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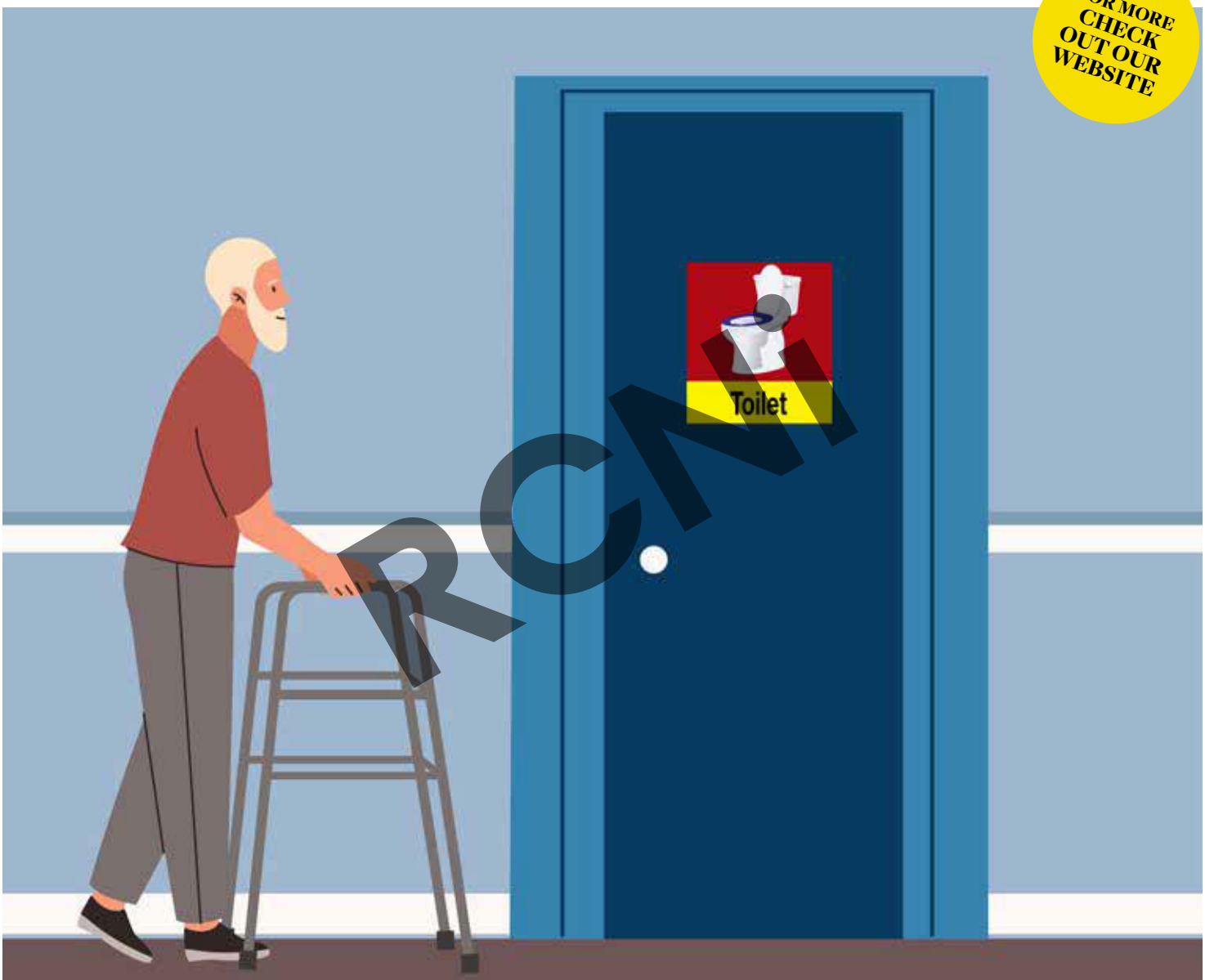

Continence

Promotion in people living with dementia

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OPINION

'It is unfair to separate migrant workers from their loved ones for years as they adjust to their new life in the UK'

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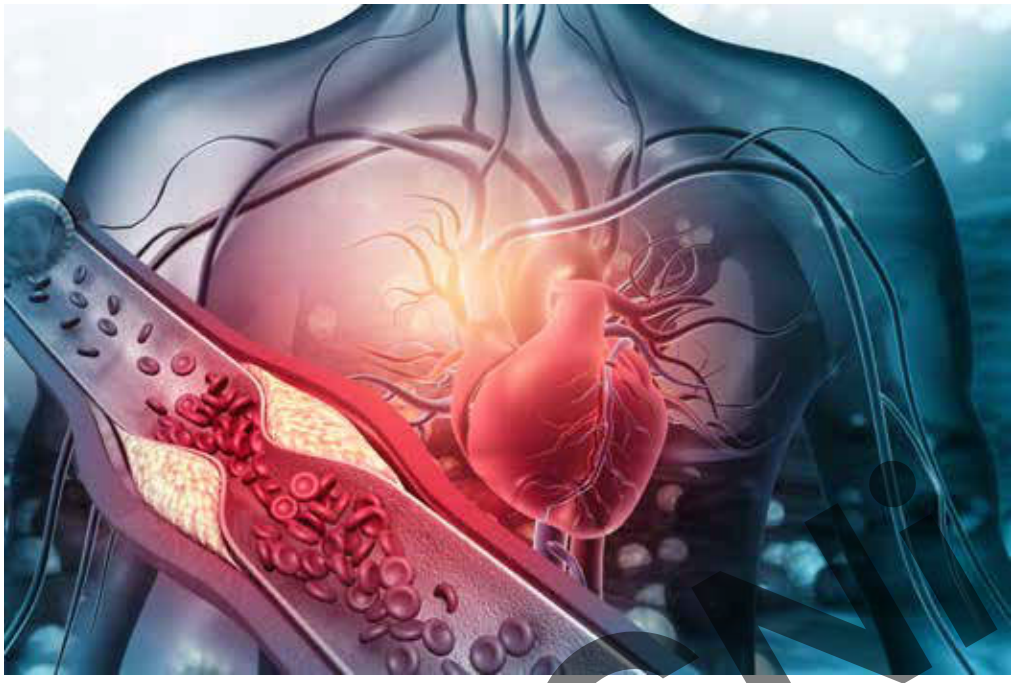

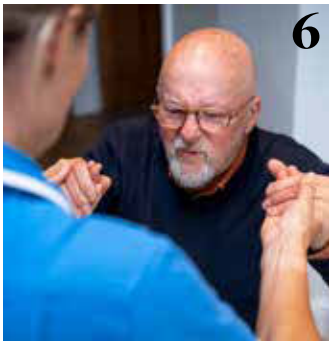

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Why we should promote continence in people living with dementia

Ageism is widespread, including in institutions providing health and social care, and in workplaces, the media and elsewhere, according to the World Health Organization. Such ageism can convey a narrative that incontinence is a normal or inevitable part of ageing – and that nothing can be done to change the outcome either for those affected or across healthcare services.

By Zena Aldridge
consultant editor of Nursing Older People

Yet incontinence has significant emotional, psychological, relational and social effects on older people's dignity and quality of life, including for those living with dementia.

Why are the effects of incontinence for older people considered so differently? Would we neglect to consider the wider effects of incontinence on younger people?

Why should an older person living with dementia be offered only containment products that are difficult to negotiate, bulky and may also require the support of their partner or another family member or carer to administer? Especially considering there may be alternative products or interventions that could help them to remain independent and protect their dignity for as long as possible.

Why would an older person not want to share a bed with their partner and be enabled to enjoy moments of closeness and intimacy that can mean so much when words might be challenging to find? I suggest that such questions are rarely asked.

This inequity needs to stop, and we must continue to highlight that older people and their families may have complex needs and emotions relating to continence, which need to be addressed.

We must advocate for change. While our bodies and minds may age, core values and beliefs – like the need to be treated as individuals with dignity and respect – do not.

Go to **rcni.com/continence-dementia**

'Incontinence has significant effects on older people's dignity and quality of life'

Further information

World Health Organization (2021) Global Report on Ageism. **tinyurl.com/WHO-global-ageism**

Our mission
Nursing Older People aims to inform, support and educate nurses in the pursuit of excellence in patient care.

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Why good communication is essential to pain management

Pain is subjective, so it is important that nurses ask the right questions and trust patients' answers to understand and assess their needs

By Erin Dean
health journalist

Up to half of adults in the UK – a staggering 28 million people – live with chronic pain. The prevalence in older age groups is even higher, with up to 62% of those aged 75 and over reporting these symptoms, according to research published in the BMJ.

Even before shorter-term pain is added into the mix, it is clear that nurses in all settings will care for people who are experiencing this issue.

Specialist pain nurses say that communicating well with patients about their pain is a critical part of nurses' work. But this can be compromised in fast-paced, overstretched care services.

'Good communication is the cornerstone of pain care,' says Royal Brompton and Harefield Hospitals senior clinical nurse specialist in pain management Christina Gullberg. 'With the pressures the NHS is under, pain is just one of many components of daily care at the bedside – but it is such a vital part.'

Recognising pain

The first critical point is recognising if someone may have pain, says Royal National Orthopaedic Hospital NHS Trust consultant nurse in rheumatology, rehabilitation and pain Kelly Warfield.

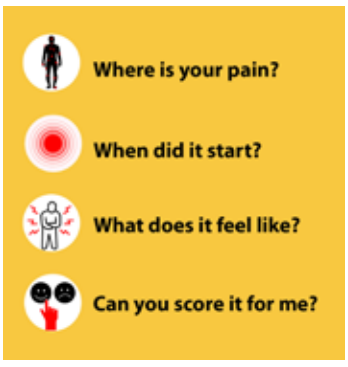
She recommends the simple RAT mnemonic for pain: Recognise, Assess and Treat, which is the foundation of the Faculty of Pain Medicine's essential pain management training programme.

The first step is to ask someone if they have pain and be alert for visual clues such as grimacing or wincing, restlessness or a reluctance to move.

Ms Warfield says nurses need to be aware the cues that someone is in pain may be easier to miss in certain groups – including those with dementia, potential cognitive impairment, those who are neurodivergent and those with learning disabilities – and could vary between settings, she says.

Pain-rating scales

Nurses can then move on to pain assessment, which for most nurses will start with some sort of pain scale, Ms Warfield says. There are many available, and this may be the widely used 11-point numerical pain rating scale, or a version developed for people with cognitive impairment or learning disabilities, or those designed for children.



Standard pain assessment questions

'There is a lot of research showing that there is a mismatch between what a nurse thinks a patient's pain level is like, and the patient experience of pain,' she says. 'The saying that "pain is what the patient says it is" is absolutely true. So nurses need to be aware of this mismatch and take it into consideration.

'Always listen to the patient and their experience – it is so important to believe them.'

'You may hear a nurse saying: "That patient says he has a pain score of ten, but he's just been out for a cigarette, so it can't be that bad." But smoking could be a coping strategy'

Kelly Warfield, consultant nurse in rheumatology, rehabilitation and pain, Royal National Orthopaedic Hospital NHS Trust

For London Complex Mesh Centre clinical nurse specialist Jigna Shah, who has a background in pain care, a thorough pain assessment uses a tool as a springboard, with further questions to find out more about the type and location of the pain.

She advises nurses to ask four questions to start getting a holistic idea of someone's pain: 'Where is your pain? When did it start? What does it feel like? And can you score it for me? These questions give you an overview,' she says.

Pain nurses agree that it is important to find out how pain is affecting the patient's usual functioning. Assessing how pain limits their normal activities and movement is an important approach for the management

of acute and chronic pain, Ms Gullberg says.

'I ask if they are able to take a deep breath or cough and if that changes their pain,' she says. 'I work in a cardiothoracic setting, so for us it is absolutely vital that patients can breathe deeply to reduce complications, so that question would be incorporated early on in my assessment. I ask them what they can't do because of their pain. I would also use an assessment tool of some sort, but add these questions in to find out more.'

Support and education

Part of nurses' work involves support and education, encouraging movement and activity and focusing on positive steps, Ms Gullberg says.

Nurses can then try to unpick other aspects that may be affecting the patient's pain. 'Often it is underlying worries or other anxieties,' she says.

Finding out which pain medication patients have used previously and whether it worked helps avoid frustrating repeat prescribing of analgesia that has not suited them in the past.

'In this environment of rapid turnover, we want to fix and manage things and we sometimes forget to actually ask important questions like that,' Ms Gullberg says. 'So when a nurse comes to the bedside with a prescribed medication, the patient tells them they had it before and it didn't agree with them. It's important to avoid this by getting the most effective answer from the beginning.'

It is important that patients can breathe without pain

Pain is such a complex area, with many layers for a nurse to explore to get a clear picture, says Ms Shah. This includes expectations and assumptions that might be made by both the patient and the nursing staff.

Tolerance thresholds

'Every patient will be different,' she says. 'Their experience with pain, their tolerance and threshold are different. So you could have someone who has a high pain threshold saying they are fine, but actually you need to question whether they are really fine.'

Ms Shah works with women who have experienced serious complications and pain related to mesh implants used to treat stress incontinence and pelvic organ prolapse. The value of a nurse listening to patients experiencing pain should not be underestimated, she says.

'There's physical trauma and there's also psychological trauma for these patients,' she says. 'And for them the biggest thing was just being listened to.'

Research has found an association between post-traumatic stress disorder and chronic pain – and rates of chronic pain are higher in deprived areas.

Guidance from the National Institute for Health and Care Excellence (NICE) highlights the impact that people's lives can have on how they experience pain. NICE advises healthcare professionals to ask about the impact pain has on day-to-day activities, including work and sleep, and physical and psychological well-being.

It also says that patients should be asked about stressful life events including previous or current physical or emotional

Tips when speaking to patients about pain

- Recognise verbal and non-verbal cues for pain and ask someone if they are in pain
- Be non-judgemental when assessing patients
- Try to pause in the conversation so that patients have time to talk about their experience
- Really listen to what people say about their pain and believe them
- Be aware that difficult experiences in the past can have an impact on pain
- Ask about the impact of pain on the person's normal functions, and ask them what they cannot do because of their pain

Sources: Kelly Warfield, Christina Gullberg and the National Institute for Health and Care Excellence

trauma, current or previous substance misuse, social interaction and relationships. Difficulties with employment, housing, income and other social concerns should be asked about and considered.

Trusting the nurse

This assessment needs to be done in a non-judgemental way, says Ms Warfield. 'It's about believing the patient, so that the patient can trust the nurse,' she says. 'You may hear a nurse saying: "That patient says he has a pain score of ten, but he's just been out for a cigarette, so it can't be that bad." But smoking could be a coping strategy. It's complex and making assumptions can take you down the wrong road.'

'Every patient will be different. Their experience with pain, their tolerance and threshold are different'

Jigna Shah, clinical nurse specialist, London Complex Mesh Centre

Further information

British Pain Society and Faculty of Pain Medicine (2019) Outcome Measures. **tinyurl.com/BPS-outcome-measures**

Faculty of Pain Medicine (2022) Essential Pain Management Training Programme. **fpm.ac.uk/epm-uk**

NICE (2021) Chronic Pain (Primary and Secondary) in Over 16s: Assessment of All Chronic Pain and Management of Chronic Primary Pain. **nice.org.uk/guidance/ng193**

Versus Arthritis (2021) Chronic Pain in England – Unseen, Unheard, Unfair. **tinyurl.com/CPE-versus-arthritis**

A pain assessment scale can be used as a springboard for further questions

Ms Warfield has found that patients with chronic pain can be poorly understood in acute settings, as they may not display what nurses consider to be the signs of pain they would expect.

'They live with pain all the time and it has become the norm, and this can be misinterpreted by healthcare staff,' she says.

'The important thing is to approach any pain assessment with compassion and understanding,' Ms Warfield adds.

While time is one of the scarcest commodities in the NHS at the moment, pausing to give people a chance to consider and verbalise what they are feeling is so valuable, Ms Gullberg says.

'Allow those pauses, those moments where patients can express what they are feeling, particularly if they are very anxious,' she says. 'Say: "We understand what you're saying," to validate and communicate that you will support them. And that's our role – to support them through that journey.'

Inequity of experience: some groups report greater levels of pain

Pain is an individual experience, and different cohorts report differences in pain levels and treatment.

A report on chronic pain from the charity Versus Arthritis highlights some of these inequities, pointing out rates are higher in areas of greater deprivation, among women and for people from some minority ethnic backgrounds.

Chronic pain is more common among women, regardless of which area of the body is affected, and more women report high-impact pain. Back pain also affects more women, with 45% of women in England reporting chronic back pain, compared with 39% of men.

The reasons for these differences are not fully understood, but are likely to be multifactorial, the charity says in its 2021 report Chronic Pain in England.

Women have a higher risk of underlying conditions that cause chronic pain, with rates of rheumatoid arthritis and osteoarthritis being less common in men.

