

SEE CHANGE
THINK PAIN



**PAIN IN PEOPLE WITH DEMENTIA:
A SILENT TRAGEDY**

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PAIN IN PEOPLE WITH DEMENTIA - A LONG WAY TO GO

Try as the plastic surgeons may to fight time, we're all getting older, and so is the population. In 2010, 17% of the population was over 65, and by 2035 it is estimated that figure will be 23%¹, with centenarians set to be the fastest growing age group for decades to come.² Pain isn't an inevitable part of ageing but it's certainly common – nearly half of all over 65s and three in four people living in residential care are in pain at any one time.³

Along with a higher likelihood of being in pain, getting older also brings an increased risk of dementia. Around 1 in 14 people over 65 and 1 in 6 people over 80 have dementia, adding to a total of 800,000 people in the UK in 2012.⁴ Add the two together and there is real potential for suffering.

If you or I are in pain, we can do something about it. We may treat the pain – or the cause of pain – ourselves. If we can't sort it out ourselves, we know someone who can. We can visit the pharmacist or make an appointment with our GP, explaining exactly what symptoms we're suffering and how they affect us. Now imagine you couldn't make your voice heard. Many people with dementia have limited language, or cannot communicate in words at all. Their behaviour is very likely to change (can you imagine carrying on as usual with a smile on your face if you had a raging migraine?). But a person with dementia may respond to pain not by pointing to where they're hurting, but by becoming agitated or withdrawn. If their carers aren't alert to pain as a possible

explanation, it's all too easy for the diagnosis to be missed, leaving the person with dementia in pain and their carer frustrated at their 'difficult' behaviour.

While it is heartening to see examples of good practice in this survey, there are some worrying findings, too. For instance, 68% (n=67) of the surveyed care and nursing homes said that half or less than half of their residents with dementia were affected by pain, far less than the 80% estimated.^{5,6} Only 1 in 6 respondents believed the figure among their residents was 75% or more.

Training to assess pain in people who are less able to communicate was clearly a challenge – almost 1 in 5 didn't have any guidelines in place for this sort of assessment. Of those with guidelines 21% (n=81) didn't use a formal set of tools to guide them. When tools were in place, there was a lack of consensus on which one to use. Almost a third of care staff didn't receive any training on detecting and assessing pain and more than two thirds saw training as an unmet need.

In total, 39% (n=100) didn't have formal guidelines outlining their approach to using anti-psychotics for people less able to communicate and almost a third had not reduced their use of anti-psychotics in line with Government guidelines.

The staff in our care homes, and the legions of informal carers in the community, provide an invaluable service in caring for people with dementia who are less able to communicate or to care for themselves. But despite the best of intentions, it's clear that there is a long way to go to make sure our vulnerable loved ones have the comfort they deserve. I believe passionately that detecting and relieving pain can make all the difference to quality of life. We need to raise awareness, and give our carers the knowledge and tools they need to make that happen. Let's all See Change: Think Pain and start to make a difference.

Dr Sarah Jarvis, January 2014

INTRODUCTION

The ravages of dementia seriously impact the ability of those with advanced stages of the disease to communicate pain. Damage to the central nervous system affects memory, language, and the higher order cognitive processing necessary to communicate their physical feelings.

Yet, despite changes in central nervous system functioning, people with dementia still experience pain in a similar fashion to cognitively intact older adults. This puts people with dementia at high risk of having their pain under recognised or under treated and can lead to unnecessary distress. While the evidence still does not tell us conclusively whether dementia as a disease in itself can cause physical pain, we do know that people with dementia experience pain just as any other older person.

Chronic pain is common among older people, who are more likely to suffer from problems such as arthritis and often a number of co-morbidities. In patients with dementia, who often have trouble communicating, this may mean they are unable to tell someone if a physical problem, such as pain, exists.

As a leader in pain management, Napp Pharmaceuticals Limited is committed to improving the lives of those suffering with pain, including those with dementia. Napp have therefore undertaken a programme of quantitative and qualitative research, gathering information, thoughts and perspectives from a sample of

independently owned care and nursing homes across the UK.

