bed space, where the toilets are and how to ask for help. There should be a settling in period with enhanced supervision. This means the transfer time must be chosen to give consideration to the working patterns of both wards.
- Orientation should be provided - clocks, calendars, placement of familiar objects, putting away personal belongings with the patient - to assist in settling the patient. Family or friends can be helpful in this activity if involved appropriately.
- Inform the ward dementia champion that a patient with dementia is on the ward. Ensure the ward staff are aware and encourage the ward to identify and adhere to the patient's usual routines. (Use of The 'What matters to me' document).

NB No matter how carefully a transfer is arranged some degree of increased confusion, anxiety or behaviour change may occur. The receiving ward should be aware of this and aim to provide increased support if necessary.

5.2 Feeding and nutrition

People with dementia commonly have problems with eating. This may be loss of appetite, inability to initiate a swallow, problems with the swallow itself or inability to feed themselves. This often leads to weight loss. When admitted to hospital there may be worsening of their eating problems and this can present challenges to staff:

- Poor swallow or holding food in the mouth
- Lack of appetite
- Inability to feed oneself
- Refusal to eat food
- Refusal to drink fluids
- Lack of initiation of eating or drinking
- Unsafe swallow

All of the above can contribute to a poor outcome and result in significant malnutrition

With regards to feeding and nutrition in people with dementia:

- It is vital to resume their normal feeding routine as soon as possible after admission. Prolonged periods of the patient being nil by mouth should not occur.
- It is important to identify their normal food preferences in terms of likes and dislikes, textures, how they are fed or feed themselves. Many people with dementia prefer finger foods, which can be obtained from the kitchen. Snack stations are also available on Care of the Older Person wards. Information should be routinely sought from carers and family and included in the Food Preference Chart. The "This is Me" document should be filled in/ updated accordingly.
- People with dementia especially those with advanced disease are at high risk of aspiration. It is never acceptable to keep them nil by mouth without consideration of alternative feeding approaches. It is often acceptable to allow some oral intake at an accepted risk level (comfort feeding) to reduce discomfort in these patients. This should always be discussed with next of kin and the decision made in accordance with best interests and documented clearly.
- In difficult cases senior input should be sought, a SALT referral should be made, and the views of close family always considered. A second opinion can also be sought. Oral intake, modified as necessary, should be the aim of a nutrition strategy in advanced

dementia cases. Even if the patient is deemed to have an unsafe swallow, a risk management strategy may offer them the best quality of life. Nil by mouth should be a last resort not the default option.

- Feeding strategies should never be about convenience for staff or carers but should be considered based on the aims of any intervention. There must be enough staff available, especially at meal times, to assist and feed those patients who require more time to eat an adequate meal. The family should also be invited to help if they so wish. Access should be available to a freezer containing meals that can be microwaved to cater for patients nutritional needs around standard meal-times. Consider a referral to the dietitian for advice.
- If a patient is near the end of life complex issues around nutrition and hydration can occur. Support can be provided by Geriatricians and the Palliative Care team and in some very complex cases, the Ethics Committee.

5.3 Mental capacity

Patients with dementia may lack capacity for decision-making but this should not be assumed. Assessment of capacity should be performed in accordance with trust policy according to the Mental Capacity Act and Best Interest Decisions framework.

5.4 Discharge

Should be planned in conjunction with all disciplines, including carers. The patient's cognitive and functional state should be reassessed and identified at discharge with any planned follow up clearly outlined. Communication with support services and primary health care teams should be timely and complete.

6.0 EXECUTIVE SUMMARY

6.1 Dementia is a condition characterised by a progressive deterioration in mental and physical health, disability and dependency. People with dementia often have co-existing physical conditions requiring admission to hospital. Physical illness, change of environment and many medical interventions are known to exacerbate the symptoms of dementia. This summary guidance has been produced to help clinicians in routinely screening for dementia managing this condition during the patient's stay in hospital and in preparation for discharge.