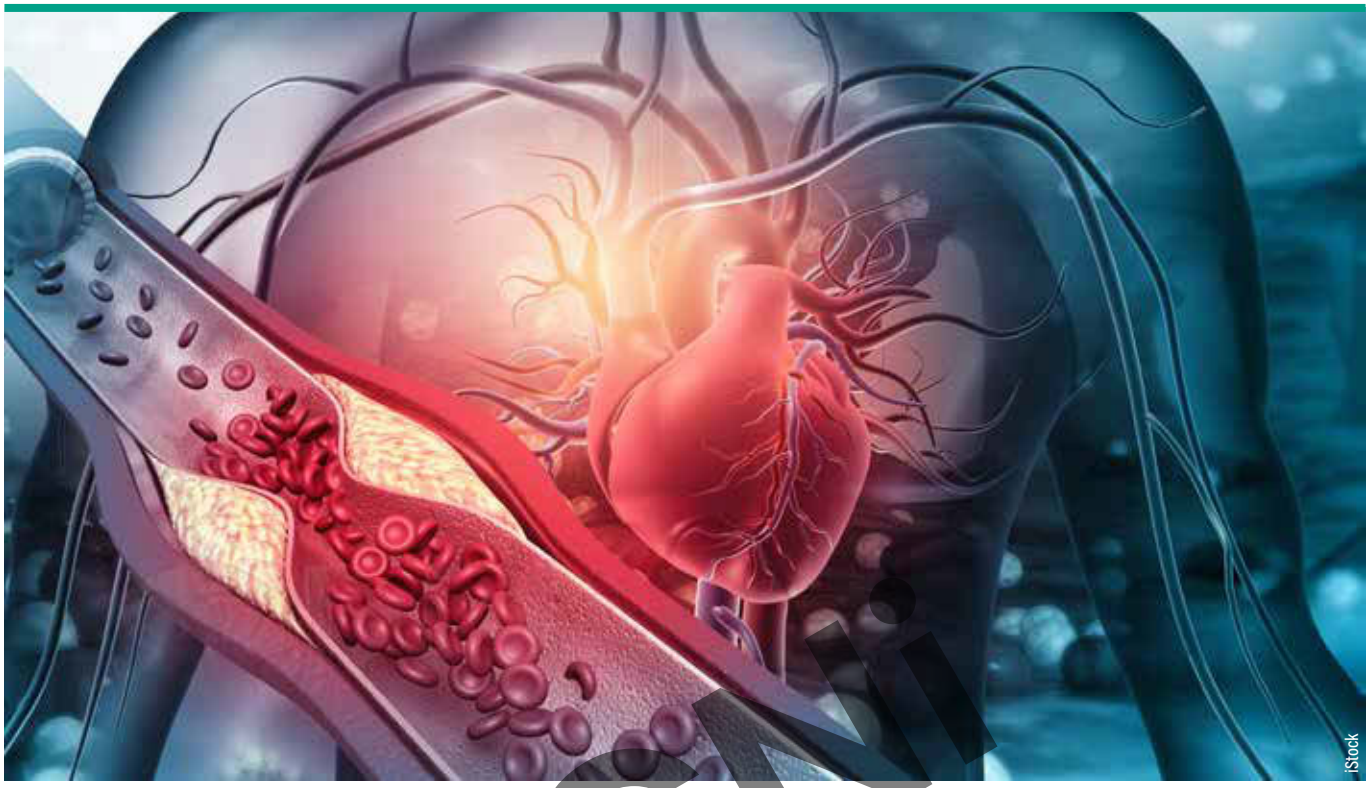
Women may also be affected by other non-musculoskeletal conditions that cause pain, such as endometriosis, which causes pelvic pain.

Social deprivation

Black people are more likely than other people to have chronic pain. 'People from minority ethnic groups often face racism, often live in socially deprived geographic areas, are more likely to be unemployed or in poorly paid manual jobs, may have fewer opportunities to be physically active and are more likely to have multiple long-term conditions,' the report says.

Research has also found that other groups may be disproportionately affected by pain. A small US study from 2020 found that autistic people experience increased pain sensitivity and pain-related anxiety.

Studies in the UK and elsewhere have also highlighted that pain seems to be poorly recognised and undermanaged in people with dementia. A study in the US found that patients with advanced dementia after a hip fracture received one third of the opioid pain relief compared with those without cognitive impairment.



Ensuring patients with heart failure receive palliative care

Palliative care often begins late, here is some practical advice on balancing advance care planning with active treatment needs

By Nick Evans
health journalist

Almost 1 million people in the UK are living with heart failure and the numbers are rising. About four in ten patients will die within a year of being diagnosed and yet too many struggle to access palliative care. Here is an overview of what experts say needs to change and what nurses can do.

Heart failure is a complex condition in which the heart does not pump blood around the body adequately. The most common causes are heart attack, high blood pressure and cardiomyopathy.

The condition leads to shortness of breath and fatigue as well as fluid retention in the chest, legs and ankles. It can occur at any age, but is most common in older people. It cannot be cured and gradually worsens over time, although the symptoms can be managed.

Some patients will be under the care of specialist heart failure nurses, but others will be supported by community teams. Palliative care works in a similar way – not every patient will be under the direct care of specialist teams. Some heart failure teams may have palliative care specialists embedded, but many do not.

'It's vital we discuss advance or future care planning early on, even when a patient may be well. Palliative care goes hand in hand with good heart failure care'

Carys Barton, heart failure nurse consultant

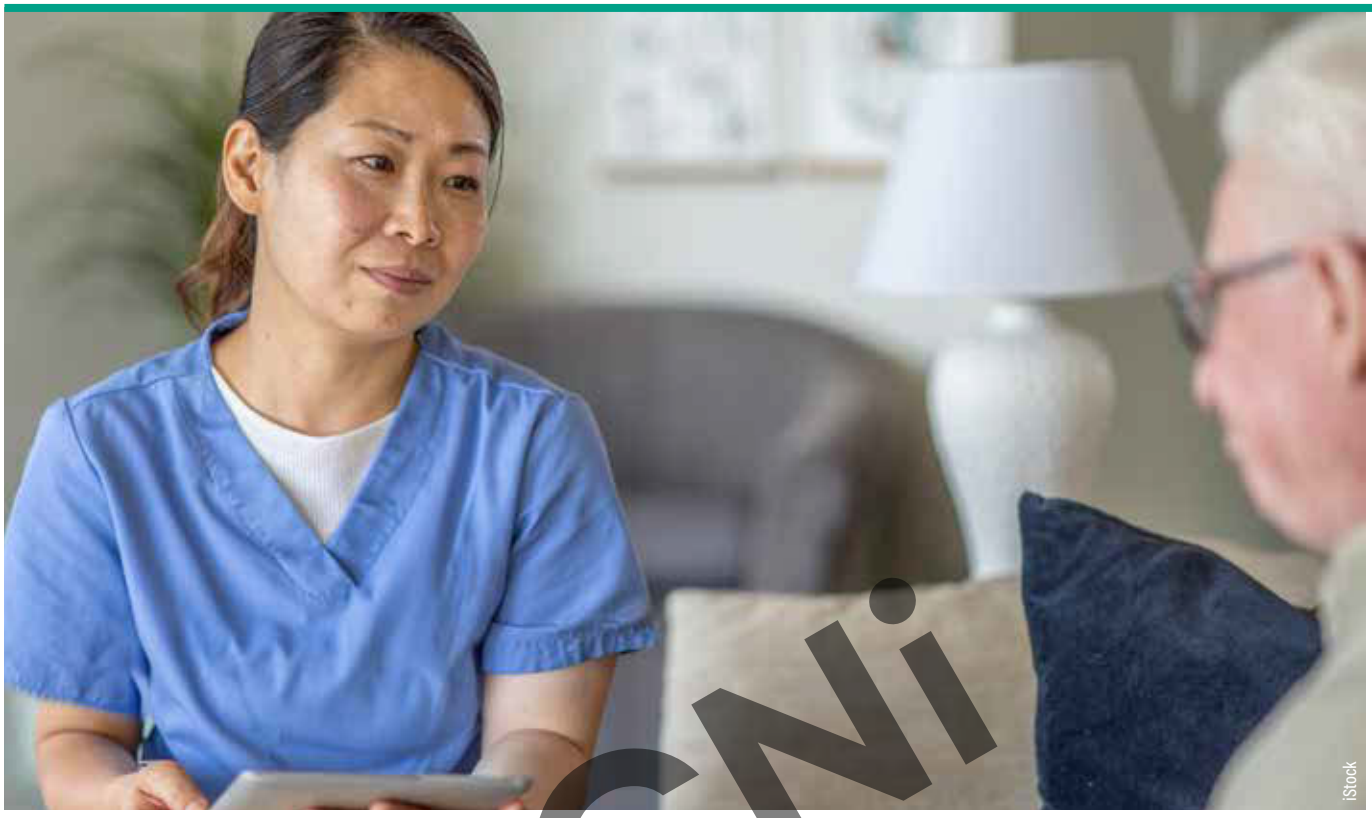
Palliative care is about helping people to live as well as possible until they die and, when the time comes, to die with dignity. It does not necessarily mean you are likely to die soon – some people can receive palliative care for years. In England, end of life care is defined as treatment and support in the final year of life and so forms part of the wider palliative care package.

Non-specialist care

RCN pain and palliative care forum member Sandra Campbell says: 'More palliative and end of life care is actually provided by non-specialist palliative care staff than specialist. But people with particular illnesses like heart failure may have more complex needs at the end of life so it is important they get specialist help.

'Heart failure teams will take a lead on it, but it does require good coordination.'

Palliative care services in the UK are over-stretched. Research by Marie Curie in 2022 found one quarter of people were not getting the palliative care support they need.



But access is particularly poor for patients in heart failure, with National Confidential Enquiry into Patient Outcome and Death figures showing that only 12.5% of inpatients who died in hospital following admission with acute heart failure had been known to palliative care services.

British Society for Heart Failure (BSHF) nurse forum committee chair Poppy Brooks says a key difficulty with heart failure is it is 'not always clear' when a patient is approaching end of life.

It is important to assess patients' life needs

'A lot of diseases are characterised by continual decline, but with heart failure it can be up and down. So often it is seen as a binary choice between active treatment and palliative care, when patients with heart failure need a combination of the two as their health deteriorates.'

Postcode lottery

She says it is further complicated by the fact that patients diagnosed with one type of heart failure, preserved ejection fraction, are not usually even under the care of specialist heart failure teams. 'It's a postcode lottery, with half of patients who have heart failure not even under the care of specialist teams – their access to palliative care is even worse.'

The problem has also been highlighted by NHS England, which recently published a framework for improving palliative care for people in heart failure. It too says the unpredictable nature of heart failure is a major barrier, with the public and healthcare professionals too often failing to grasp the need to be more proactive in thinking about palliative care.

The NHS England framework is for integrated care boards that now have a legal duty to commission palliative care services. But it contains a number of steps individual nurses can take too.

It stresses the importance of assessing palliative and end of life care needs from the moment of diagnosis, including

'So often it is seen as a binary choice between active treatment and palliative care, when patients with heart failure need a combination of the two as their health deteriorates'

Poppy Brooks, nurse forum committee chair, British Society for Heart Failure

Discussing palliative care with patients in heart failure

- **Broach the subject as early as possible** Give the person time to think and have control over their decisions
- **Explain what heart failure is** and what it can lead to
- **Be honest, but kind**
- **Arrange a time to meet again** It is important to discuss things more than once
- **Use open questions**, for example, 'what's important to you?' and 'what are your fears?'
- **Provide written information**
- **Stay open to change** Make it clear that the patient can change their mind about choices or decisions
- **Enable discussion** about making a will and funeral arrangements

Source: British Heart Foundation

developing advance care plans. It says there is often a reluctance among non-specialist staff to engage in palliative care conversations for fear of removing hope, but it says most patients prefer honesty.

Spotting signs of advanced heart failure is also crucial, says Ms Brooks. 'Regular emergency admissions are a red flag that a patient may be reaching the end of their life. But patients can face repeated admissions at the end of life that are not related to their condition – they have falls, kidney problems, chest infections.

'Other signs may be a greater difficulty in tolerating medications, or less response to medications such as diuretics. The challenge is to join the dots and get people asking the right questions.'

The NHS England framework recommends following the BSHF's guidance on palliative care. That recommends the early identification of the current stage of symptoms and whether they are mild, moderate or severe.

A comprehensive assessment should take place that ensures the patient has a good understanding of the condition and expectations for the future, it says. This should cover the patient's physical, psychological, social, spiritual and financial needs, including looking at the entitlement to benefits, as well as an assessment of any carer's needs.

Cardiac devices

Advance care planning is also needed, which should cover whether the patient wants cardiopulmonary resuscitation or not and whether any cardiac devices, such as an implantable cardioverter defibrillator, should be deactivated when the patient is at end of life.

The guidances stresses the need for cohesive working between heart failure and palliative care specialists and community teams.

Heart failure nurse consultant Carys Barton, who contributed to the NHS England framework, says: 'What's vital is that we discuss advance or future care planning early on, even when a patient may be well, in fact this is often the best time. Palliative care goes hand in hand with good heart failure care. Evidence shows good palliative care improves the quality of life and can actually lengthen life.

'Although we have fantastic therapies to treat heart failure now and we can ensure people often remain well for a long time, it remains a devastating diagnosis.

'Heart failure has a poorer prognosis than the four most common cancers combined. We would offer these discussions to someone with cancer, but somehow often not in heart failure.

'This applies to all nurses and healthcare professionals – even heart failure nurses.

'And those conversations about advance and future care plans should be continually updated – things change and a patient's views change.'

Further information

British Society for Heart Failure (2022) Cardiac Supportive Palliative Supportive Care Core Components **tinyurl.com/BSHF-cardiac-care**

National Confidential Enquiry into Patient Outcome and Death (2018) Failure to Function. **tinyurl.com/NCEPOD-failure-to-function**

Palliative care goes hand in hand with good heart failure care

No health professionals told me I was dying

Stephen Kirkham is in a unique position: he has experienced the shortcomings in palliative care for patients with heart failure, but is now in a position to talk about it thanks to a heart transplant he received when he was close to death.

Mr Kirkham, who is 72 and lives in Kinross, north of Edinburgh, was diagnosed with cardiomyopathy and heart failure in 2005. Ten years later he was very ill.

'I had received the standard care for nine years, but by late 2014 I was getting frail. I was struggling. But at no point did anyone provide me with some targeted palliative care emotionally or practically to deal with the tough symptoms, beyond some ineffective fiddling with my diuretics.

'I didn't help myself, I suppose. I kept saying everything was okay. But if anyone had pushed and asked the right questions it would have been obvious I wasn't. I could not even lift my arms above my head I was so weak.'

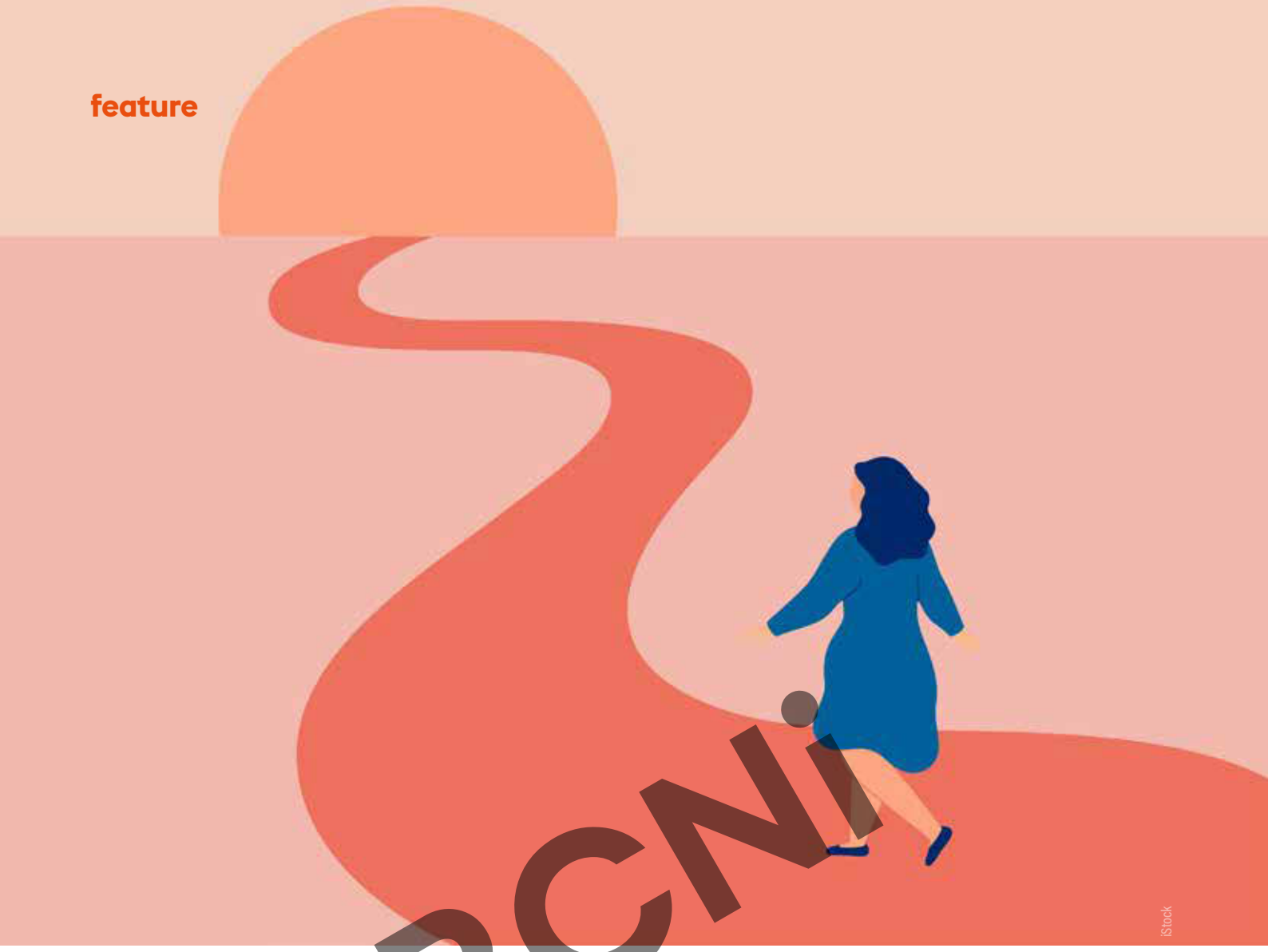
Quality of life

'My quality of life and that of my wife, who was caring for me, was wretched. No one thought about an advance care plan or moving me on to advanced treatment,' adds Mr Kirkham, who is now a trustee of Cardiomyopathy UK. 'It was only when I was sent to the transplant centre that I was told I was dying. It was like they didn't want to broach the subject with me.'