This included:

- Interviews with representatives from each of the largest four care home chains (Sunrise Senior Living, BUPA, Barchester and Four Seasons) to gauge current management approaches with regards to pain in their residents with dementia
- Questioning a sample of 100 independently owned care and nursing homes around provision in their homes to identify and manage pain in dementia patients
- Desk based research around previously published studies on pain in dementia to gauge the current state of affairs

Napp have also produced booklets for at home and professional carers detailing the signs to look for in people who are less able to communicate their experience of pain. This is part of the 'See Change: Think Pain' programme, which will be rolled-out across the UK during 2014 with the aim of raising awareness of undiagnosed and undermanaged pain in dementia patients.

At the core of the initiative, a simple mnemonic has been created to help carers identify what signs to look for to identify possible pain.

P pick up on mood changes

A assess verbal cues

I inspect facial expressions

N notice body language

Napp have also engaged with the Care Quality Commission (CQC) on this issue and are delighted to hear that they are conducting a themed review this year around care of people with dementia and that one aspect of this will be to look at diagnosis and management of pain.

Napp will be sharing the results of this survey and all materials with the CQC, look forward to the results of their audit later this year, and hope to see this lead to change in the way that care homes are advised to identify pain in their residents who are less able to communicate their distress.

SUMMARY OF FINDINGS AND RECOMMENDATIONS

The members of the advisory board included:

Sunrise Senior Living

University of Greenwich

RCGP

Four Seasons

National Care Homes Association

Admiral Nursing at Dementia UK

Alzheimer's Society



The key findings drawn out from the results of the interviews, survey and desk research, are as follows:

- It is estimated that 50% of the elderly population suffer from chronic pain, with this figure increasing to 80% in a care home setting.^{5,6} However 68% (n = 67) of independently owned care and nursing homes surveyed reported that half or less than half of their dementia patients were affected by pain. Perhaps most worryingly, nearly 85% (n=67) of independently owned care and nursing homes believe that less than 75% of their residents with dementia are affected by chronic pain. This represents a startling number of people with dementia who are highly likely to be in pain that has gone unrecognised.
 - Availability of guidelines to help staff assess pain in those who are less able to communicate was variable. In addition, there was a lack of consensus about which assessment tool to base these guidelines on. The Abbey tool was most popular with 61% (n=64) of guidelines based on this, but no other strong contender emerged.
 - Nearly a third of the independently owned care and nursing homes questioned stated that their anti-psychotic use had not reduced in line with government guidelines. Additionally, few non-pharmacological alternatives were offered as an alternative.
- Upon consultation with a number of prominent experts in pain and dementia, Napp propose the following recommendations are considered by policy makers in order to improve the care and management of chronic pain in people with dementia:
- The creation and dissemination of a comprehensive set of national guidelines focusing on how to identify and treat pain in people with dementia.
 - An acknowledgment at a national policy level that with the reduction in anti-psychotic usage, identifying and treating the source of challenging behaviours in people with dementia should now be a priority.
 - A campaign from Public Health England to educate people around signs of pain in people with dementia.
 - The creation of a joint training programme for staff in hospitals and care homes of all levels to ensure a joined up approach when assessing patients for pain.
 - A national study exploring adherence and administration of analgesics compared with the levels prescribed to patients.
 - The CQC to consider including a section of their inspection about provision and regularity of training around how to assess people with dementia for pain.
 - Greater sharing of medical records throughout the NHS to help to identify potential sources of pain in a patient with dementia who cannot identify it themselves.
 - Engage family and carers with the personalised care budget scheme and enable them to make decisions about treatment for agitated behaviour for their loved one with dementia.

PAIN IN DEMENTIA – AN OVERVIEW

Under-diagnosed and under-managed pain in people with dementia is a serious issue. With the government’s recent drive towards a reduction in the use of antipsychotics in dementia care, it is imperative that all causes of possible agitation in dementia patients are considered and addressed at the source.

Agitation and aggression are common in people with dementia, in particular those with moderate to severe dementia living in nursing homes.^{7,8} Agitation is associated with increased distress to residents, family and professional care givers and is one of the most challenging symptoms of dementia.