6.2 Screening

Cognitive screening tests should be carried out on all patients age 75 years+ (or 65 years+ if cognitive changes noted) on admission to hospital using the Abbreviated Mental Test Scale (AMTS 4 or 10) and the 4AT for delirium. A history from a carer or relative of the onset of any cognitive impairment or confusion is essential to distinguish dementia from delirium. The use of delirium assessment tools - the 4AT (& CAM on ITU) can improve diagnosis rates of delirium and should be routinely used to assist in the patient's management.

6.3 Diagnosis

The diagnosis requires careful history and examination and should be made at an appropriate time and with full support for both patients and carers. Patient's should always receive a follow-up plan after diagnosis.

Differential Diagnosis would include delirium and depression

If a diagnosis of dementia is made in the acute hospital setting

- Explain the diagnosis to patient and carers

- Provide a patient information pack (available from the Care of the Older Person Department)
- Ensure appropriate follow up is provided, including appropriate referrals to the Memory clinic, and dementia advisory service.

6.4 Investigation

Routine investigations are indicated in all cases to attempt to identify potentially reversible causes. Further investigations are indicated in specific circumstances.

6.5 Care and Treatment

Care should involve explanation to the patient and carers of the diagnosis, giving relevant information and support. Care should be person-centred, safe and compassionate. It should recognise a person's unique circumstances and respect them as a person. This should be shared at ward MDT meetings. Ward transfers should be avoided unless clinically indicated.

Non-pharmacological approaches are an important aspect of care particularly around reality orientation and symptom management and should be utilised. Sedation is rarely needed and if used may cause delirium and increase the risk of falls. Pharmacological interventions are a last resort. If used they should be chosen to reduce any potential adverse reactions.

Particular attention should be focused on feeding and nutrition, pain management and advance care planning and treatment escalation plans and these communicated to the GP and carers.

Referral to Mental Health / Specialist Psychiatric Liaison Services Should be considered in diagnostically difficult cases, where there is severe behavioural or psychiatric disturbance and in cases of complex discharge planning.

7.0 REFERENCES

7.1 Dementia: supporting people with dementia and their carers in health and social care NICE guidelines [CG42] Published date: November 2006 Updated June 2018.