While on the urgent list for a transplant, Mr Kirkham had a cardiac arrest and received mechanical support before a donor heart was offered.

Eight years on, he is in good health, enjoying regular walks in the countryside.

'Things are changing now – we are talking much more about palliative care for heart failure patients and there is more training for staff. I hope others don't have to go through what I did.'



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Get your head round retirement with advice from former nurses

Leaving the nursing profession can lead to a loss of identity. Find out how to plan ahead, emotionally and practically, and work toward a new purpose

By Claire Read
health journalist

Even though Pip Hill opted for a gradual retirement from clinical research nursing, she had not anticipated the extent to which stopping work would hit her.

After a spell working two days a week, she retired fully in March 2023 – yet it was not until six months later that she felt ready to relinquish her registration.

'I just could not bring myself to come off the register,' she says. 'When I did, it felt huge. I just felt, "I'm not a nurse anymore."'

Her experience is far from unique. When a group of retirees aged 55-75 was asked which life milestones had provoked the biggest emotional response, almost one quarter named retirement. It was the third most common answer after having children and getting married.

'I knew in my head that nursing wasn't who I was, but I needed to accept it emotionally as well'

Jane Bates, retired nurse

The research, conducted in 2021 by the Financial Services Compensation Scheme, sums up the profound effect that a career coming to an end can have on someone beyond the monetary.

Sense of identity

For nurses, the emotions generated by this milestone can be particularly acute. That is because nursing is a profession with a strong sense of identity, generated by practitioners themselves and from a societal view of what it means to be a nurse.

For Ms Hill, that loss of identity was tied up with the loss of aspects of her work that had been particularly important to her. One such loss was patient contact, which had still been central to her pre-retirement role in clinical research.

'I had mainly been dealing with men on the prostate cancer trial, and over the years we'd built up good relationships,' she says. 'I was seeing them every few weeks and going through all sorts of things with them.'

Although she had looked forward to the end of office politics, the extent to which she missed being part of a team also surprised her. And while her siblings and best friends were occupying their time in retirement looking after young grandchildren, her grandson was now in his late teens and so did not need support in the same way.

'I felt a bit useless really. I felt as if I wasn't of use to anyone anymore.'

Emotional gap

It is commonly accepted that retirement will leave a financial gap, and people are rightly reminded to prepare for it. Living comfortably on the state pension alone is challenging and so, as UNISON acting deputy head of health Alan Lofthouse puts it: 'The earlier someone starts planning for their retirement the better.'

Retirement preparation can valuably go beyond considerations of money. It is not enough to think through the financial gap; it is also important to prepare for what Ms Hill experienced – the emotional gap, and the potential sense of lost identity and purpose.

These are areas in which former doctor Jonathan Collie specialises. He is the founder of a social enterprise called the Purpose XChange, which helps people to establish their purpose and find ways of fulfilling it at every stage of their life – including after a career has ended.

Dr Collie stresses that retirement does not have to be a distinct line between working and not working. 'You could continue work, readjust your work,' he says. 'You could look at a startup or innovation: do you want to start a social enterprise, do you want to monetise a hobby?'

Jane Bates (right) helping out at the weekly coffee morning for her local community

And there are other ways of feeling purposeful, he says. 'There's learning and personal development. Do you want to go back to school? Do you find a mentor? Do you start reading [about a topic that interests you]?

'Giving back is a big one too. Do you want to volunteer? Volunteering is working, it's just unpaid. But there's also coaching, mentoring, the transfer of knowledge, helping other people, getting involved in your community, connecting more with others.

'And then there's creative expression. It can be art, it can be writing, it could be music, it could be acting, it could be learning a language. Your "purposeful plan" could dabble with any or all of these things. It's entirely up to you.'

Mid-career disillusionment

Importantly, this is a plan that can be built at any stage of a career – it is not retirement-specific.

Dr Collie would like to see nurses and their employers engage in conversations on purpose regularly.

He believes such conversations would help to address the potential for mid-career disillusionment or

Pip Hill, retired research nurse, exploring the Grand Canyon, Nevada, US


Marcus Chung

Courses, training and hobbies can also provide a creative outlet

frustration among nurses. It can be difficult to feel a sense of purpose and identity if, for example, it is starting to feel like administrative work rather than patient care is dominating working hours.

Community support

For Ms Hill, retirement has already been busy. She and her husband travelled to the US for a long touring holiday, and are in the process of doing up their house. She is also doing lots of walking and Pilates.

And she has applied to be a volunteer for Macmillan Buddy, a service of Macmillan Cancer Support that offers weekly support to people with cancer. She says she had thought of becoming a community-based Macmillan nurse at the start of her career, but interesting roles on an oncology ward and then on a chemotherapy unit intervened.

She hopes retirement may provide a different way to meet her original ambition of offering community support to people with cancer. It is a sign, perhaps, that things never truly end – they just change.

'I felt a bit useless – as if I wasn't of use to anyone anymore'

Pip Hill, retired clinical research nurse

Further information

Macmillan Cancer Support (2024) Volunteering as a Macmillan Buddy. **www.macmillan.org.uk/volunteering/macmillan-buddies**

How a stranger's wise words changed Jane Bates's feelings about retirement

When Janes Bates (pictured) retired, the emotional impact was such that she decided to take herself on a retreat. She travelled to the Scottish island of Iona, telling herself she 'had to get her head around' the complex range of emotions she was experiencing.

'It felt as though I was losing my identity and that was hard,' says Ms Bates, who retired in 2019 after a long career working across multiple specialties, most recently in ophthalmology.

'I had been a sister on an eye ward for a while, now I wouldn't be, so who was I? It was a funny feeling because nursing is about identity and I think it is more than a job. It's hard to give up.'

While walking on Iona she met 'a lovely, slightly older lady' and the two got chatting. Her new friend asked what had brought her to the island. Ms Bates explained how affected she felt by her retirement and how nursing had been so central to her identity.

'And she said: "It's not who you are. I want you to take this on board. It [nursing] is what you do, not who you are."

'I don't know why, but a stranger saying that made it hit home. It helped me, because I knew in my head that nursing wasn't who I was, but I needed to accept it emotionally as well.'

She says one reason her profession felt so tied to her identity was the number of friends she had made along the way. 'A strong link with other nurses has been one of the backbones of my life – my nurse friends.'

Keeping in touch

So when she retired, she ensured that connection remained. 'I keep in touch with loads of my ex-colleagues. It was fortunate that my retirement came around at a time when a lot of people had left, the personnel were changing. So a lot of my friends retired around that time. That made it easier, because I would have missed them terribly otherwise. We still see each other of course, so that helped ease the passage of retirement.' She also retains her connection to the profession via her regular column for Nursing Standard.

During the lockdowns, she began writing what she describes as her 'nursing life story'. 'I was thinking about how the health service has changed, why it has changed. I've written reams but I don't know what I'll do with it yet.

'Writing is what I would have loved to have done when I left school – studying English and becoming a writer,' she adds. 'But I felt I ought to do something that was for other people, not just for myself. So I got into nursing and it gets into your blood. It's who you become.'

Since her retirement she has found a multitude of ways to continue that sense of serving other people. As well as supporting her daughter and two grandchildren she also helps her local community.

'We have a coffee morning at our local church, which I help with, and it's mainly elderly people who come. I also have a few elderly neighbours who I visit, and who know if they want anything that I'm there.

'And people often come to me and ask me about their eyes,' she adds with a chuckle.

Curbs on migrant care worker numbers are cruel

New rules to prevent overseas staff bringing family to the UK could be disastrous for the care sector and the NHS

By Francis Fernando
director of the Filipino Nurses Association UK and associate director of nursing and quality at the North East London NHS Foundation Trust

Spouses and children of international social care staff will no longer be allowed to accompany them to the UK – unless the worker earns above £29,000 a year – under new government policy set to come into force in the spring. This policy is, to put it mildly, contentious. I would even go so far as to say that not allowing care workers to bring their families with them to the UK is cruel.

The UN International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families (1990) states that migration frequently results in major issues for the families of migrant workers and highlights the dispersion of the family as a prominent issue.

I moved to the UK from the Philippines in 2000 and have worked in the care sector – including during the COVID-19 pandemic – as well as in the NHS. I cannot begin to fathom how I would have done it without my family here.

Working in the care sector is not an easy life – especially when you are working in a different culture. But for me and so many thousands of others who do it, our families provide us with inspiration and motivation to carry on doing our best through the most difficult of times.

It is unfair to separate migrant workers from their loved ones for years as they adjust to their new life in the UK, a period that represents a massive upheaval in their lives.

In November 2021, the governments of the Philippines and the UK co-wrote a memorandum of understanding which, among other things, said the UK would 'promote the welfare of Filipino nurses and other healthcare professionals' while they were in the country. Does the implementation of this new immigration law comply with the standards outlined in this agreement?

Since the Windrush era that followed the second world war, the UK has relied on foreign health and care workers to deliver its health and care services. But with these new rules and others – such as the rise in the annual healthcare surcharge to more than £1,000 for temporary migrants – the UK is effectively sending a message to prospective care staff from overseas that they are no longer welcome. They may well find that they and their families will be more warmly received by other G20 nations, such as Canada, Australia and Ireland.

Workforce strategy

Unlike the NHS, which recently released its ten-year workforce plan, the UK care sector does not have a workforce strategy and will therefore continue to rely on international recruits to fill positions. Despite offering relatively low average salaries, the care industry nevertheless draws a sizeable influx of foreign workers. But will this continue when the new immigration laws come in? If not, this could have a disastrous effect on the already stretched care sector – with inevitable ramifications for healthcare services.

The lack of capacity and staffing shortages in the care sector are already causing problems for the NHS, with patients who need community placements often unable to be discharged in a timely manner. This means that the patients who are most in need of acute hospital beds cannot access them. The most vulnerable members of society suffer, as do their families. This will only worsen if numbers of care staff coming here from overseas start to dwindle.

Migrant workers are often told that they should embrace British culture and traditions. And what could be more British than family values? So why does this government wish to impose an oppressive policy that would keep these workers apart from their families?

The government is using the families of legal migrants as political pawns. This cannot be allowed to happen. It is imperative that those employed in the care and health sectors voice their dismay and disillusionment with the new immigration regulations.


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Further information

Milling A, Bello S (2021) Memorandum of Understanding on the Recruitment of Fillipino Healthcare Professionals. **tinyurl.com/HMG-uk-phillipnes-statement**

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How a toolkit can help in identifying Parkinson's

A toolkit for detecting and managing Parkinson's dementia can help nurses start important patient conversations

By Cathy Magee
advanced clinical practitioner, University College London Hospitals NHS Foundation Trust

By Frankie O'Shea
nurse consultant, University College London Hospitals NHS Foundation Trust

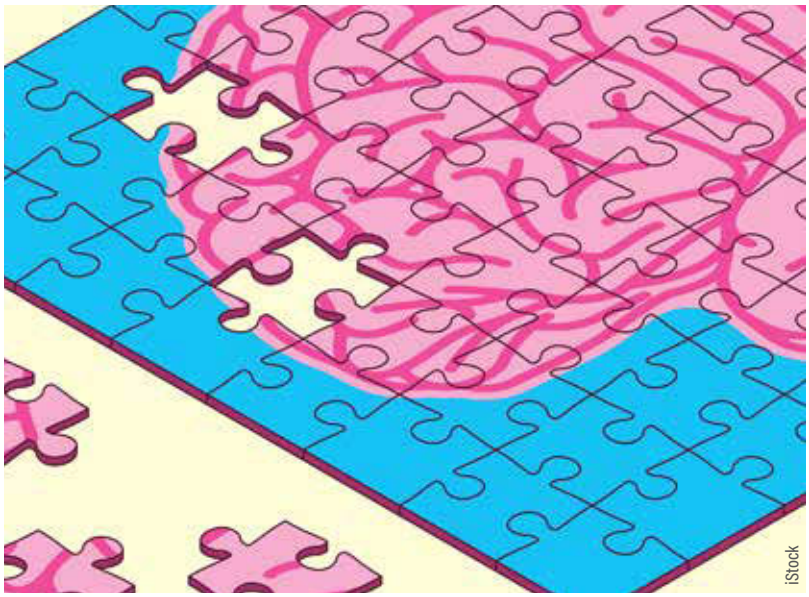
Parkinson's disease is a neurodegenerative disorder that affects predominantly the dopamine producing (dopaminergic) neurons in a specific area of the brain called the substantia nigra. It is associated with motor symptoms such as tremor, rigidity and slowness of movement.

Parkinson's dementia is diagnosed when dementia develops in people with established Parkinson's, with onset of cognitive symptoms at least 12 months after the onset of motor symptoms. Dementia is common in patients with Parkinson's and occurs in around 50% of people with Parkinson's within ten years of their diagnosis.

Why is the toolkit needed?

Although dementia is common in people with Parkinson's it is not talked about enough. People with the condition and their carers can be reluctant to discuss the topic and are not always aware that dementia is associated with Parkinson's. Some healthcare professionals may also delay or feel unsure how to bring up the topic with patients in the clinical setting.

Parkinson's UK has introduced a toolkit for detecting and managing Parkinson's dementia aimed at helping nurses and medics start conversations with patients and carers in the clinical setting, improving timely interventions and access to treatment and carer support, as well as helping with research into underlying causes.



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Why is it necessary to look for dementia in patients with Parkinson's?

A positive diagnosis of Parkinson's dementia allows for prompt treatment and provides help, support and access to general and more specific management interventions.

Parkinson's dementia – and associated symptoms such as hallucinations, depression and anxiety – can respond to treatment and this can improve a patient's quality of life and reduce the burden on their carer. This diagnosis can affect the choice of treatments for motor symptoms, with medication regimens often simplified where possible.

Patients can also be targeted for emerging disease-modifying treatments in future.

Who is at greatest risk?

The greatest risk factors for developing Parkinson's dementia are:

- Older age at onset (around 70 years), and older age in general.
- Vascular disease, especially hypertension and diabetes.
- Depression and anxiety.
- Genetic risk groups, for example GBA-associated Parkinson's.
- REM sleep behaviour disorder.
- Orthostatic hypotension (low blood pressure when you stand up).
- Presence of visual illusions or hallucinations.
- Previous episodes of delirium, for example during episodes of infection.

What are the symptoms?

Patients may have trouble doing everyday tasks and may lose independence due to cognitive deficits. Sometimes more than one cognitive domain is affected on testing. Visuospatial and executive function deficits are particularly common in Parkinson's dementia. Executive dysfunction is the term for a range of cognitive and behavioural difficulties that can occur after injury to the frontal lobes of the brain.

Patients or their families may become aware of cognitive changes but they can manage day-to-day activities unless there is significant functional impairment. This is termed Parkinson's with mild cognitive impairment (PD-MCI).

People may experience prominent fluctuations in thinking – sometimes lucid, other times sleepy, confused or disoriented. They may also experience visual hallucinations or delusions, especially delusions of jealousy or

of identification, such as thinking they are not at home when they are, and Capgras delusions (thinking a family member has been replaced by a person who looks similar).

There may also be general suspiciousness and paranoia, and they may experience a high degree of daytime somnolence and autonomic symptoms, especially postural hypotension.

What are the best tests?

Neurology teams may test for Parkinson's dementia with:

- A brief cognitive assessment such as the Mini-Addenbrooke's Cognitive Examination (Mini-ACE), Mini Mental State Examination (MMSE) or Montreal Cognitive Assessment (MoCA) – these are useful to provide measures of severity and to assess change over time.
- Blood tests for reversible metabolic causes, such as full blood count/urea and electrolytes/vitamin B_{12}/folate/thyroid function/calcium.
- Screening for constipation/infection.
- Structural imaging: magnetic resonance imaging brain, or computed tomography if not feasible.
- Or refer the patient for formal neuropsychological assessment, if available.