Many people with dementia, as with the majority of the elderly population, have a number of painful conditions.⁹ It has been proposed that pain in patients with impaired language and abstract thinking may manifest as agitation.¹⁰ It has also been suggested that many of the challenging behaviours associated with dementia may be a result of the patient experiencing pain, but struggling to communicate this.¹¹

There are a number of reasons why people with dementia may not be receiving optimum pain management:

- As dementia progresses, a person’s speech ability may decline so that they can no longer effectively communicate.
- Carers and care staff often do not recognise when a person is in pain or do not know how to help.
- People may think that some behaviour – for example, calling out for help repeatedly – are due to ‘the dementia’ rather than poorly managed pain.
- A carer may believe that a person is manifesting an expression of the emotional pain that they feel due to their dementia and not physical pain.



There are also issues associated with management in conditions commonly accompanied by pain, such as post-operative pain, in people with dementia. A study of 97 people, 38 of who had been diagnosed with dementia, examined the treatment of pain following hip fracture, where patients were assessed daily to see how well their pain was managed.¹²

The data not only revealed that a majority of elderly hip fracture patients experienced undertreated pain, but that advanced dementia patients received one-third the amount of opioid analgesia as compared to cognitively intact subjects. It can therefore be seen that dementia patients received less pain relief post-operatively than those without dementia, despite comparative illness.¹²

With 800,000 people with dementia in the UK and the numbers set to rise to over 1 million by 2021¹³ standards of care in fundamental aspects of well-being like pain, need to improve.

CURRENT GUIDELINES

In 2006, updated in October 2012, NICE and the Social Care Institute for Excellence (SCIE) published a clinical guideline on 'Supporting people with dementia and their carers in health and social care'.¹⁵ This guideline stated that:

If a person with dementia has unexplained changes in behaviour and/or shows signs of distress, health and social care professionals should assess whether the person is in pain, using an observational pain assessment tool if helpful. However, the possibility of other causes should be considered.

The treatment of pain in people with severe dementia should involve both pharmacological and non-pharmacological measures. Non-pharmacological therapies should be used with the person's history and preferences in mind.

In addition, in 2010 NICE published a quality standard for care in people with dementia.¹⁴ While this did not immediately address best practice of care around diagnosis and treatment of pain in people with dementia, it did state that every patient in the later stages of dementia should have an assessment from a palliative care service, and one of the aspects that they should look at is whether the individual is in pain.

However, pain provision should not only be thought of within the context of palliative care. As previously stated, evidence shows that ageing is associated with a high rate of painful conditions, irrespective of cognitive status, and so should be a consideration throughout an elderly person's experience of care.

There are also a number of guidelines that have been created by individual hospital trusts, the Royal College of Nursing and the British Pain Society. However, a unifying set of guidelines for all secondary care and care home settings has yet to be developed, leaving room for geographical inconsistency and variation.

The NHS should strive toward a system that treats every patient as an individual, with each of their co-morbidities addressed as a whole, and treatment determined with the full set of facts to hand.

The best thing about pain tools is that they make carers and healthcare professionals think about pain.

Dr Liz Sampson, old age psychiatrist and Senior Lecturer at UCL

What has distressed me over many decades as a nurse is that pain in people with dementia is often poorly recognised, poorly assessed and, by consequence, poorly managed.

Karen Harrison Denning, Head of Admiral Nursing, Dementia UK

NOTE: the question of who might create a unifying set of guidelines should be addressed, as NICE may not be as familiar to those in community care as those in secondary care. Alternatives, such as the CQC's Essential Standards and the National Skills Academy for Social Care should additionally be considered.

IDENTIFYING PAIN IN PEOPLE WITH DEMENTIA

When caring for someone with dementia, there are many everyday challenges to take into account and overcome in order to provide the best care.

One of the most difficult symptoms of dementia can be agitation or aggressive behaviour, which can be both distressing and difficult to understand.

Whilst there are a number of reasons a person with dementia may exhibit agitation or aggressive behaviour, untreated or undertreated pain can be a significant factor in this.¹¹

There are a number of signs and clues that one can use to help you identify if someone with dementia is experiencing unidentified pain. These can be easily remembered using the PAIN acronym.

MOOD

A person may become tense or 'on edge' and become unusually challenging or angry, being unusually resistant to care, sometimes pushing people away. Depression and withdrawal are also common.

VERBAL CUES

Repeatedly shouting out, screaming or groaning.

FACIAL EXPRESSION

This may include frowning, sadness or crying, grimacing, and tense and frightened expressions.

BODY LANGUAGE

Signs include guarding and bracing or rubbing or holding a particular part of the body.