www.nice.org.uk

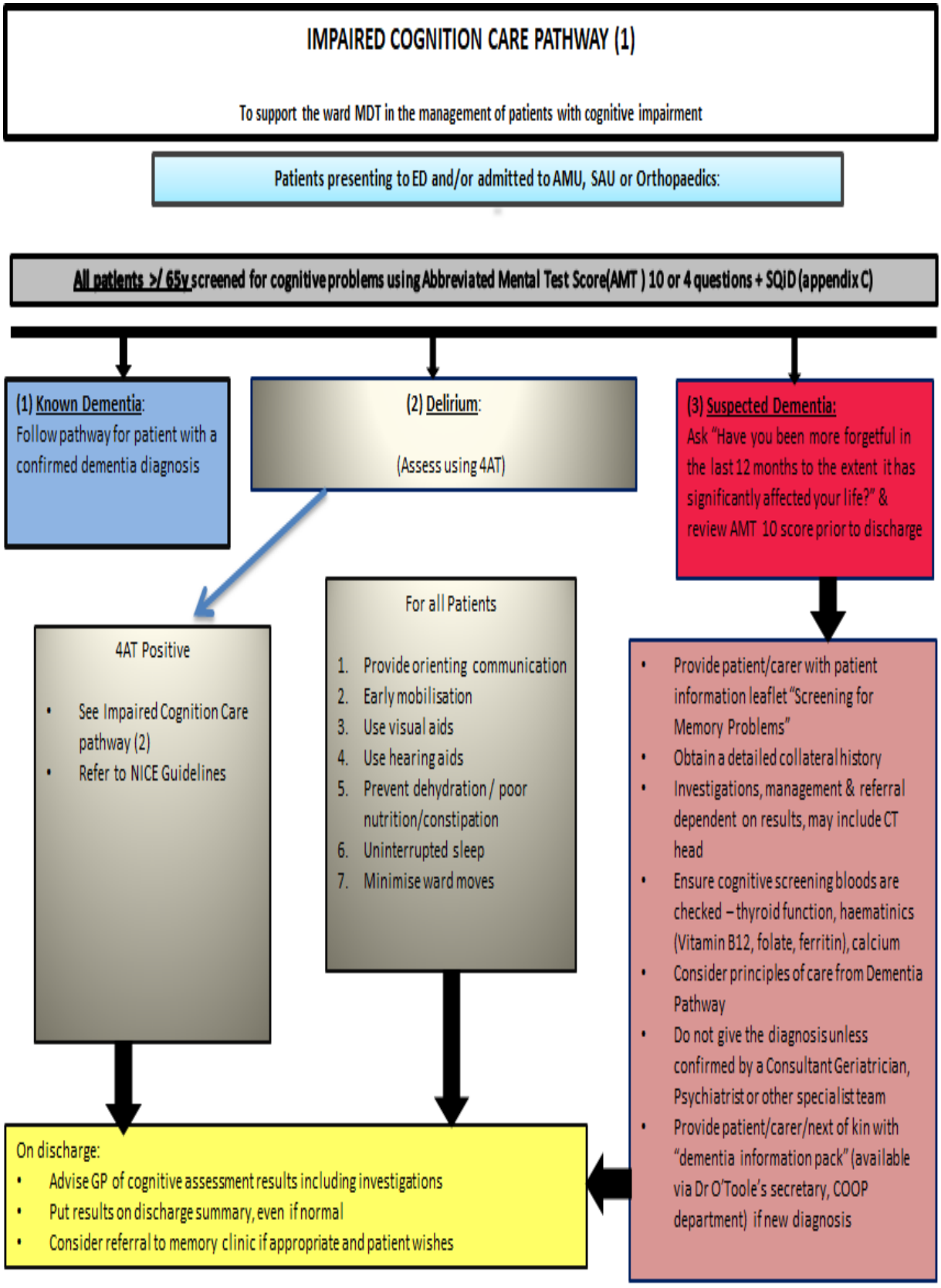
7.2 **SIGN** 157: Risk reduction and management of **delirium**.
www.sign.ac.uk

7.3 Dementia action alliance, Dementia Friendly hospital charter
https://www.dementiaaction.org.uk/dementiafriendlyhospitalscharter