What sources of support are there?

Patients are eligible to try a cholinesterase inhibitor (rivastigmine, donepezil or galantamine), provided there are no contraindications, and memantine. Rationalise other medications such as withdrawing anticholinergic medications and simplify their Parkinson's drug regimen to use levodopa-based drugs only, if possible. Treat anxiety, depression, nocturia and postural hypotension if present. Also consider sleep and bone health.

For general health and well-being, promote a combination of aerobic and postural exercises such as brisk walking and yoga for half an hour, five days a week, and maintain social activities by seeing friends or social groups.

Also consider:

- Cognitive stimulation therapy if available.
- Interventions for carers, for example psychoeducation such as STrAtegies for RelaTives (START).
- Regular follow-up and point of contact for carers and patients.
- Referring to memory clinic if appropriate or community mental health if psychosis is prominent.
- Controlling vascular risk factors.
- Treating sensory impairment: cataracts and hearing loss.
- Suggesting the person eats a balanced diet, stops smoking and reduces alcohol intake.
- Physiotherapy assessment and intervention.


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Dementia is common in people with Parkinson's, but people with the condition can be reluctant to discuss it

What practical things can be highlighted to patients?

Encourage your patient to open up to friends and family about the diagnosis.

Ensure the new dementia diagnosis is documented on your clinic letter – this will prompt an annual review by their GP. The GP can also make a referral to community mental health to access dementia nurses and navigators.

There are options for further referrals for patients and carers. Nurses can request a carer's needs assessment and occupational therapy home assessment through the GP or directly.

Check whether the patient and the people who care for them are linked to the local Parkinson's service and Parkinson's nurse, and consider referring to Lewy body dementia nurse or local Admiral Nurse.

The patient or carer will need to notify the DVLA and the issuer of their travel and car insurance of a dementia diagnosis. If you have concerns about a patient driving, recommend a driving assessment.

Advise patients about lasting power of attorney for health and finance – this needs to be actioned early while the patient has capacity. For advance care planning consider the ReSPECT framework if appropriate.

A patient and/or their carer may be entitled to a range of benefits.

Signpost to other resources through Parkinson's UK, the Lewy Body Society, Age UK, Alzheimer's Society and Rare Dementia Support. You can also ask the GP for NHS Talking Therapies, formerly known as Improving Access to Psychological Therapies (IAPT), for carers.

The toolkit was developed by professionals from the National Hospital for Neurology and Neurosurgery in London, researchers from University College London and a person with lived experience. The project was supported by Parkinson's UK and funded by the Wellcome Trust.

Further information

Age UK. **www.ageuk.org.uk**

Alzheimer's Society. **www.alzheimers.org.uk**

Lewy Body Society. **www.lewybody.org**

NHS England (2023) NHS Talking Therapies, for Anxiety and Depression. **tinyurl.com/NHSE-talking-therapies**

Parkinson's UK. **www.parkinsons.org.uk**

Parkinson's UK (2023) A Toolkit for Detecting and Managing Parkinson's Dementia. **tinyurl.com/PUK-toolkit**

Rare Dementia Support. **www.raredementiasupport.org**

University College London (2019) START (STrAtegies for RelaTives). **tinyurl.com/UCL-start**

If you know someone we should interview or profile email ***clare.lomas@rcni.com****, call 020 8872 3161 or* 𝕏*@rcni_clarelomas*

Benefits of moving from NHS to social care nursing

There are career opportunities and patient care rewards for newly registered nurses in the social care sector

By Lianne Ford
lead nurse at
Exemplar Health Care

Adult social care is a vitally important sector, employing more people than the NHS and delivering much-needed care and support to millions of people each year.

Social care nursing is deeply relational; it involves building trust with and supporting people over a long period of time. Rather than focusing solely on illness and disability, we empower people to maximise their independence, and encourage them to pursue their goals and aspirations so they can live meaningful and fulfilled lives.

Why filling social care nursing staff vacancies is crucial

Social care nursing is an incredibly rewarding career, but analysis from the Health Foundation reveals just 5% of nurses chose to move from the NHS to adult social care in the past decade. It also suggests not enough nurses understand the value, career opportunities and rewards on offer in the social care sector.

The latest data from Skills for Care show the sector has a serious nurse shortage, with 11.3% of roles in England currently vacant. Filling these roles is crucial if we are to enable more people to be supported in a community-based home, closer to friends and family, while also relieving pressures on acute NHS services.

What skills or experience would I need as a social care nurse?

To excel as a social care nurse, you need to be compassionate, a great communicator, able to adapt to different working environments and have strong interpersonal skills. Building trust and rapport with service users and their families is paramount, so patience, empathy and good active listening skills are also a must.

These are skills that NHS nurses have in abundance and that are transferable to social care.

Social care nurses also work in a range of settings, from care homes for people with complex needs to someone's own home, and a diverse range of specialisms, including learning disabilities, mental health, palliative care, and caring for people with conditions such as dementia and Huntington's disease.

Why should I move from the NHS to social care?

I am a registered mental health nurse and moved from the NHS to the social care sector ten years ago, taking up a post with Exemplar Health Care, which provides nursing care for adults living with complex needs. After progressing to unit manager, clinical nurse manager and quality manager, I became lead nurse in 2022.

We have a broad range of roles available at Exemplar, from registered nurse, unit manager, lead nurse and clinical nurse manager positions to department heads.

The social care setting also offers career advancement opportunities in regulatory, governance and health and safety roles, as well as care home leadership, regional oversight and condition-specific specialist roles.

During my career in social care, I have had the opportunity to develop and enhance my general nursing skills, with specific training on tracheostomies, PEG feeding tubes and ventilators.

Social care nurses are often the most experienced clinical leads working in their setting, so you need to be confident in your clinical abilities and able to support the wider team.

'For nurses seeking a different type of work environment, the social care sector can offer more flexible working hours'

RCNiLearning
rcnilearning.com

‘The biggest draw of social care nursing is the opportunity and time to build long-term relationships with those you support’

All our teams at Exemplar are nurse-led. This gives our nurses greater professional autonomy and decision-making authority, and enables them to demonstrate their people and clinical leadership skills day in, day out, as the most senior decision-makers on shift on their unit.

Supporting nurses to develop their leadership and management skills is as important as helping them maintain and develop their clinical skills. We offer a wide range of in-house leadership and management development training programmes to enhance colleagues’ leadership abilities and equip them with the necessary skills to excel as they progress their careers.

For nurses seeking a different type of work environment, the social care sector can offer more flexible working hours and shift patterns to help you achieve greater work-life balance.

Pay is broadly equivalent to the NHS, often matching the Agenda for Change framework, with different employers offering different employment benefits, particularly in relation to pensions. But by far the biggest draw of social care nursing is having the opportunity and the time to build long-term relationships with the people you support. Our small units tend to support around ten people, and with our high staffing levels, nurses are able to build deep relationships and see the difference they make to people’s lives over time.

I am a newly registered nurse – can I work in social care?

Yes, you can. At Exemplar, we have a unique preceptorship programme designed to help our newly registered nurses get the best possible start in their social care career.

The 12-month programme includes a thorough induction, 12 weeks of supernumerary support in practice, access to the RCNi Learning online platform and the Royal Marsden Manual of Clinical and Cancer Nursing Procedures, and regular supervision with a preceptor.

If the care sector is serious about attracting, supporting, and retaining more nurses, all providers need to consider launching their own preceptorship programmes – perhaps with a set of unified national standards, co-produced with sector bodies – which would more closely align the training and support offered to social care nurses with that on offer at an NHS trust.

How can we change perceptions of social care nursing?

Perceptions of the care sector will only change when there is a clear career pathway and aligned training standards between the health and care systems, so nurses can more easily transition between the two as they move up the career ladder.

Changing the perception of social care nursing needs to be a national priority, particularly as demand for especially complex and high acuity community-based services continues to increase.

While work is already underway, we must go further to spread these pockets of best practice across the whole system.

We need closer collaboration between social care providers and universities that provide nursing programmes, as well as reforms to nursing associate apprenticeship programmes to incorporate a social care element.

Working together across health and social care to keep more nurses in the profession

Meanwhile, enhanced leadership education programmes and clearer progression pathways will empower nurses to advance their careers in the care sector.

Rather than see healthcare and social care as separate systems competing for a limited pool of nurses, leaders in both sectors need to align training and development programmes and work to make moving between settings a viable, and even desirable, way to develop a nursing career.

Combined, these initiatives may go some way towards keeping more nurses in the profession, irrespective of which setting they are in.

Why we need a long-term workforce plan for social care too
rcni.com/longterm-socialcare

Moving from the NHS to social care – things to consider

- **Research and understand the role** There are many different nursing roles, care settings and models of care in the social care sector. Research how these differ and what that will mean for your working day to find the best fit for you
- **Assess personal and professional goals** Social care is an amazing sector to work in, but it won’t match everyone’s career aspirations and personal goals. Consider what is important to you, the type of care you want to focus on, and see how that aligns with the benefits social care offers
- **Look at different employers** The social care sector is made up of thousands of different employers, each with their own pay, pension, training and career development offerings. Find the one that is best for you
- **Prepare for a different approach to care** Social care involves more in-depth interactions and a focus on providing holistic care to support people to achieve their goals. This could be full rehabilitation for some, while for others it may be a focus on quality of life
- **Network and seek advice** Connect with nurses already working in social care for insights, advice and a real-world perspective

Why you should read this article:

- To read about a replicable skills-led learning programme to equip multidisciplinary adult community teams with the knowledge, skills and competencies required to meet the complex needs of older people at home
- To recognise the benefits of a versatile, multiskilled workforce for individual practitioners and for the wider healthcare system
- To understand the need for organisations to invest in their current workforce's abilities and skills to support the move towards community-based care

Equipping the healthcare workforce to meet the complex health needs of older people in the community: a skills-led approach

Marie Prior, Susan Blake and Helen Lyndon

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Abstract

The shift towards delivering more clinical care in the community not only supports the healthcare system by avoiding unnecessary hospital admissions, but can also improve outcomes, particularly for older people with complex healthcare needs. Therefore, healthcare organisations need to consider how to ensure their workforce has the capabilities required to provide care in accordance with this new model. This article details a project that involved the design and development of a replicable Ageing Well programme of learning to increase knowledge, skills and confidence among registered and unregistered practitioners, underpinned by a 'skills not roles' strategy. Although evaluation of the programme is ongoing, the authors encourage its wider adoption by outlining its benefits, how the challenges encountered during this project were overcome and the learning points gained from the experience.

Author details

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Keywords

community, community care, competence, healthy ageing, older people, professional, professional development, professional issues, workforce

In the UK, people are living longer now than at any other time in history, but this does not necessarily mean that they are in better health as they age (GBD 2019 Demographics Collaborators 2019). There is evidence that the gap is widening between longevity and health span (the length of time that a person is generally in good health) (All Party Parliamentary Group for Longevity 2021). This means that a greater number of people are living with several long-term conditions and are therefore at increased risk of clinical deterioration and hospital admissions (National Institute for Health and Care Research 2021).

The NHS (2019) Long Term Plan outlined the long-term goals to move from reactive care towards proactive models centred on early intervention and to transfer more hospital-based care to community-based care. This includes the implementation of services that focus on avoiding hospital admissions, such as urgent community response (UCR) services (NHS England 2023a) and virtual wards (NHS England 2023b). UCR services provide a rapid response within two hours to assess, treat and support individuals in health crisis in their usual place of residence, with the aim of preventing an acute admission to hospital. Examples of typical presentations which may

require a UCR include frailty symptoms, urgent catheter care, acute delirium with unknown cause and new or deteriorating mobility issues.

A literature review into the clinical effects of moving care closer to home found that community-based care carries less risk and is of greater benefit for individuals compared with hospital-based care (Monitor 2015). A later study found that outcomes for a group of older patients with frailty could be enhanced at home through an admission avoidance hospital at home intervention (Shepperd et al 2021). With larger caseloads becoming the norm for community practitioners, the changes in how clinical care is delivered – together with the growing clinical complexity of patients – have implications for the scope of community practice. As a result, the health and social care workforce may feel underequipped and unprepared to manage the clinical demands placed on them. The implementation of new services with a focus on avoiding hospital admissions might not always consider the skills and capabilities of existing staff to provide these services. The term 'capabilities' is used here to refer to a level of competence that includes the ability to perform successfully in situations that may be complex and necessitate adaptability and creativity (Skills for Health 2022).

This article presents a project from a community NHS trust in south west England, describing how the trust has responded to the shift in healthcare services by enhancing the knowledge and confidence of the workforce with a focus on 'skills not roles'. Although this may be a challenging cultural and professional transition, it is necessary for moving towards integrated care systems detailed in the NHS (2019) Long Term Plan. While the emphasis is frequently on the integration of the health and social care sectors, it is crucial to acknowledge that there is still work to be done in organisations to avoid silo working.

This project highlights how the development of a versatile and multiskilled workforce can be a driver of integration at all levels, with benefits to the wider healthcare system and workforce in terms of flexibility, morale and career progression. The project fits within a 'bottom up' rather than 'top down' approach, which is a critical element in the effective deployment of integrated care systems (Wodchis et al 2015). The development of an integrated system that prioritises what is essential to older people requires input at clinical, service and system levels (Lawless et al 2020).

Background

Historically, in addition to traditional community nursing teams, new services were commissioned to support specialist care in the community, such as heart failure services, respiratory teams and intermediate care services. Contrary to the structural changes brought about by the Health and Care Act 2022, which were characterised by collaboration and integration, these new services evolved based on contracted commissioning specifications and had an underlying transactional relationship. In the authors' professional experience, this contributed to the development of a culture where teams were detached from each other, only delivering activities contained in service specifications. As a result, skills such as venepuncture and catheterisation were perceived to be procedures for the community nursing service and no longer recognised as requiring specialist services and intermediate care. Additionally, the growth of specialist services has led to greater depth of knowledge in specific clinical areas, for example Parkinson's disease or diabetes mellitus, but with a narrower scope in skills and confidence in general community care.

The authors observed that there was a tolerance of task-oriented care in community nursing, with practitioners identifying that they were not allocated sufficient time to undertake comprehensive assessments for complex individuals, for example those with multiple long-term conditions or frailty. This local trend was reflected nationally in research that revealed an increasingly task-oriented care model, practitioners who were hurried and abrupt with patients, a decline in preventive care and a loss of continuity of care (Malbin et al 2016). In 2019, an analysis of what makes an outstanding community nursing service by The Queen's Nursing Institute and the Royal College of Nursing (2019) found that district nurses were 'compelled' to work in a task-oriented way due to a lack of investment in community nursing.

As part of its role as one of ten accelerator sites for delivering a UCR service, the trust committed to investing in the expansion of its current workforce and skills rather than setting up a standalone service. The development of a UCR service as an integral part of a wider community offer was aligned with the move towards an integrated care model. It aimed to provide seamless access to a multidisciplinary team of professionals, optimising the efficiency and effectiveness of the workforce. This approach also reflected the emphasis in national guidance for a two-hour UCR service to use practitioners in an interdisciplinary way,

whereby people from other disciplines agree to take on elements of others' roles to best use their skills and knowledge as a team (NHS England 2022). This was particularly important for older people with frailty, many of whom had complex needs and/or multimorbidity, who would meet the clinical criteria for the UCR service and would be at high risk of hospital admission if they were experiencing a health crisis.

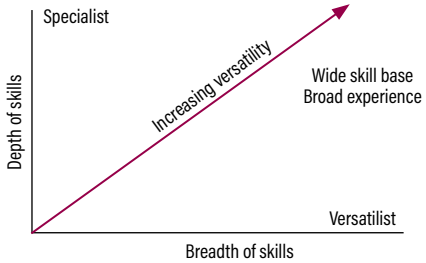
Rather than concentrating on specific roles, a 'skills first' strategy was used. The purpose of this was to identify the multifaceted abilities that all practitioners require to function efficiently and flexibly, not to formally redesign roles. The NHS England (2020) People Plan encouraged this shift towards versatility by emphasising the value of developing capabilities and adaptable skills rather than traditionally defined roles. It describes the importance of staff working and learning together in multi-professional teams as critical to keeping patients and staff safe. Figure 1 shows the theory used for developing a versatile workforce.

While the focus of the project at this stage was on skills and not structures or pathways, some of the challenges centred on out-of-date working practices and patterns that did not reflect the requirements of the current healthcare landscape. The project's focus on skills acknowledged the workforce as the most important resource in the organisation. It was also a response to the widening gap between service demand and delivery that could not be filled by simply recruiting more staff.

Aim and initial steps

The aim of the project was to develop versatile and confident practitioners whose practice was evidence-based and who had the clinical competence to meet the complex needs of older people at home. The starting point was to gain an understanding of the skill mix required to achieve this aim and the current competencies of practitioners working in the community. A peer consultation involving community practitioners enabled the development of a skills matrix that identified the skills required to meet the complex needs of older people with multimorbidity and/or frailty. Between October 2021 and July 2022, practitioners were asked to complete the matrix and assess themselves as competent or not competent and to specify the reason if they were not competent or not using the skill.