There are also a number of other highly recommended tools that can be used to help identify pain in those who are less able to communicate. These include:

NGPC LEAFLET

The National Council for Palliative Care (NCPC) is the umbrella charity for all those involved in palliative, end-of-life and hospice care in England, Wales and Northern Ireland. They have developed a booklet called "How would I know? What can I do?" which aims to help anyone looking after someone with dementia to understand and help alleviate any pain or distress they might be suffering. The leaflet can be found here:

www.ncpc.org.uk/publication/how-would-i-know

ABBAY PAIN SCALE

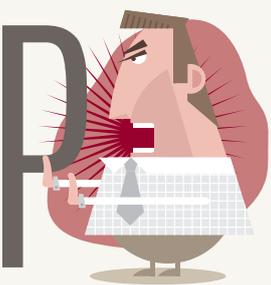
The Abbey Pain Scale is a pain tool which can be used to evaluate if someone is in pain, and can be found on page 12 of the BPS' National Guidelines on the assessment of pain in older people. An app of the Abbey Pain Scale has been developed in collaboration between the BPS, the University of Greenwich and the British Geriatric Society for use on smartphones, and can be found here: <http://cms1.gre.ac.uk/gwizards/pain-app/>

PAINAD

The PAINAD tool is used to assess pain in older adults who have dementia or other cognitive impairment and are unable to reliably communicate their pain. The PAINAD can be found here: www.geriatricpain.org/Content/Assessment/Impaired/Pages/PAINADToolInstructions.aspx

DOLOPLUS2

The Doloplus-2 was developed for pain assessment in the cognitively impaired and rates somatic, psychomotor and psychosocial behaviours as indicators of pain. The DOLOPLUS2 tool can be found here http://prc.coh.org/PainNOA/Doloplus%202_Tool.pdf



PICK UP ON MOOD



ASSESS VERBAL CUES



INSPECT FACIAL EXPRESSIONS



NOTICE BODY LANGUAGE

SUMMARY OF RESEARCH

Napp Pharmaceuticals Limited undertook a program of quantitative and qualitative research, gathering information, thoughts and perspectives from a sample of independently owned care and nursing homes across the UK.

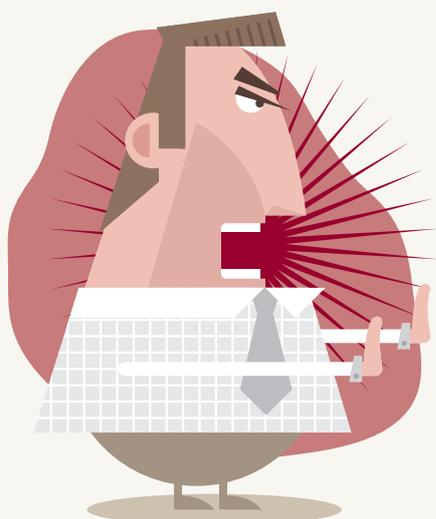
This included:

- Interviews with representatives from four of the largest residential care homes providers in the UK (Sunrise Senior Living, Bupa, Barchester and Four Seasons) to gauge current management approaches with regards to pain in people with dementia
- Questioning a sample of 100 independently owned care homes around provisions in their care homes around identifying and managing pain in people with dementia
- Desk based research around previously published studies on pain in dementia

To supplement and validate these activities, Napp organised a round table meeting, to hear the opinions of experts in the field of dementia with regards to how the challenge of unmanaged pain can be better addressed.

The research was conducted throughout Q4 2013 and the round table was conducted in Q1 2014.

The information presented within this section has been anonymised.



Pain in older people we know exists in 50% in the community - and in people with dementia that increases to 80%. So our most frail, our most vulnerable population has more severe pain than any others.