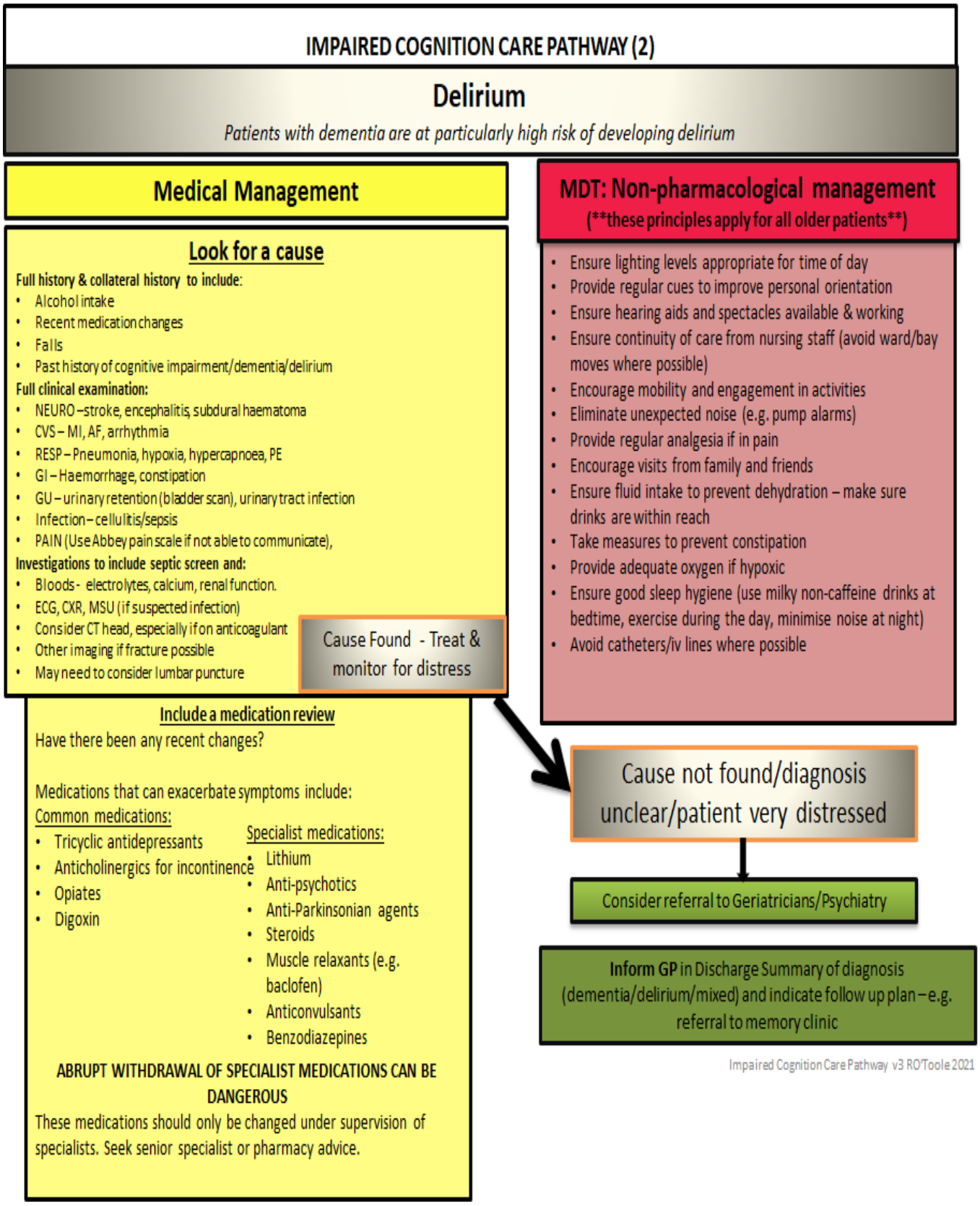
Alzheimer's Society Website

7.4 Supporting people with dementia in acute care
www.knowledge.scot.nhs.uk

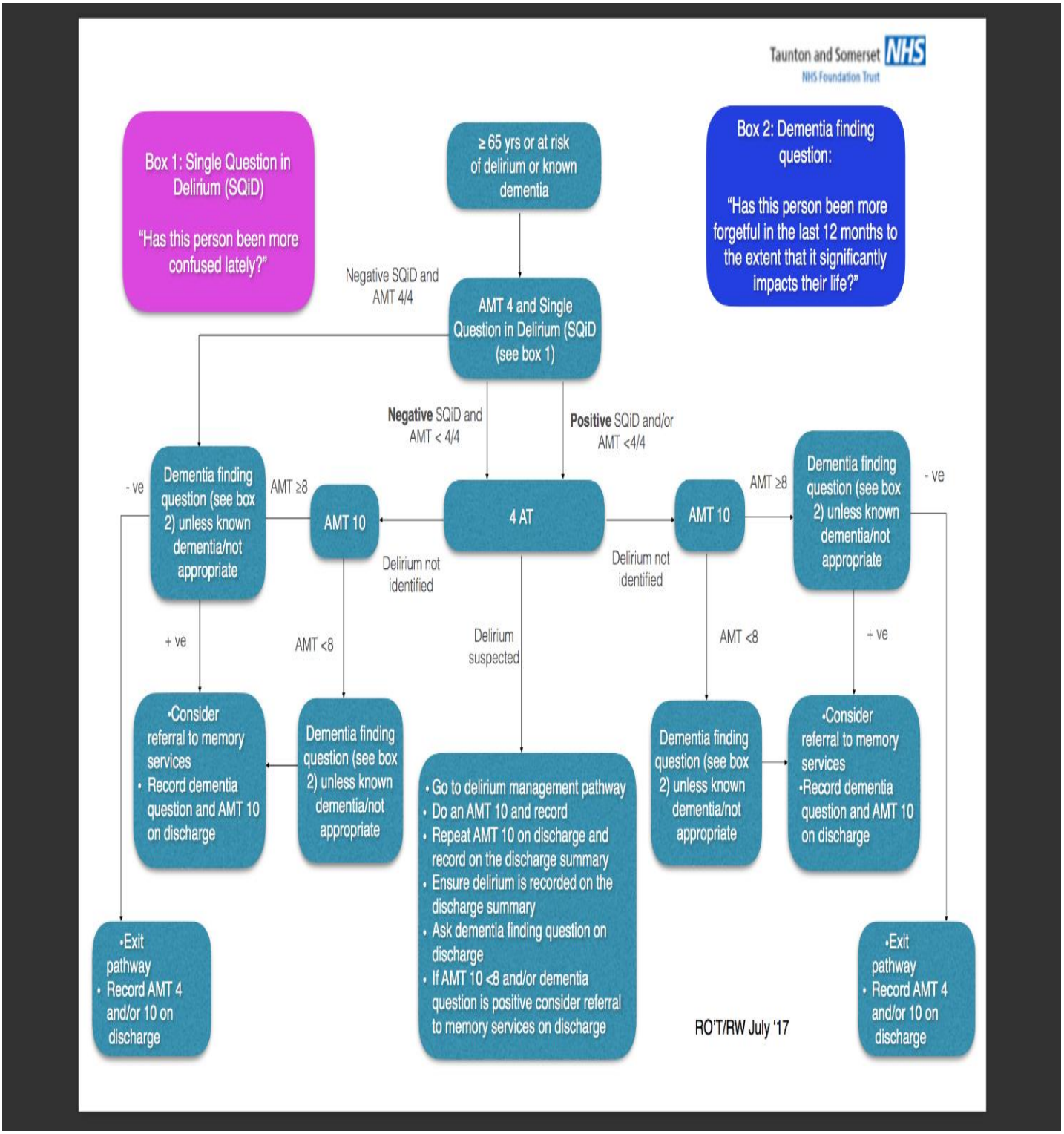
8.0. APPENDIX A - Impaired cognition pathway 1



9.0 APPENDIX B Impaired cognition pathway 2



10.0 APPENDIX C Summary of impaired cognition pathway



11.0 APPENDIX D

Abbey Pain Scale

Patient label

NHS
MUSGROVE PARK HOSPITAL
Abbey Pain Scale

WHILE OBSERVING THE PATIENT SCORE QUESTIONS 1 TO 6

DATE:…… TIME: …… PERSON COMPLETING:

……

Latest pain relief given was …… at

…… hrs

Q1 Vocalisation
e.g. whimpering, groaning, crying
Absent 0 Mild 1 Moderate 2 Severe 3
Q1 ☐

Q2 Facial expression
e.g. looking tense, frowning, grimacing, looking frightened
Absent 0 Mild 1 Moderate 2 Severe 3
Q2 ☐

Q3 Change in body language
e.g. fidgeting, rocking, guarding part of body, withdrawn
Absent 0 Mild 1 Moderate 2 Severe 3
Q3 ☐

Q4 Behavioural change
e.g. increased confusion, refusing to eat, alteration in usual patterns
Absent 0 Mild 1 Moderate 2 Severe 3
Q4 ☐

Q5 Physiological change
e.g. temperature, pulse or blood pressure outside normal limits, perspiring, flushing or pallor
Absent 0 Mild 1 Moderate 2 Severe 3
Q5 ☐

Q6 Physical changes
e.g. skin tears, pressure areas, arthritis, contractures, previous injuries
Absent 0 Mild 1 Moderate 2 Severe 3
Q6 ☐

Add scores for 1 -6 and record here → Total Pain Score ☐

Now tick the box that matches the Total Pain Score →

0 – 2 No pain	3 – 7 Mild	8 – 13 Moderate	14+ Severe

Finally, tick the box which matches The type of pain →

Chronic	Acute	Acute on Chronic

Abbey et al Funded by the JH & JD Gunn Medical Research Foundation 1998 – 2002