Figure 1. Developing a versatile workforce



The findings of this skills review, along with anecdotal observations in practice, were captured on a spreadsheet. A subsequent analysis of these data provided insight into trends relating to the competence and confidence levels of practitioners and these teams' attitudes and cultural norms. The analysis produced some rich information on practitioners' skills and capabilities and valuable insights into why they were not always using some of the skills they deemed themselves competent in. Reasons staff gave for not using their skills included:

- 'We don't do that in our service.'
- 'It's not on my job description.'
- 'I always refer to a specialist service for that.'
- 'I'm not allowed to do that because I'm not registered.'
- 'I haven't done it for so long, I don't know how to do it now.'

The main issues identified from the skills review were:

- Existing interventions were task-oriented or disease-specific and were not routinely reflecting the changing complexity of clinical needs being met in the community rather than in a hospital setting.
- Lack of knowledge regarding the management of long-term conditions and assessment of people with frailty, evidenced by the frequent use of a task-oriented rather a person-centred approach.
- Subsequent overreliance on referrals to specialists rather than first considering 'What can I do?'.
- Overreliance on GPs for clinical decision-making and subsequent loss of clinical autonomy.
- Silo working, resulting in some practitioners' loss of capability to perform clinical skills regularly used in the community setting, for example venepuncture and catheter care.
- A lack of confidence in responding to and managing complex older people, including those in health crisis.
- A process of reactive care that addressed the patient's presenting signs and symptoms but did not explore the additional underlying issues that may have led to a health crisis or that could become a health crisis in the future if not identified proactively.

Development of the Ageing Well programme

The findings from the skills review prompted the development of an education and coaching programme that emphasised clinical curiosity and learning throughout the entire clinical team, with an aim of empowering practitioners to optimise and value their skills. A core feature was registered and unregistered practitioners from nursing and allied health professions learning together, embracing Health Education England's (2017) philosophy of lifelong, flexible, adaptive and interdisciplinary learning. Registered practitioners included nurses (community, ward, specialist and digital health nurses), nursing associates, occupational therapists, physiotherapists and dietitians. Unregistered practitioners included community support workers, generic therapy assistants, healthcare assistants, assistant practitioners and falls technicians.

Developing a curriculum where unregistered and registered practitioners from different professions would be learning together in a classroom setting required careful planning. To support this, two sets of learning objectives and competencies were developed that were informed by relevant capability frameworks, for example the frailty framework (Health Education England et al 2018), virtual ward and urgent community response (Skills for Health 2022) and the Nursing and Midwifery Council (2018) standards of proficiency for registered nurses.

While it was uncertain how effective this joint learning approach would be, interprofessional and multilevel learning was an important element that would encourage new ways of thinking and challenge norms and working practices in the context of a supportive learning environment.

Structure and content of the programme

The programme consisted of five face-to-face taught classroom days focused on increasing knowledge and skills in a range of subjects relevant to the healthcare of adults with complex needs in the community. All the sessions included the identification and interpretation of symptoms and clinical signs, underpinned by a structured model of clinical enquiry and strategies to promote clinical reasoning and decision-making. There was also an emphasis on skills to support the proactive management of long-term conditions, all with a focus on older people and how to support individuals to age well.

A holistic approach ensured that physical and mental health dimensions were included. Box 1 outlines the content of the Ageing Well programme.

The content took into account the needs of registered and unregistered practitioners and the differing levels of practice and proficiency they required. During the sessions, a clear distinction was made between the actions, behaviours and responsibilities that were within the scope of practice of all practitioners and those specifically relating to registered practitioners.

Following the taught days, participants received place-based one-to-one coaching to reinforce the transfer of knowledge into practice. The trust invested in three clinical facilitators, a new band 7 role that would work with practitioners in the workplace. The ethos was one of 'being alongside', characterised by an emphasis on coaching that also provided an opportunity for modelling professional behaviours and standards and challenging cultural norms.

Learning and competence were demonstrated by the completion of an online portfolio comprising ten sections (Box 1). Each section contained a list of learning objectives and competencies, along with content and a range of resources to develop and demonstrate competence. The portfolio was developed not simply as a record of competence, but as a comprehensive resource of learning materials. The online platform used for the competency portfolio enabled real-time editing and facilitated the sharing of further resources and support. Participants could continue to access their portfolio after programme completion, as a record of their competence and to encourage ongoing learning and professional development.

Box 1. Content of the Ageing Well programme

Five taught classroom days focusing on:
- 'Top-to-toe' screening and assessment
- Clinical enquiry and reasoning
- The biology of ageing
- Long-term conditions
- Dementia, delirium and depression
- Nutrition
- Medicines reviews
- Identifying patients who are approaching the end of life
- Falls and reablement
- Health promotion and prevention

Followed by:
- Place-based coaching in practice to support completion of a competency-based portfolio

Key points

- A move away from reactive care towards proactive models centred on early intervention requires services that focus on avoiding hospital admissions
- The implementation of new services that focus on avoiding hospital admissions might not always consider the skills and capabilities of existing staff to provide these services
- Adopting a 'skills first' strategy identifies the multifaceted abilities all practitioners require to function efficiently and flexibly to meet patients' complex needs
- Workforce development strategies where the focus is 'skills not roles' are necessary, practical and achievable

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Evaluation of the programme

At the time of writing, 102 practitioners across three cohorts had completed the programme. Evaluation has focused on its effect on the clinical practice of individual practitioners who have completed the training, with interviews conducted with each participant from the first cohort (*n*=30). For subsequent cohorts, baseline data were also captured at the start of the programme via the questionnaire, which asked practitioners to self-report their levels of knowledge and confidence in relation to the programme's aims and objectives. The same questionnaire was administered at the beginning of the programme and after the follow-up coaching to assess improvement in participants' knowledge and confidence. All 102 practitioners completed these baseline and post-programme evaluation questionnaires. During the place-based coaching, further insights into the effect of the programme were gained from the clinical facilitators, who received informal feedback from managers, team leads and the wider teams in which participants worked.

Consistent feedback was received that, following completion of the programme, participants were less task-oriented when they visited patients, using new knowledge and skills that enabled them to identify subtle changes in patients' conditions and provide timely preventive care and advice. One allied health professional who completed the programme said:

'The programme gave me the knowledge and confidence to be able to support my patients to age well, regardless of their age. It has brought forward in me a different way of thinking, treating and assessing older people.'

The clinical facilitators who were accompanying practitioners on their visits identified that, after completing the programme, the practitioners were able to 'do more' for the patients they visited and were more confidently able to draw from a wider skills base. They also observed that a shift in mindset towards a more proactive and holistic response had taken place among those who had completed the programme. This was demonstrated primarily by their more thorough 'top-to-toe' assessment skills, which enabled practitioners to explore potential underlying causes for patients' presenting signs and symptoms and to integrate elements of preventive healthcare.

When comparing baseline and post-programme evaluation questionnaires, registered practitioners demonstrated improvements in their levels of knowledge, skills and confidence, which enabled them to do more for patients and increased their job satisfaction:

'I now have a better understanding of how medications can impact older people and always check whether a medication review would be beneficial to see if deprescribing may be an option.' (Cardiac specialist nurse)

'It has had a fantastic impact on my role. My assessments have improved tenfold. I provide more in-depth holistic care and have been sharing this within my team to ensure we are making the most of our visits and stopping the scattergun approach to referrals.' (Community nurse)

Unregistered practitioners also demonstrated improvements in the questionnaires, with one community support worker stating:

'It's completely opened up how I work and how I look at things. Doing a top-to-toe assessment during each visit is really important. I'm now more aware of what to look for, picking up subtle changes in the patient's condition and providing preventative care and advice.'

However, there were some differences in relation to specific components, for example malnutrition and falls assessments. Interviews with the participants identified that these differences were mainly due to inconsistencies regarding the skills that unregistered practitioners were permitted to undertake in different teams, rather than a lack of knowledge and confidence. One issue highlighted by the programme was discrepancies in the scope of roles, particularly for unregistered practitioners.

Many unregistered and registered practitioners expressed how the programme had reinvigorated their desire for learning. Observations by clinical facilitators in practice found that unregistered practitioners wanted to develop their skills and be able to do more for patients. Furthermore, team leads and managers said they had noticed a difference in members of their team who had completed the programme, specifically in relation to their holistic approach to patients and the move away from a task-oriented model.

Beyond the teams directly involved, other teams reported improvements in the quality of referrals they received. For example, practitioners described making fewer referrals to GPs and specialist teams, recognising an increase in their clinical autonomy. Post-programme interviews with participants identified that, overall, it had created 'curious' practitioners who wanted to enhance their learning and understanding. This was notable

among the unregistered practitioners, many of whom reported feeling more valued as part of the team following the programme. Furthermore, it was identified that both registered and unregistered practitioners were sharing their learning and influencing the working practices and culture of the individuals and teams they worked with:

'I am now more confidently able to apply evidence-based strategies in my practice. As part of the programme, we learned about the importance of nutrition. I used this knowledge to generate an evidence-based resource pack for patients, to promote the importance of protein in wound healing.' (Nursing associate)

Costs and other resources

The initial start-up costs for this project were measured more in time than in direct financial input, as the design and development of the skills matrix and the curriculum were undertaken alongside existing roles. While it is challenging to determine exactly how much time this took, the overall timescale of this phase was approximately 12 months. The skills matrix and curriculum are now available as resources and may be adapted for any local context.

Three clinical facilitators were employed to provide place-based coaching as part of a wider role in facilitating learning and quality improvement in practice. The expertise of the programme clinical lead (MP) and trust-employed specialist practitioners was used together with the clinical facilitators to support the five taught classroom days. While new roles such as that of the clinical facilitator required investment, one of the main strengths of the 'skills first' approach is its focus on maximising the skills and potential of the existing workforce rather than recruitment of additional staff.

Finally, an emphasis on place-based learning minimises the number of days that practitioners need to be released from their duties to attend classroom-based learning.

Challenges during the project

The initial work of gathering baseline skills data via the skills matrix and review was time-consuming and took significantly longer than expected, primarily due to service pressures. In addition, it was challenging to engage some of the practitioners in a process that some approached with suspicion.

Accessing the online competency portfolio and resources was a challenge for some practitioners who were less familiar with the platform used and/or had limited information technology (IT) skills. Some practitioners had not undertaken any classroom-based learning for some time and needed support to complete the online competency portfolio. The importance of effective design, development and IT support should be recognised, and the success of the project was due in large part to the commitment and tenacity of the programme support manager (SB).

It is important to recognise that the challenges in using a 'skills not roles' strategy often related to the systems, cultures and practices in which the skills and capabilities were used. Therefore, it is not possible to undertake any meaningful skills and capability-based work without exploring these systems, cultures and practices.

The challenges that occurred during the project offered some insightful information for individuals and the organisation. Some practitioners were initially concerned about being expected to perform tasks they felt were outside of their scope of practice. Examples of this included nurses carrying out reablement, which they perceived to be a therapist's role, or therapists undertaking clinical skills that they perceived to be nursing tasks. Other practitioners expressed concern that, due to their high workloads, they were learning new skills that they would not have time to use. As the curriculum progressed from the teaching days to the completion of the portfolio in practice, these anxieties lessened. Practitioners could see the advantages of learning new skills for their patients, and they reported an increase in job satisfaction because of their improved ability to take the initiative and act with more self-assurance. At an organisational level, areas were identified where the efficiency and effectiveness of teams could be improved, for example by ensuring consistency in the scope of skills in the same roles.

The clinical facilitators provided support in overcoming challenges that the individual or team encountered, whether these were practical issues, such as accessing the portfolio, or role-specific concerns. They were also able to support participants to apply and embed new knowledge and skills into their practice.

Next steps, sustainability and scaling

At the time of writing, the programme has been developed and tested in adult community services, in line with organisational priorities. This has demonstrated its potential and scalability. Future aspirations include extending the programme to primary care, social care and private providers of nursing and residential care.

An important next step will be to evaluate the effects of the programme from the patient perspective, ensuring that the measures used reflect what older people consider important. To do this, an evaluation will be conducted using a qualitative and appreciative enquiry approach, drawing on the findings from a report commissioned during the UCR accelerator phase (Healthwatch Cornwall 2023). Interviews with 20 older people who had received a UCR visit were conducted, in which they identified their healthcare priorities as (Healthwatch Cornwall 2023):

- A service that enables people to be cared for in their own homes, avoiding hospital admission whenever possible. This is particularly important in rural areas since the nearest hospital may be some distance away.
- One practitioner being able to assess, treat and deliver support needs rather than involving several people over several visits.
- Skilled, knowledgeable and compassionate healthcare practitioners who can organise tests and follow-up results without the person having to leave their home.
- Practitioners who can signpost people to other services and help them 'navigate the system'.

Learning points from the project

The primary aim of this article is to share knowledge with organisations who want to replicate the Ageing Well programme, or elements of it, in their services. The main learning points from the project are shown in Box 2 and may serve as a guide when considering its implementation. For further information about this project, please email: cft.ageingwelldevelopmentteam@nhs.net

Conclusion

The establishment of a community UCR service prompted the creation of the Ageing Well programme of learning. The programme was designed to equip multidisciplinary teams in adult community services with the knowledge, abilities and self-assurance they needed to maximise the health, happiness and independence of older people with a variety of complex needs. To meet this need, organisations should invest in the abilities and skills of their current workforce to reflect contemporary patient profiles and the move towards more community-based care. Workforce development strategies where the focus is 'skills not roles' are a necessary, practical and achievable response to this need.

Box 2. Main learning points from the project

- Undertake a skills review before introducing the Ageing Well programme as this will provide a rich source of information
- Consider the resources needed for developing the competency portfolio and keeping it up to date. It should be reviewed annually to ensure it reflects contemporary evidence and best practice. The original version is available for sharing, but it will need to be tailored to local areas as some content is geographically specific
- Practitioners need to be able to see the value of taking part in the Ageing Well programme, for themselves and for the people they care for, so explain its purpose clearly
- The aim of the programme is not to redesign roles; however, it may challenge perceptions of professional boundaries since participants are encouraged to 'think differently'. As the emphasis is shifted to skills and not roles, rather than asking 'Is this part of my role?' participants should ask 'Do I have the skills needed to meet this person's needs?'. It is about giving practitioners 'permission to act' rather than imposing changes on the scope of their roles
- Operational managers will be acutely aware that it can be challenging to release staff for education and training. The role of clinical facilitator and a place-based approach to learning ensured the programme had minimal effects on service delivery. Teaching and facilitation skills are necessary to ensure the effectiveness of the classroom-based taught days. If in-house practitioners are asked to facilitate and teach on these days, the support they may need to develop these skills must be considered
- Communicate the aim and content of the programme to the whole team to ensure that participants' practice development is not limited by traditional expectations of their roles
- Be aware that some participants will require support with basic information technology skills, for example to be able to save and upload evidence to their online competency portfolios
- The quality of the learning experience and credibility of the programme were enhanced by achieving accreditation from the Continuing Professional Development Certification Service
- The project highlighted the need to undertake further skills-related work, including the development of a list of fundamental skills which all practitioners will be expected to undertake regardless of their role or banding. This will support the shift towards versatility, providing clarity and consistency in relation to the scope of skills required
- Be prepared to experience challenges. It will not always be comfortable to talk about issues related to skills, capabilities and culture, but the outcome will be more effective and efficient practitioners and ultimately a better experience of care for patients

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Why you should read this article:

- To enhance your awareness of the potential benefits of music therapy for people with dementia
- To learn about how a music therapy intervention was implemented in a dementia inpatient unit
- To understand the experiences of people with dementia attending individual and group music therapy sessions

Implementing music therapy interventions in a dementia inpatient unit: reflections and practicalities

Chris Atkinson and Kate Martin

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Abstract

There is a growing evidence base to suggest that music therapy is an effective clinical intervention for people with dementia, having positive effects on mood, emotion, communication and memory, and reducing agitation, anxiety and apathy. However, the evidence to support this is predominantly from community settings such as residential care homes or people's own homes. This article captures the authors' experiences and reflections regarding their implementation of a music therapy intervention in a dementia inpatient unit. It explores some of the considerations and learning points gained from their experience, including the practicalities around engaging individuals and staff, the use of space, the timing of sessions, available resources and the potential benefits for patients, family members and the unit as a whole. The authors' experiences suggest that the benefits of music therapy appear to be transferable to the dementia inpatient setting.

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Keywords

clinical, complementary therapies, dementia, health promotion, medicines, music therapy, neurology, wellbeing

MUSIC THERAPY is a psychologically informed clinical intervention that uses music as a medium for supporting people whose lives have been affected by trauma, illness or disability, through supporting their psychological, emotional, cognitive, physical, communicative and social needs (British Association for Music Therapy 2020).

Dementia is a term for several diseases that affect memory, thinking and the ability to perform daily activities, and its effects vary between individuals (World Health Organization 2023). The cognitive changes associated with dementia can include issues with different types of memory, attention, visual-spatial abilities, executive functioning and psychological and/or behavioural changes (Langa et al 2004, Solomon et al 2019). Dementia brings challenges as individuals and their family adjust to the diagnosis and knowledge of what the condition may entail, its day-to-day effects and its progression (Adelman et al 2014, Cheng 2017, Kuring et al 2018).