Professor Patricia Schofield, Professor of Nursing at the University of Greenwich

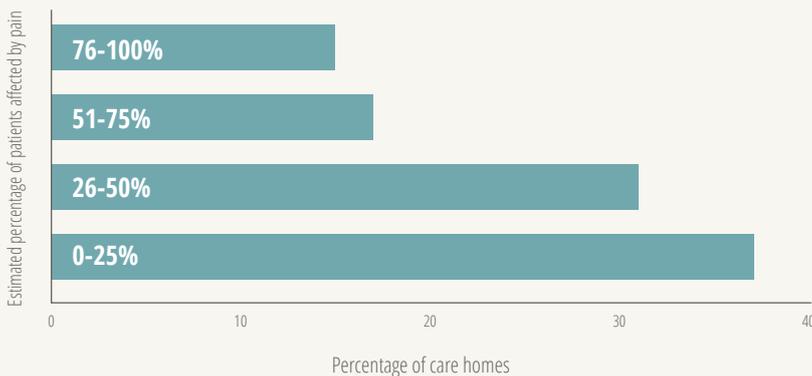
RESEARCH FINDINGS

AN UNDERSTANDING ABOUT THE SCOPE OF THE ISSUE

Amongst the respondents to our survey, 37% (n=67) of care homes said that 25% or less of their dementia patients were affected by pain and 31% (n=67) said it was between a quarter to half their residents.

Previous estimates indicate 50% of older adults who live on their own and 80% of the elderly in care facilities suffer from chronic pain.^{5,6} This suggests a significant gap in the number of elderly people with dementia who are likely to be suffering pain and those being effectively treated.

What percentage of dementia patients are affected by pain?



In addition, interviewees from each of the large group care home providers expressed a recent and yet strong sense of importance that dementia in particular, and often pain within people with dementia, was a key priority for them. A series of quotes from these providers are included below:

“

There is a misconception around whether people with dementia actually feel pain, and it is rare to admit people to a care home who just have dementia. These people have a range of comorbidities. GPs don't tend to recognise that dementia is just one element of a collection of comorbidities patients have.”

“

Approximately 8 years ago, [we] initiated an audit on our dementia wards to determine how many patients had been prescribed analgesics. The results showed that less than 10% of patients on a dementia ward had been prescribed analgesics in comparison to 60% on our general care ward. Following a 40% increase in pain relief for these patients, there was a direct correlation to a reduction in anti-psychotic prescribing”

“

Dementia is included within [our] ‘top to toe’ philosophy of care approach - which also includes pain management. However, there is always room for improved training and knowledge sharing”

RECOMMENDATIONS

An acknowledgment at a national policy level that, with the reduction in anti-psychotic usage, identifying and treating the source of challenging behaviours in people with dementia should now be a priority.

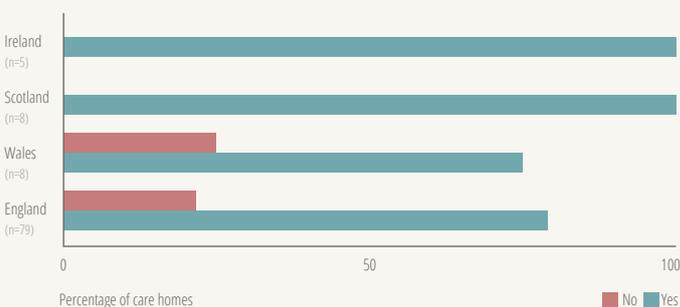
A campaign from Public Health England teaching people to identify signs of pain in people with dementia.

GUIDELINES

In the independently owned care and nursing homes included in the survey, provision of written guidelines differed greatly across the UK. Wales showed the least amount of provision, with 25% (n= 6) of care homes surveyed not having written guidelines and in England 22% (n=61) did not have guidelines for assessing pain in those less able to communicate.

Amongst the largest four providers, some interesting insights were obtained about perspectives around written guidelines. Training featured heavily, as did the importance of peer to peer interaction:

Do you have guidelines to help assess pain in those less able to communicate?



We do have written guidelines for our dementia specific care homes, which take in to account medication, infection, pain, and progression of the disease when assessing change in the behaviour of people with dementia. In these homes pain would be considered first and infection second. However in our non-specialist care homes progression of the disease is likely to be thought of as the first cause.”



We have written guidelines that are included within the written policy care and quality folder. These are also included in the planning documentation for resident’s care plans. There is also a planning document for pain, which includes how to write a care plan.”

RECOMMENDATION

The creation and dissemination of a comprehensive set of national guidelines focusing on how to identify and treat pain in people with dementia.

PAIN ASSESSMENT

There are a number of pain assessment tools to help healthcare professionals diagnose pain in those who are less able to communicate. These include the Abbey scale, DOLOPLUS 2 and PAINAD.