There is a growing evidence base to suggest that music therapy is an effective clinical intervention for people with dementia, but this evidence is predominantly gained from community settings, either with people living in their own homes or in residential care homes (Livingston et al 2014, Hsu et al 2015, Schall et al 2015, Hack et al 2021). Evidence indicates that music therapy can offer many benefits to people with dementia, such as having positive effects on mood, emotion, communication, self-expression and memory, and reducing agitation, anxiety and apathy

(Bright 1997, Melhuish 2013, Ridder et al 2013, Hsu et al 2015). Music therapy is also a recommended psychological intervention for promoting well-being in the National Institute for Health and Care Excellence (2019) quality standard on dementia.

Establishing a music therapy training placement for a student in a dementia inpatient unit enabled the authors to explore whether these benefits could be transferred to patients in this setting. The placement also offered an opportunity to explore various considerations when introducing music therapy as an intervention in such a setting. It is beyond the scope of this article to provide detailed outcomes of this project and a separate evaluation has been published which reports on these in greater depth (Drewitt et al 2022). Instead, this article focuses on the process of implementing the music therapy intervention, discussing the considerations, potential benefits and learning points gained from the experience.

Dementia inpatient unit

The unit is a specialist dementia inpatient setting in central England that aims to help patients who are experiencing the challenges and symptoms of dementia. It comprises a men's ward and a women's ward linked by a shared corridor which can be used for group activities. Patients are typically admitted to the unit due to a crisis, deterioration in their dementia symptoms or a breakdown in their care. They may be admitted from home, care homes or specialist facilities. Patients' length of stay varies greatly; some are on the unit for a few weeks while they are assessed and suitable care is put in place, while others require a longer period to settle and for staff to adjust their medicines, assess their needs and find suitable ways to meet these needs.

While the unit comprises specialist dementia wards, sometimes patients with mental health issues that are not related to dementia are placed there because of a lack of bed availability elsewhere. At any time, the patient mix can vary considerably in terms of dementia presentation, primary diagnoses, severity of symptoms and levels of functioning abilities.

Considerations when designing the music therapy intervention

What form should music intervention take?

The literature outlines a range of music therapy interventions that have proved successful with people with dementia. These include group work using primarily musical improvisation, singing groups, individual sessions and sessions with family members present (Clair 1996, 2000, Brotons and Marti 2003, Pavlicevic et al 2015, Baker and Yeates 2018, Melhuish et al 2019).

To offer patients a range of opportunities that would suit their abilities and preferences, two types of music therapy groups were offered on the unit: a group that primarily entailed instrumental improvisation, and a singing group. There was an additional opportunity for two patients to have individual music therapy sessions.

The authors considered how to organise the groups; that is, whether the groups would be open, allowing anyone from the unit to attend any week, or closed, comprising the same limited group of people each week. Due to the nature of the inpatient setting, the patient group was transient and fluctuating. Therefore, offering a closed group was considered impractical because regular, consistent attendance from the same group of people could not be guaranteed from week to week for any length of time.

Another consideration was the nature of an instrumental group compared with a singing group. The authors thought that people might need a higher music therapist-to-patient ratio for instrumental improvisation work, since this would enable the music therapist to respond more effectively to individual patients within the group. Conversely, the authors thought that a singing group would not need such a high music therapist-to-patient ratio and patients might find greater benefit from having more voices present, both male and female. Therefore, they decided to provide two separate instrumental groups for the male and female wards, and to join the two wards together to form one larger singing group. All the groups would be open to anyone who wanted to attend each week.

How to collaborate as a multidisciplinary team?

The support of nursing staff was integral to setting up a music therapy intervention that could be incorporated into, and sustained in, the inpatient setting. The authors were reliant on discussions with management, care staff and activity coordinators to identify which patients would be able to access group work and which patients would find a group too challenging. Effective collaboration between the therapists and nursing staff was important to facilitating patient attendance, engagement and support. Careful thought was given to encouraging nursing staff to feel part of the process, to understand the main principles and aims of music therapy, and to feel able to support patients attending the groups.

Key points

- Music therapy can be a valuable intervention in dementia inpatient settings
- Music therapy may not only benefit people who attend the sessions, but can also have wider systemic effects
- Careful consideration of the area used for music therapy is necessary to ensure it is accessible, comfortable and protected from interruptions during sessions
- Instruments readily associated with particular stages of life or which hold meaning for patients should be made available
- It is important to spend time investigating people's musical preferences, cognitive abilities and challenges to promote engagement and attention, and accommodate sensory sensitivity

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The music therapy student – referred to as Ashley – facilitated workshops for the ward staff which offered practical experiences of improvising together, discussions about the theoretical principles that underpin the music therapy process and opportunities to watch video clips of music therapy with people with dementia.

Where should the music therapy intervention take place?

Inpatient wards for people with dementia can be busy and chaotic, often causing feelings of bewilderment and disorientation among patients. Additionally, many people with dementia become increasingly sensitive to noise, either becoming easily overwhelmed or needing greater levels of auditory stimulation (Rhodus et al 2022). Therefore, consideration was given to:

- Finding a space large enough to accommodate participants that was physically accessible to all.
- Choosing a room where interruptions could be minimised and attendance could be maximised, in a location that would preserve the quietness of the rest of the ward.
- Using the same room, laid out in the same way each week, to establish a sense of familiarity and expectations for the patients.
- Selecting the texture and timbre of the instruments consistently available, to offer the appropriate level of stimulation according to people's needs.

The space chosen for the groups had comfortable chairs and was on the ward, so required less physical ability and effort for people to attend. It had the additional advantage of enabling people who felt ambivalent about the groups to sit apart and experience them from a distance if they wished. It was hoped that these patients might feel able to participate once the groups became more familiar to them. However, remaining on the edges of the group, within hearing and/or visual distance, might still be beneficial in offering some stimulation and emotional connection for patients.

When should music therapy sessions run?

Regarding the timing of the music therapy sessions, consideration was given to:

- Avoiding clashes and replicating other interventions that were being offered to patients.
- Minimising sensory and cognitive overload.
- Maximising patients' ability to engage, given the fluctuating nature of dementia symptoms.

Patients met with their clinical care team during ward rounds, which could be cognitively demanding and emotionally challenging for some of them, so might affect their ability or motivation to engage in other activities. Therefore, running sessions on the same day as ward rounds was avoided.

Initially the singing and instrumental groups ran on the same day, but this was later changed so that the groups ran on different days. This provided further opportunities for patients to attend and reduced the potential for sensory and cognitive overload.

Practical application of these considerations

Examples of the work undertaken in individual sessions with two patients are outlined as vignettes to demonstrate the practical application of the areas that were considered when designing the music therapy intervention. Names and details have been changed to protect confidentiality.

Michael

Michael was a 78-year-old man with vascular dementia who had been admitted to the ward due to a deterioration in his symptoms. Michael was quiet and reflective. He often found verbal communication challenging and needed an unhurried, low stimulatory approach to support him to process and engage in conversation. The lounge chosen for his sessions was private and could be protected from interruptions. Each week the same range of instruments were available to him to establish a sense of familiarity, and he always chose the triangle. He would then improvise with Ashley. At the beginning of the sessions Michael barely spoke, but following improvisational music making his speech increased in fluency and he was able to recall significant events from his past. During one of the first sessions, Michael relayed that when he was at school he was not allowed to play any musical instruments, but that they 'trusted me to play the triangle'. This was a link to his past which was stimulated and accessed through playing the triangle, enabling him to relive a part of his personal narrative.

Retaining memories of the past and being able to recall lived experiences may contribute significantly to one's sense of self-identity and existence. When personal memories begin to fade as dementia progresses, people can become disoriented and anxious as they lose hold of their life stories; they can lose a sense of who they are (Kotai-Ewers 2000, Matthews 2015). Through playing the triangle – something familiar to him – Michael was able to access memories of his formative years, which appeared to reassure him and give him a sense of presence.

For Michael it was important to use an accessible space that was private and uninterrupted, and to provide familiarity and an unhurried approach. This may have helped to maximise Michael's ability to engage with the sessions and to connect with his past and self-identity.

Faye

Faye was an 88-year-old woman with Alzheimer's disease who had been on the ward for four weeks. Faye frequently experienced restlessness. She regularly wandered around the ward, finding it challenging to settle in one place for any length of time. She also found it challenging to engage meaningfully with any activities. Any pressure put on her to participate in activities seemed to cause her to feel overwhelmed, which she expressed through physical aggression. The authors felt that it would be most helpful for Faye to be offered therapy in a room that was situated centrally on the ward, so that she could access it readily without assistance. This enabled Faye to self-regulate her sensory and cognitive stimulation by coming and going as she wished.

Faye needed a different approach from Michael to maximise her willingness to attend. She was invited to the room at the start of the session, then left to decide whether she wanted to attend or not. Ashley remained in the designated room, with the door open, for the duration of the session. The central position of the room on the ward enabled Faye to hear Ashley playing an instrument or singing in the room from wherever she was on the unit. Staff were asked not to prompt Faye to attend or to put any pressure on her to engage after the initial invitation. Ashley wanted to offer a secure base for Faye to return to if and when she felt able (Gomez 1997, Bowlby 2005), so that Faye could decide her level of engagement.

In the first session Faye chose not to enter the room at all, but during the second session, as Ashley stood in the doorway to the room gently playing the rainstick, Faye showed interest and focused on it for about a minute from the corridor. During the third session, Faye was able to enter the room and remain for 20 minutes, with the door left open. It appeared that Faye was fully aware of Ashley, what was being offered to her and that she was in control of whether she attended or not. The authors suggest that this may have facilitated feelings of empowerment in Faye, which in turn may have led to her feeling safe enough to begin to make connections and relate to Ashley through the music.

Michael and Faye had varying needs regarding a suitable room to use for their sessions and needed different approaches to maximise their willingness to engage. For each of them it was important to establish familiarity and expectations in a space where distractions, pressure and the potential for sensory and cognitive overload were minimised.

Music therapy group process and outcomes

The music therapy groups were held over a seven-week period in January and February 2020. Each group was attended by up to six people and 59 attendances were recorded over the course of the project.

To aid the patients' familiarity and orientation, the groups had the same beginning and end to the session. Each group session was attended by a psychology trainee who supported patients as needed and helped to complete outcome measures for the instrumental groups. Staff supported patients where necessary by holding instruments, assisting them to move around the room or to leave the group if they wished.

Instrumental groups

Some examples of the music therapy group process and outcomes are taken from the women's instrumental group. The group always started by passing the bongo drums around the group and inviting members to greet each other. As the weeks progressed and the women became increasingly familiar with the process and the setting, their drumming greetings became more elaborate. Each week they demonstrated further exploration of rhythm as they each began to discover their musical voices using the instruments. They became playful, building on each other's ideas, and whoever was the last player each week invariably finished with a universally known rhythm. This began to draw the group together.

In the group improvisations that followed the drumming, the women began to show an awareness of their cohesion as a group. The first piece they performed in each group usually reflected that they had come to the session as individuals; it was less unified and more fragmented. This was demonstrated by comments such as 'it's a clash on the ears' and 'that didn't sound very nice'. However, by the second piece the women were becoming increasingly aware of each other, listening and adapting to each other and valuing each other's contributions to the music. Comments at this point included 'that was more satisfying', 'it was more musical' and 'it was nicer on the ear'.

A comfortable, accessible space away from the busyness of the main ward area contributed to maximising attendance. Familiarity with

the process and the setting appeared to enable participants to feel secure enough to explore and develop their relationships and self-expression.

Singing group

The singing group was a rare opportunity for the two wards to meet, offering an important social element to the sessions. Patients would sometimes attend with their family members if visits coincided with the group time, and at times ward staff would also attend. All of them would then participate in the singing.

Careful thought was given to the repertoire of songs used over the course of the groups. Discussions took place with patients, families and staff to learn about individual musical tastes and to incorporate songs that patients would recognise or have some association with. This meant that patients whose communication was affected by dementia were also considered, since people who knew them well could advocate for them, for example by providing information about their preferred music and songs.

Using songs familiar to the patients prompted recollections and discussions about their earlier lives. One woman shared how she used to dance with her husband to one of the songs, while others spoke about their memories of the original artists who sang them. On one occasion a song was requested and a patient indicated that he wanted to dance with his wife, who had joined the session. This was the song they had danced to on their wedding day. The music from the group had reminded him of this moment, an event which his wife believed he had forgotten. They danced and reminisced together, providing a moment of connection, whereas typically he had difficulty recognising who she was. The room was accessible and large enough to accommodate people dancing together and the patient and his wife felt comfortable to connect in this way in the space.

Potential benefits of music therapy in the dementia inpatient setting

Detailed information on the findings and outcomes of this project and its evaluation are available in Drewitt et al (2022). The findings suggested that music therapy is an effective intervention for people with dementia in inpatient settings, with potential benefits such as increased engagement and a reduction in behaviours that challenge. Familiar music and songs appeared to stimulate memories from the past, linking people to important times in their lives, to others and to their personal stories.

The effects of the music therapy intervention also appeared to reach beyond those directly participating in the group. A sense of connection was observed between staff and patients during the sessions, as staff learned which music patients enjoyed and this stimulated the sharing of mutual interests. The use of music also enabled the ward staff to see patients in a different light and context; they were able to see patients who usually found it challenging to engage with activities were seen to pay attention and display curiosity about the music or singing. Staff commented that they found it rewarding to be able to see patients enjoying themselves and could report to family members that their loved ones had engaged in the music and songs. This may have given families a sense that their loved one was able to experience some enjoyment in their lives and was being cared for. Additional research is warranted to further explore this sense of connection and the effects of music on relationships in the context of inpatient dementia care.

The positioning of the music groups within the main ward area also had several benefits. It enabled patients to move freely in and out of the room, with some choosing to wander past or to sit outside the room, which enabled them to observe others or listen to the music on their own terms. The authors observed that one benefit of this freedom to engage receptively was that patients' dementia symptoms and mood often improved when they were engaged in the activities, and this led to fewer incidents of behaviour that challenges.

One effect of having several patients taking part in the group was that it left other areas of the ward physically quieter, with fewer people moving around. This may have benefited patients who, because of their dementia, typically found this movement and noise overstimulating. It also left a higher staff-to-patient ratio for the patients who were not participating in the groups. Staff commented that they were relieved when music therapy sessions were taking place, as these enabled them to concentrate on patients who required additional support to engage in other activities.

Learning points and recommendations

The following learning points arose from this project:

- Music therapy can be a valuable intervention in dementia inpatient settings.
- Music therapy may not only benefit people who attend the sessions, but can also have wider systemic effects.
- It is important to work collaboratively with the ward team to ensure the music therapy sessions are valued and supported.

- Space is often limited in inpatient settings, so careful consideration of the area used for music therapy is necessary to ensure it is accessible, comfortable and protected from interruptions during sessions, and the space is consistent from one session to another.
- People's sensory processing may be affected in the advanced stages of dementia, so consideration needs to be given to the timbre and texture of instruments to avoid sensory overload. Instruments readily associated with particular stages of life, such as childhood, or which hold meaning for patients, should also be made available.
- It is important to spend time investigating people's musical preferences, cognitive abilities and challenges to promote engagement and attention, and to accommodate sensory sensitivity.

Further research is recommended to explore which forms of music therapy provide the greatest benefit and the duration of the effect of music therapy on individual outcomes. Research could also be undertaken to capture other important outcomes such as staff attitudes towards, and experiences of, music therapy.

Music therapists are trained to provide specialist individual and group interventions and can oversee music therapy interventions in inpatient settings, designing, coordinating and supervising their delivery by other professionals (Pavlicevic et al 2015, McDermott et al 2018). However, various additional music resources are available that do not require specialist input and can be used by ward staff, family members, carers and patients themselves. Box 1 provides some examples of these.

Conclusion

This project offered an opportunity to explore the diverse ways in which music therapy can be used as an intervention in dementia inpatient settings and to identify the expertise and equipment required to facilitate this. Music therapy appeared to have several benefits for patients, such as increasing engagement and reducing behaviours that challenge, as well as wider systemic effects for staff, family members and the unit. The authors' experiences suggest that the benefits of music therapy interventions appear to be transferable to dementia inpatient settings.

Box 1. Additional music resources

- Platforms such as Playlist for Life (www.playlistforlife.org.uk), which guide carers to collate lists of songs that hold special meaning across the duration of a person's life. This can then be used by the person with dementia or those around them
- Music for Dementia Radio (m4d Radio), which can be accessed at www.m4dradio.com. This enables songs to be played from a certain decade or songs to be selected based on the year someone was born
- Groups such as Singing for the Brain, which are available in various settings across England, Wales and Northern Ireland (Alzheimer's Society 2023)

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Why you should read this article:

- To understand the causes and risk factors for incontinence in people living with dementia
- To learn about practical strategies that can support people living with dementia and their family carers to manage incontinence
- To contribute towards revalidation as part of your 35 hours of CPD (UK readers)
- To contribute towards your professional development and local registration renewal requirements (non-UK readers)

Identifying incontinence and promoting continence in people living with dementia

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Conflict of interest
Zena Aldridge is consultant editor of Nursing Older People. Laura Elsegood, Sarah Murray and Alison Wileman work for Essity, a company that sells personal care and continence products. Zena Aldridge undertakes some work with Essity in her capacity as independent dementia nurse consultant but did not receive any payment for this article

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Abstract

Urinary and faecal incontinence are more prevalent among older people but, like dementia, incontinence is not a normal or inevitable part of ageing. The number of people living with dementia who experience continence issues is likely to be underestimated because many people avoid reporting them as a result of embarrassment and stigma, or because they think incontinence is an inevitable symptom of dementia and that nothing can be done about it. Increased awareness and understanding of the relationship between dementia and incontinence is needed so that nurses can persuade people living with dementia and their family carers to discuss continence issues, assess their needs and provide support. There are several practical strategies that can reduce the incidence of incontinence, counter its negative effects and promote continence in people living with dementia.