Although over 60% (n=64) of guidelines used in independently-owned care and nursing homes were based on the recognised Abbey tool, 15% (n=64) of people couldn’t remember if their guidelines were based on an approved and recognised pain assessment tool, 10% (n=64) of people used non-recognised tools and 11% (n=64) of people used a care plan or pathway specific to their care home, leaving room for much variation.

Amongst the chain care homes interviewed, the Abbey tool was also the most often used to help staff assess pain in dementia patients. Selected perspectives about these tools are included below:



We use Abbey regularly, however we also occasionally use DCM, Wellbeing and Doloplus.”



The Abbey pain scale is used by care workers and nurses to assess pain levels in our patients with dementia. The lead care and lead nurse will monitor pain levels in the patients. In addition each medicines administrator has a list of the 100 most-used medicines and their side effects, to help monitor where pain may occur as a side-effect of any medication they are already on.

RECOMMENDATIONS

The CQC to consider including a section of their inspection about provision and regularity of training around how to assess people with dementia for pain.

TRAINING

Our survey highlighted that 30% (n=100) of care homes provide their staff with no training related to pain detection, assessment or management. With estimates of up to 80% of elderly people in the care home setting affected by pain, this highlights the need for greater provision of training materials and implementation.

The expert panel also raised the important issue of the need for improved training on how to increase adherence and administration rates of pain medication for people with dementia, and a need for training to ensure that carers are aware of the importance of regular medication to ensure sustained efficacy.

Within the chain care homes included in the research, there were a number of innovative training methods being utilised, however they identified that gaps in this training were often created by the high staff turn-over.

RECOMMENDATION:

The creation of a joint training programme for staff in hospitals and care homes of all levels to ensure a joined up approach when assessing patients for pain.

“

There is a significant rotation of staff in our homes, which means that 20-25% of staff move on over a 12-month period, creating a challenge in terms of keeping all staff regularly trained and refreshed on assessment methods. That said, all our staff are highly trained. All carers are provided with extensive training materials”

“

We have progressed from a more E-learning based system of learning towards a more experimental, workshop based peer-to-peer training. That said we have some excellent training resources, and as such we are taking care not to reinvent the wheel.”

FREQUENCY OF PAIN ASSESSMENT

Of the independently owned care and nursing homes included in the survey, 46% (n=99) of pain assessments were conducted by non-medically qualified care workers.

The research also assessed how often a routine pain assessment was carried out in people with dementia living in independently owned care or nursing homes. The results encouragingly showed:

England (n=79): 86% always, 13% sometimes, 1% never

Wales (n=8): 100% always

Scotland (n=8): 100% always

Northern Ireland (n=5): 80% always, 20% sometimes

RECOMMENDATION:

A national study to be initiated in adherence to and administration of analgesics vs. those prescribed to patients

These findings were echoed by the big four chain care homes:

“

“In our [care homes] the majority follow an internal assessment system which consistently tracks any changes in our resident’s behaviour. This involves the Abbey pain scale being completed routinely once a month and most importantly with a well-being scale at the same to try and catch the important changes in mood that can also be a signified of pain.”

“

“It tends to be covered on initial assessments (and on an ad-hoc basis) but it’s not something which is routinely tested / recorded - there is probably a gap here. [We] have a huge commitment to up skilling our colleagues on a range of competency frameworks and we are working on improving knowledge around behaviours associated with unmet need including pain management”

“

“In our [dementia focused] care homes the Abbey Pain Scale is completed routinely once a month, along with a well-being score. If there are any concerns both of these results are then presented to the GP. The Abbey Pain Scale is also routinely completed on admission. However, in our non [dementia focused] care homes this is completed only on an ad hoc basis”

“

“We’ve initiated an innovative scheme which monitors all our residents (with their express consent) and highlights patterns or changes which may indicate, amongst other things, poorly controlled pain. This enables our carers to investigate and identify symptoms of pain and to initiate some form of intervention”

PHARMACOLOGY AND PRESCRIBING

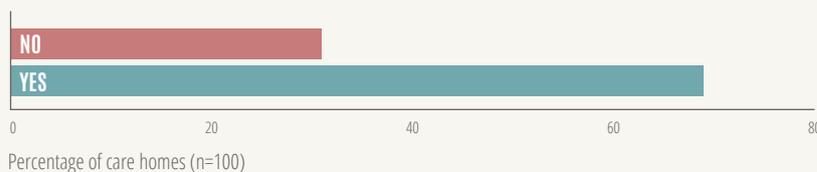
Improved pain management can and should also be seen as part of the Government's drive to reduce the number of dementia patients on antipsychotics.