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Keywords

advanced dementia, clinical, constipation, continence, dementia, dignity, faecal incontinence, neurology, patient experience, patients, professional, urinary incontinence

Aims and intended learning outcomes

The aim of this article is to enhance nurses' understanding of the relationship between dementia and incontinence, the causes of and risk factors for incontinence in people living with dementia, and practical strategies that can support the management of incontinence in people living with dementia. After reading this article and completing the time out activities you should be able to:

- Identify the causes and risk factors for incontinence in people living with dementia.
- List some of the physiological, cognitive and environmental issues that may affect the ability of a person with dementia to remain continent.
- Explain the negative effects of incontinence on people living with dementia and their family carers.
- Encourage people living with dementia and their family carers to talk about continence issues.
- Suggest practical strategies that can support people living with dementia and their family carers to manage incontinence.

Introduction

Dementia is an umbrella term used to describe a group of symptoms such as memory impairment, mood changes, loss of cognitive and social functioning and behavioural and personality changes caused by progressive neurodegenerative diseases such as Alzheimer's

disease, frontotemporal dementia, dementia with Lewy bodies and Parkinson's disease (Qiu and Fratiglioni 2018, Gauthier et al 2021). These conditions are life-limiting and there are no known cures for them at present (Sampson and Harrison Dening 2020). As dementia progresses to its advanced stages, people experience severe cognitive and physical impairment and are increasingly likely to become unable to communicate verbally, to require support with all activities of daily living and to experience urinary and/or faecal incontinence (Kupeli et al 2018). Identifying incontinence and promoting continence are crucial elements in delivering dignified person-centred care for people living with dementia and their family carers across health and social care settings.

Based on projections by Wittenberg et al (2019), it has been estimated that there are 944,000 older people living with dementia in the UK, 593,200 of whom have advanced symptoms. By 2040, the number of people living with dementia in the UK is expected to rise to almost 1.6 million (Wittenberg et al 2019). Although the risk of developing dementia increases with age, dementia is not a normal or inevitable part of ageing (Qiu and Fratiglioni 2018). Furthermore, dementia is not only a condition of older age. Prince et al (2014) estimated that there were around 42,330 people under the age of 65 years living with dementia in the UK.

Urinary incontinence

Urinary incontinence is defined as any involuntary leakage of urine (International Continence Society 2023). It can have various causes and there are several types (Table 1).

Up to 3 million people in the UK experience urinary incontinence (British Association of Urological Surgeons 2023). In addition, between 30% and 40% of people over the age of 65 years, and between 60% and 70% of older people living in care homes, experience urinary incontinence (Suskind et al 2022). This is significant in the context of this article because more than 70% of care home residents have dementia on admission or develop dementia after having been admitted and many are not assessed for dementia or diagnosed with dementia (Organisation for Economic Co-operation and Development 2018).

Faecal incontinence

Faecal incontinence is described as an involuntary loss of solid or liquid stool that represents a social and/or hygiene issue (National Institute for Health and Care Excellence 2022). In the UK, an estimated 6.5 million adults have bowel issues and approximately half a million of them experience faecal incontinence (NHS England 2018). Faecal incontinence is associated with increased age and its prevalence is estimated to be between 12% and 22% among people aged over 80 years (Harari et al 2014).

Similarly to urinary incontinence, people living with dementia are up to four times more likely to experience faecal incontinence than people who do not have dementia and the prevalence of faecal incontinence is higher among care home residents (Goodman et al 2015). This is likely to be linked in part to the high prevalence of dementia in care homes (Organisation for Economic Co-operation and Development 2018) and the fact that care home residents are more likely to live with advanced symptoms of dementia and therefore have continence issues (Kupeli et al 2018).

Faecal incontinence can be caused by severe chronic constipation leading to faecal impaction (British Geriatrics Society 2020). Constipation is common in older people due to factors including polypharmacy, frailty, multimorbidity, suboptimal diet, reduced

Table 1. Main types of urinary incontinence

Urge incontinence (overactive bladder)	» The person is unable to prevent involuntary bladder contractions and experiences a sudden urge to pass urine with little or no warning » Urge incontinence can lead to increased frequency of passing urine
Stress incontinence (pelvic floor weakness)	» The person experiences a small leakage of urine on exertion and physical activities such as standing, coughing, sneezing, laughing, exercising and lifting objects » Stress incontinence is the most common type of urinary incontinence in middle-aged women and is seen in some men after prostatectomy
Overflow incontinence (urinary retention)	» The person is unable to empty or completely empty their bladder » They may have a large post-void residual urine volume and experience continuous dribbling or symptoms resembling those of stress incontinence » Overflow incontinence can be caused by diabetes mellitus and some types of nerve damage » It can also occur in men with prostatic obstruction
Outflow obstruction	» The person has difficulty starting micturition, poor urinary stream and/or dribbling after micturition, perhaps with a feeling of inadequate emptying » Caused by an obstruction that either stops or slows down the flow of urine from the bladder » Outflow obstruction almost always occurs in men and its most common causes are an enlarged prostate, bladder cancer, pelvic cancer, scarring of the urethra and bladder stones
Functional incontinence	» The person is unable to go to and/or use the toilet, for example because of impaired communication, impaired cognition, depression, mobility issues, loss of dexterity, confusion or disorientation

(Adapted from British Geriatrics Society 2018)

Online archive
For related information, visit **nursingolderpeople.com** and search using the keywords

mobility and dehydration (De Giorgio et al 2015). Documenting occurrences of defecation and using the Bristol Stool Chart (Lewis and Heaton 1997) to assess stool consistency can help nurses establish the person's normal bowel pattern and identify evidence of constipation and/or faecal incontinence.

TIME OUT 1

What is your understanding of the relationship between dementia and incontinence? What do you think can cause incontinence in people living with dementia?

Ageing and incontinence

Ageing is associated with physiological and cognitive changes as well as increased risks of comorbidities, side effects of medicines and polypharmacy, all of which increase the likelihood of continence issues (Table 2). As explained above, urinary and faecal incontinence are more common in older people. However, like dementia, incontinence is not a normal or inevitable part of ageing (Spencer et al 2017). When assessing older people for continence issues, it is important to avoid making assumptions based on age or diagnosis and conduct a comprehensive person-centred assessment, with the aim of identifying causes and risk factors, managing incontinence appropriately and promoting continence as much as possible.

Table 2. Age-related changes and risks that increase the likelihood of continence issues

Physiological changes	» Changes in the nerves, muscles and hormones of the bladder can result in diminished sensation and reduced capacity, leading to changes in urinary rate and flow » Changes in skeletal muscle mass and strength can impair the person's mobility and function
Cognitive changes	» The effects of ageing on the brain and cognition are widespread and have multiple causes inclusive of dementia » Some degree of memory decline can occur with ageing. Genetics, hormones and neurotransmitters can affect an ageing brain
Increased risk of comorbidities	» Older people are at increased risk of developing conditions such as diabetes mellitus, heart failure, degenerative joint problems and arthritis, which can increase the likelihood of continence issues » This could be as a result of the condition or medicines prescribed to manage symptoms
Increased risk of polypharmacy	» The increased risk of developing comorbidities increases the risk of polypharmacy, with a subsequent increased risk of medicine side effects » For example, cholinesterase inhibitors prescribed for Alzheimer's disease may cause or worsen incontinence » Diuretics and ACE inhibitors are among some of the medicines that may cause issues with incontinence, as could the interactions between drugs; so a regular medication review is important

(Adapted from Alzheimer Europe 2014)

Dementia and incontinence

People living with dementia have different continence needs than people who do not have dementia (Murphy et al 2022). People living with dementia are disproportionately affected by functional incontinence because of the cognitive and communication impairments associated with dementia (Gove et al 2017, Edwards et al 2021). People who experience functional incontinence may have normally functioning urinary and digestive systems but undergo physiological and cognitive changes that affect their ability to go to and/or use the toilet (Harwood and Cowan 2020).

There is evidence to suggest that the number of people living with dementia who experience continence issues is underestimated, notably because people may not report symptoms to avoid feeling ashamed and being exposed to the perceived stigma around dementia and incontinence (Drennan et al 2013); because people may believe that nothing can be done to address continence issues in a person living with dementia (Gove et al 2017); and/or because people may assume that incontinence is necessarily a symptom of dementia (Aldridge and Harrison Dening 2021).

In the advanced stages of dementia, there is an increased prevalence of incontinence because people's cognition and communication are impaired to the point where their ability to remain continent is affected (Alzheimer Europe 2014, Harwood and Cowan 2020). In the early stages of dementia, however, impaired cognition or communication are not necessarily the primary causes of incontinence (Harwood and Cowan 2020). People living with dementia often have multiple comorbid conditions (Browne et al 2017) – for example, diabetes mellitus, heart failure, degenerative joint conditions, arthritis, chronic lung disease, depression and stroke – and their continence issues may be caused or compounded by these comorbid conditions and/or by the side effects of medicines prescribed to treat them (Aldridge and Harrison Dening 2021).

When assessing older people for continence issues, it is important to consider all the possible underlying causes of changes in the person's ability to remain continent. It should never be assumed that the person has functional incontinence just because they have a diagnosis of dementia or show signs of cognitive impairment (Aldridge and Harrison Dening 2021).

CPD CONTINUING PROFESSIONAL DEVELOPMENT

TIME OUT 2

Reflect on your experience of assessing people living with dementia and incontinence. What difficulties have you encountered in identifying and exploring their continence issues? How did you manage these difficulties? How could you improve your practice in that area?

Identifying continence issues

People living with dementia and their family carers often have complex health, social and emotional support needs, which if left unmet can negatively affect their ability to manage episodes of incontinence effectively. Poorly managed incontinence can compromise a person's dignity and negatively affect not only their physical health but also their emotional and psychological well-being, which in turn can have detrimental effects on their mood, relationships and quality of life (Cole and Drennan 2019, National Institute for Health and Care Research 2022). Family carers and healthcare professionals need to be able to identify the signs that a person living with dementia may be experiencing continence issue (Box 1), since this will increase the chances of them receiving a comprehensive person-centred assessment and subsequent care planning (Aldridge and Harrison Dening 2021).

Family carers as well as people living with dementia may be reluctant to share their concerns regarding continence due to embarrassment and fear of stigma. Furthermore, family carers sometimes feel that healthcare professionals do not understand the challenges of caring for a person living with dementia and incontinence, such as the physical demands of continence care and the emotional demands of managing potentially distressed behaviour when providing continence care (Gove et al 2017).

A study by Drennan et al (2011) found that the needs of family carers who support a person with dementia and incontinence at home are often overlooked, with carers reporting a lack of appropriate support and effective advice from healthcare professionals, inconsistent access to suitable continence products, and a lack of understanding of their needs when considering the appropriateness of continence products. Creating an environment where people living with dementia and their family carers feel safe and comfortable raising concerns regarding continence and where they feel listened to and understood is crucial.

TIME OUT 3

Listen to our podcast on 'dementia and pad culture' in hospitals, which you can access at: **rcni.com/podcast-dementia-and-pad-culture** What potential harm can a 'pad culture' cause? What can be done to change it?

Promoting autonomy and dignity

Research has shown that people living with dementia are often automatically considered to be incontinent and that management is often focused on containment with continence pads, as opposed to identifying and treating any underlying cause and promoting continence (Gove et al 2017, Featherstone et al 2022). Edwards et al (2021), Featherstone et al (2022) and Northcott et al (2022) identified that there can be a 'pad culture' in acute hospitals whereby the routine use of continence pads is the primary management strategy for people living with dementia, even those who are continent and able to mobilise on admission. This 'pad culture' may be driven by safety concerns – for example, concerns regarding falls – but also by ward staff's perception that continence care is burdensome (Featherstone et al 2022).

Acute hospitals are not the only practice area that has been shown to require improvements regarding the management of continence

Box 1. Signs that a person living with dementia may be experiencing continence issues

The person may:

- Spend longer than usual in the toilet
- Have urinary symptoms – for example, frequent urination, rushing to the toilet, hesitancy, itching, dribbling after micturition and pain
- Get up more frequently at night to pass urine (nocturia)
- Change their clothes at unusual times
- Use sanitary towels in the absence of menstruation
- Be reluctant to go out, particularly to unfamiliar places, due to concerns about accessing a toilet
- Have nausea, vomiting or pain – for example, if they are severely constipated
- Start using natural remedies against diarrhoea or constipation
- Be anxious or agitated
- Have suboptimal personal hygiene routines

Other signs:

- Unpleasant odours and suboptimal personal hygiene
- Soiled furniture and/or bedding
- Soiled clothes, bedding or toilet paper hidden or forgotten in strange places
- Changes in the person's frequency of urination and defecation
- Changes in the person's eating and drinking habits
- Changes in the person's behaviour

(Adapted from Alzheimer Europe 2014)

FURTHER RESOURCES

Alzheimer Europe – Improving Continence Care for People with Dementia Living at Home
www.alzheimer-europe.org/sites/default/files/2022-02/Improving continence care Report_Alzheimer Europe_2014.pdf

British Geriatrics Society – Continence Care in Residential and Nursing Homes
www.bgs.org.uk/resources/continence-care-in-residential-and-nursing-homes

National Institute for Health and Care Research – Continence, Dementia, and Care That Preserves Dignity
evidence.nihr.ac.uk/collection/continence-dementia-and-care-that-preserves-dignity/

issues in people living with dementia. In a qualitative study of continence service provision for people with dementia living at home, Murphy et al (2021) identified six factors that negatively affect people's outcomes, three intrinsic and three extrinsic (Box 2). These factors concur with the findings of Drennan et al (2011, 2013) and Alzheimer Europe (2014), which indicated that little has changed in the past decade.

The poorly managed continence needs of people living with dementia can lead to pressure ulcers, urinary tract infections, catheterisation and faecal impaction (NHS England 2018, Edwards et al 2021). Such issues increase the risk of hospital admission and hospital admissions are known to increase mortality and morbidity in people living with dementia (Fogg et al 2017, 2018). Poorly managed continence can also increase the burden on family carers and is often a significant factor in the decision to move people living with dementia to a care home (Young et al 2015, Cole and Drennan 2019, National Institute for Health and Care Research 2022).

Reducing the negative effects of incontinence can improve people's social engagement, reduce the burden on carers and on people's finances, improve relationships and maintain emotional well-being (Gove et al 2017). People living with dementia and their family carers must not be disadvantaged in their access to appropriate specialist support and advice, investigations, treatments and products aimed at managing incontinence and promoting continence (Aldridge and Harrison Dening 2021). Containment should not be the sole focus of management and nurses must consider providing support, care and products that promote the person's autonomy and dignity and enable them to remain independent for as long as possible.

Box 2. Factors that negatively affect outcomes for people with dementia and incontinence living at home

Intrinsic factors
- Cognitive and behavioural issues
- Mobility issues such as joint problems and physiological issues such as bladder and bowel problems
- Psychosocial issues, for example when the person and/or their family carer are reluctant to talk about continence difficulties

Extrinsic factors
- Societal stigma associated with incontinence and inadequate access to toilets in public places
- A care system where there is a lack of skills and knowledge about dementia and incontinence and a lack of access to suitable continence products
- Suboptimal design of continence products and limited choice of products to meet people's continence needs

(Adapted from Murphy et al 2021)

TIME OUT 4

Having read Brian and Marie's fictional case study (Case study 1), reflect on:
- The associated emotional, psychological, physical, practical and relational issues for Brian and Marie
- The risks for Brian and Marie in the short and long term
- The strategies that may help reduce the incidence of incontinence and its negative effects on Brian and Marie
- How you would approach Brian and Marie's case and what support you would provide

Person-centred assessments

In the case of Brian and Marie, the nurse's aim is to support Marie in her caring role and suggest practical strategies to promote continence and reduce the negative effects of incontinence while maintaining Brian's dignity. Incontinence is a stigmatising condition, and given people's possible reluctance to disclose their concerns or seek support (Drennan et al 2013), it is crucial that nurses actively but sensitively enquire about symptoms in known high-risk groups – such as people living with dementia – and discuss potential concerns with family carers (Gove et al 2017). Communication is critical and the language used needs to respect people's dignity and avoid causing embarrassment or distress. It is important to consider people's individual circumstances and listen to the person's and their carer's fears or concerns in a non-judgemental manner.

When assessing continence in a person living with dementia, there is a need to consider wider issues – for example, in Brian and Marie's case, how continence issues affect their relationship and how to maintain Brian's privacy and dignity. The authors suggest that, as part of a comprehensive person-centred assessment, nurses need to consider not only the type of incontinence, its possible causes and risk factors and practical strategies including containment solutions, but also the effects of incontinence and dementia on the person and their carer. Selecting the most appropriate continence product – for example, pull-up pants, slips or pads – is important, since it may support the person and their carer to manage continence and personal hygiene needs independently for longer (Alzheimer Europe 2014).

In Case study 1, Brian is either unaware or does not believe that he has continence

issues. Like Brian, people living with dementia might not recognise or acknowledge their continence needs; they might refuse to be assessed; or they might be found to lack mental capacity to make a decision regarding their continence care. However, even in such cases, nurses can support the person and their family carer by exploring the factors listed in Table 3 and implement subsequent strategies to reduce the effects of continence issues and promote continence.

Table 3 lists factors to consider and enquire about when exploring changes relating to continence in a person living with dementia.

Case study 1. Brian and Marie*

Brian is a 77-year-old man who has recently been diagnosed with vascular dementia. He lives at home with his wife Marie who is 73 years old and has rheumatoid arthritis, leg ulcers and chronic heart disease. Brian is a proud and physically active man who so far has always managed his personal care independently.

Recently Brian has started to urinate in inappropriate places at night, for example in the wardrobe or in a corner of the bedroom. Marie has tried to divert him to the toilet, but he became verbally and physically aggressive, so she now sleeps in the spare room. In the morning, Brian has no recollection of what has happened during the night and asks Marie why she sleeps in the spare room. When Marie tries to explain, Brian calls her a liar and says someone else must be responsible for the nighttime urination. He suggests that she is trying to find excuses to leave him because he has dementia. Marie thinks Brian's behaviour is a symptom of dementia and that nothing can be done about it. Being a private person, she is reluctant to talk to anyone about the situation.

During a home visit, a community nurse notices how tired Marie looks and asks her about this. Marie explains that she is not sleeping well and it must be because of her age. While taking note of Marie's body language and listening to the tone of her voice, the nurse senses that there is 'more to it' and continues to gently ask questions. After pausing for a while, Marie concedes that Brian is getting up frequently at night. She is reluctant to say anything more, so the nurse tries a different approach and mentions that people living with dementia can become disorientated at night and therefore struggle to find the toilet, but that there are potential solutions. Marie then tearfully discloses to the nurse that Brian has been urinating in inappropriate places at night.

The nurse suggests practical strategies Marie could try, for example installing nightlights on the way to the toilet, placing a urine bottle near the bed, reducing caffeine intake in the afternoon and evening, and prompting Brian to use the toilet before going to bed. The nurse asks Marie if she consents to being referred to the local dementia support service and Marie readily agrees.

*Brian and Marie's case study is fictional

Table 3. Factors to consider and enquire about when exploring changes relating to continence in a person living with dementia

What is normal for the person?	» What is the person's normal pattern of urination and defecation? » Has the person had a previous continence assessment? » Have the person's needs changed? » Is the person using the most appropriate continence products for their needs and the needs of their carer?
What might be causing changes relating to continence?	» Has the person's diet changed, for example because of a reduced ability to go shopping or prepare meals? » Is the person getting adequate nutrition and hydration? » Does the person take laxatives or diuretics? Are they taking them as prescribed? » Could the person be constipated? » Is the person taking medicines with sedating effects? » Could the person have an acute health issue, such as a urinary tract infection or gastroenteritis? » Does the person have any known underlying health condition? » Are there other changes in the person's health and well-being? » Has the person's cognition deteriorated? » Is the person experiencing issues with dexterity and coordination? » Does the person take multiple medicines? Do they need a medicines review?
Does the person have communication or sensory needs?	» Does the person have a hearing or visual impairment? » Does the person use or need hearing aids or glasses? When were these last checked? » Does the person find it challenging to communicate verbally? Do they use non-verbal modes of communication? Are there any non-verbal cues that can facilitate communication with the person? » What is the person's first language?
Does the person have mobility issues?	» Is the person in pain when mobilising? » Does the person have the appropriate mobility aids? » Can the person safely access the toilet? » Would the person benefit from equipment such as a urine bottle, a commode, a toilet raiser and/or grab rails?
Is the environment appropriate?	» Does the person get disorientated? If so, would a sign on the toilet door help? » Is there appropriate lighting on the way to the toilet and in the toilet, particularly at night? » Does the person have visuospatial issues? If so, would a coloured toilet seat help? » Are there any pieces of furniture that make it more difficult for the person to access the toilet? If so, could they be removed?
What are the emotional and psychological effects on the person and their carer?	» What effects is incontinence having on the person's relationships, in particular with their family carer? » Is the person able to maintain intimacy with their partner or spouse? » How is incontinence affecting the person's and their carer's mood? » Are the person and/or their carer experiencing increased anxiety?
Does the person and/or their carer need social support?	» Does the person and/or their carer need support with: — Using the toilet? — Preparing meals and drinks? — Personal care? — Taking medicines? » Have the carer's needs been assessed? » Have the person and their carer been given information and advice on dementia and its effects?
Does the person need to be referred?	Does the person need to be referred to a GP, a pharmacist, a social worker, an occupational therapist, a physiotherapist, a continence nurse, a dementia support worker, a dementia nurse specialist, a dietitian, a district nurse and/or a psychotherapist?

(Adapted from Aldridge and Harrison Dening 2021)

Conclusion

In the early stages of dementia, incontinence can be caused or compounded by comorbid conditions and the side effects of medicines. In the advanced stages of dementia, cognition and communication may be impaired to the point where people are no longer able to remain continent. Nurses have an important role in identifying continence issues in people living with dementia and in assessing people's continence needs, which often involves in-depth discussions with family carers. Nurses' role in supporting people living with dementia and their carers to manage incontinence also involves suggesting practical strategies and referring people to specialist support. Containment should not be the sole focus of management and nurses must consider providing support, care and products that promote the person's autonomy and dignity and enable them to remain independent for as long as possible.

TIME OUT 5

Identify how promoting continence in people living with dementia applies to your practice and the requirements of your regulatory body

TIME OUT 6

Now that you have completed the article, reflect on your practice in this area and consider writing a reflective account: **rcni.com/reflective-account**

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Continence in people living with dementia

TEST YOUR KNOWLEDGE BY COMPLETING THIS MULTIPLE-CHOICE QUIZ

1. As dementia progresses to advanced stages, people living with the condition are increasingly likely to:

a) Communicate verbally ☐
b) Experience urinary and/or faecal incontinence ☐
c) Perform all activities of daily living without support ☐
d) Have no severe cognitive and physical impairment ☐

2. A person who has functional incontinence:

a) Cannot prevent involuntary bladder contractions and experiences a sudden urge to pass urine ☐
b) Cannot go to and/or use the toilet ☐
c) Experiences a small leakage of urine on exertion and physical activities ☐
d) Has difficulty starting micturition, poor urinary stream and/or dribbling after micturition, perhaps with a feeling of inadequate emptying ☐

3. Which of the following statements is false?

a) Dementia is not a normal or inevitable part of ageing ☐
b) Ageing is associated with physiological and cognitive changes that increase the risk of continence issues ☐
c) Incontinence is a normal and inevitable part of ageing ☐
d) Urinary and faecal incontinence are more common in older people ☐

4. Which of the following is a reason why the number of people living with dementia who experience continence issues may be underestimated?

a) People may not report symptoms to avoid being exposed to perceived stigma ☐
b) People may believe that nothing can be done to address continence issues in a person living with dementia ☐
c) People may assume that incontinence is necessarily a symptom of dementia ☐
d) All of the above ☐

5. Poorly managed incontinence in a person living with dementia can:

a) Compromise the person's dignity ☐
b) Increase the chances of the person receiving a comprehensive person-centred assessment ☐
c) Have beneficial effects on the person's mood and quality of life ☐
d) Decrease the person's risk of hospital admission ☐

6. Signs that a person living with dementia may be experiencing continence issues are unlikely to include:

a) Spending longer than usual in the toilet ☐
b) Getting up more frequently at night to pass urine ☐
c) Being increasingly willing to engage in social activities ☐
d) Hiding or forgetting soiled clothes, bedding or toilet paper in strange places ☐

7. Which statement is true of family carers for people living with dementia and incontinence?

a) They are never reluctant to share their concerns regarding the person's continence ☐
b) They do not seem to think they face specific challenges ☐
c) They report a lack of understanding of their needs in considering the appropriateness of continence products ☐
d) They think that healthcare professionals understand the demands of what they do ☐

8. According to Murphy et al (2021), which of the following does not negatively affect outcomes for people with dementia and incontinence living at home?

a) Societal stigma associated with incontinence ☐
b) The person's and/or their family carer's reluctance to talk about continence issues ☐
c) A care system where there is a lack of skills and knowledge about dementia and incontinence ☐
d) Suboptimal design and choice of continence products ☐

9. Which of the following factors should be considered when conducting a person-centred assessment of a person living with dementia and incontinence?

a) Possible causes of and risk factors for incontinence ☐
b) Practical strategies including containment solutions ☐
c) The effects of incontinence and dementia on the person and their family carer ☐
d) All of the above ☐

10. Which of the following strategies is unlikely to promote continence?

a) Helping them to get fully dressed before they go to the toilet ☐
b) Putting a sign on the toilet door ☐
c) Having appropriate lighting on the way to the toilet and in the toilet ☐
d) Installing a coloured toilet seat ☐

How to complete this assessment

This multiple-choice quiz will help you test your knowledge. It comprises ten multiple choice questions broadly linked to the previous article. There is one correct answer to each question.

You can read the article before answering the questions or attempt the questions first, then read the article and see if you would answer them differently.

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This multiple-choice quiz was compiled by Anne-Claire Bouzanne

The answers to this quiz are:

1.b 2.b 3.c 4.d 5.a 6.c
7.c 8.b 9.d 10.a

This activity has taken me ___ minutes/hours to complete. Now that I have read this article and completed this assessment, I think my knowledge is:

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As a result of this I intend to: _____

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For example: Nursing and Midwifery Council (NMC) at first mention, NMC thereafter. Articles that refer to policy or legislation must state the country to which it applies.

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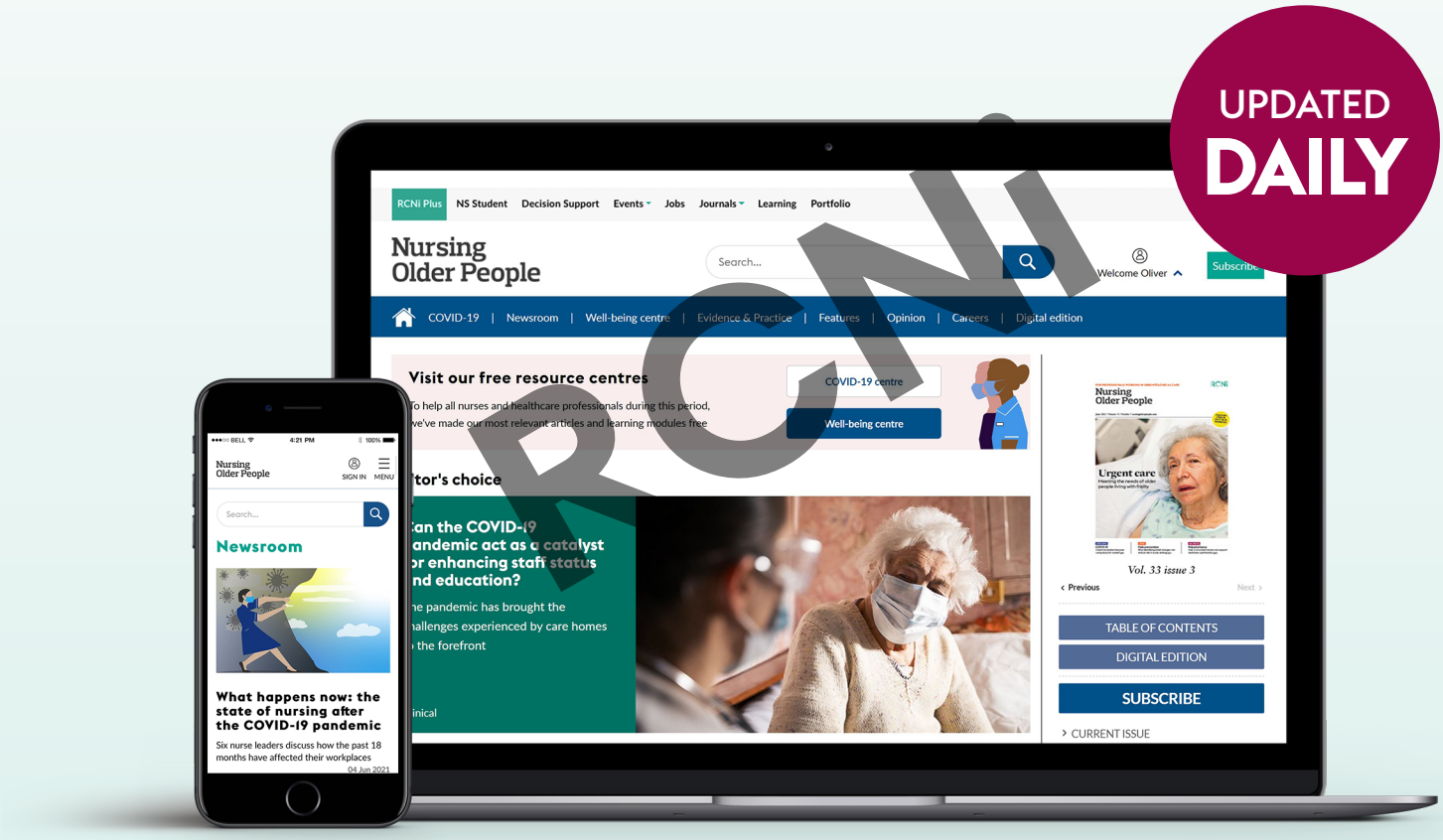

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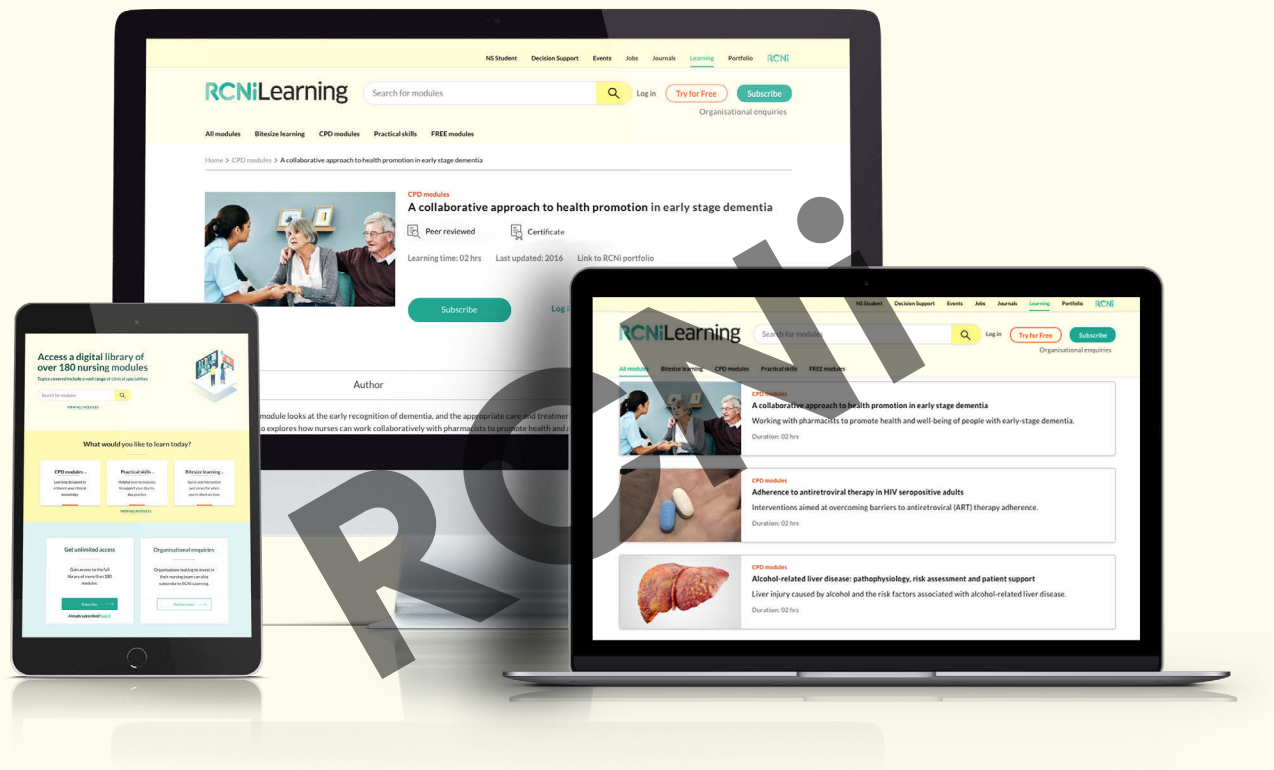

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