In the UK, the Department of Health (DH) estimated that there are approximately 180,000 people with dementia being prescribed antipsychotic drugs, of which 144,000 of them are being prescribed inappropriately, resulting in as many as 1800 unnecessary deaths a year.¹⁶

A recent study has shown that a standard protocol of treatment with analgesics in residents of nursing homes with dementia and agitation significantly improved agitation, overall neuropsychiatric symptoms and pain.¹⁰ However, it should be noted that assessment and a multi-modal approach to treating people with dementia is always crucial.

However, when independently owned care or nursing homes were asked whether they had reduced their anti-psychotic use in line with government guidance, nearly a third of respondents said no.

Reduced antipsychotic use in line with government guidelines?



When asked what alternatives to antipsychotics were being put in to place now that a reduction was being implemented, 27.5% (n=69) of people said analgesics and 23% (n=69) said sedatives, with 29% (n=69) saying active therapy, 14.5% (n=69) stating distraction and 14.5% (n=69) saying they did not know rather than nothing at all.

The top 5 alternatives used instead of antipsychotics are:

Active therapy (29%) (n=69)

Analgesics (27.5%) (n=69)

Anxiolytics / sedatives (23.2%) (n=69)

Distraction and diversion tactics (14.5%) (n=69)

Nothing (14.5%) (n=69)

Other answers included hypnotics, diet replacement, additional staffing, antihistamines and behavioural management.

The expert roundtable group noted that other important factors to consider were that many patients are resistant to care and to medication, so properly managing analgesia is a challenge and, while we have seen a noted reduction in the use of antipsychotics, there has been an increase in the use of sedatives such as diazepam and other benzodiazepines.

The panel also expressed surprise at the lack of alternatives offered for antipsychotics and suggested that personal care budgets should play a part in encouraging people with dementia and their families to be more involved in discussions about treatments.

Within the largest four care homes a number of interesting insights were expressed with regards to pharmacological management of patients:



Any decision around the use of antipsychotics should be based on a robust clinical assessment and we would always use a behavioural management plan first alongside the use of antipsychotics.”



The use of anti-psychotics is very serious. Today care home staff are more aware of pain in dementia patients, but now unfortunately many GPs are switched off from this. GPs tend to think more about drugs of control rather than pain when they are presented with a person with dementia who is experiencing behaviour change.”

Several of the larger care home providers reported being in partnership with large pharmacy chains, and are investigating whether there is scope to monitor the extent to which repeat prescriptions for analgesia are filled as a potential trigger to investigate poorly controlled pain.

RECOMMENDATIONS

Greater sharing of medical records throughout the NHS will help to identify potential sources of pain in a patient with dementia who cannot identify it themselves.

Engage family and carers with the personalised care budget scheme and enable them to make decisions about treatment for agitated behaviour for their loved one with dementia.

STRATEGIES FOR IMPROVEMENT

Napp Pharmaceuticals Limited has undertaken this research to try to highlight the extent to which identification and management pain in people with dementia may need improvement in the UK, and to begin to compile knowledge, evidence and stakeholder perspectives to improve care and treatment for people with dementia.

The findings of our research, combined with the perspectives of a number of experts have:

- The creation and dissemination of a comprehensive set of national guidelines focusing on how to identify and treat pain in people with dementia
- An acknowledgment at a national policy level that with the reduction in anti-psychotic usage, identifying and treating the source of challenging behaviours in people with dementia should now be a priority
- A campaign from Public Health England teaching people to identify signs of pain in people with dementia
- The creation of a joint training programme for staff in hospitals and care homes at all levels to ensure a joined up approach when assessing patients for pain
- A national study to be initiated in adherence and administration of analgesics vs. those prescribed to patients
- The CQC to consider including a section of their inspection about provision and regularity of training around how to assess people with dementia for pain
- Greater sharing of medical records throughout the NHS to help to identify potential sources of pain in a person with dementia who cannot identify it themselves.
- Engage family and carers with the personalised care budget scheme and enable them to make decisions about treatment for agitated behaviour for their loved one with dementia



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