

The untapped potential of the student nurse

Rebranding reinforces the QNI's commitment to the community

Issues in asthma treatment and diagnosis: new guidelines

Back on track: tackling the problem of toilet training

Falls management in care settings and the community

Idiopathic pulmonary fibrosis: an overview

Tension location: putting theory into practice

Understanding wound malodour: patient and clinician perspectives

HCPs' attitudes regarding current wound care treatments

Purple urine bag syndrome: what community nurses should know

Mental health first aid: a role for community nurses

Parkinson's disease at end of life: a guide for community nurses

Short exploration of the psychological stresses of type 2 diabetes



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References: 1. NHS Improvement (2018) Pressure ulcers: revised definition and measurement summary and recommendation. The S.M.A.R.T. Resource is the property of Medicareplus International and supports the implementation of recommendations in the NICE guidelines on: Pressure Ulcers: Prevention and Management (CG179), Urinary Incontinence and Pelvic Floor Organ Prolapse in Women: Management (NG123), Faecal Incontinence in Adults: Management (CG39) December 2019.

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Supporting student nurse community placements



The 'community matters' feature in this issue is definitely worth taking time to read (pp. 8–12). It discusses student nurses and the value that each and every one of them brings to our practice and workplace. I am sure we have all felt an additional pressure to the ever increasing demands on our time and workload when we are allocated a student nurse to assess or supervise. There is no doubt about it — students can be challenging, but this is positive for us as well as our patients and workplaces. We are

all continually learning and students are receiving knowledge based on the latest available evidence, which can support our own development. Their questions are a catalyst for reflection on our own practice and can instigate change, thus enhancing patient care. Remember — we have all been a student at some point in our careers and without the support, guidance and experiences we had, we would not be where we are today.

Community nursing is such a diverse field, as seen by the range of topics covered in this issue. From falls management and idiopathic pulmonary fibrosis to type 2 diabetes and the lesser-known condition of purple urine bag syndrome (PUBS), the scope of care is huge. Mental health first aid (MHFA) is another role that community nurses should familiarise themselves with and be trained in to ensure that mental health does indeed receive the same recognition as physical health (pp. 50–54).

End-of-life care for patients with Parkinson's disease also falls within the community nurse's remit, presenting unique challenges in delivering patient-centred care while supporting carers as the disease progresses. As Victoria Bartlett highlights (pp. 56–61), nurses are pivotal to the interdisciplinary team, ensuring compassionate and holistic care.

As always, the JCN study days are rolling out around the country this year. Don't forget to check when we are in your area, as they are a great way to hear experts speak, meet exhibitors and discuss latest products and treatments and, of course, to network and catch up with colleagues — www.jcn.co.uk/events.

I hope that you enjoy reading this issue as much as I did and that you find it useful for your day-to-day practice. If there are any areas that you would like to see covered, please just get in touch.

Annette Bades, editor-in-chief, JCN

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References: 1. Djokic-Gallagher J. *et al.* Steroid-sparing effects and acceptability of a new skin gel containing the anti-inflammatory medicinal substance-nicotinamide. *Clinical, Cosmetic and Investigational Dermatology* 2019;12:545-552. 2. Gallagher J. *et al.* Performance of Adex Gel: A retrospective survey of healthcare professionals with an interest in dermatology. Data presented at the Austrian Society for Dermatology and Venereology (OGDV) Science Days, September 2022, Bad Gastein, Austria.

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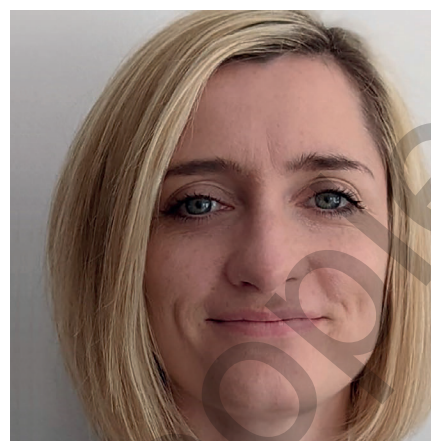
I am a clinical research advisor, district nurse and Queen's Nurse. I am passionate about community care and developing evidence-based care to provide better outcomes for patients and amplifying the patient voice via qualitative research. I am pleased to be part of the JCN editorial board as the journal provides an accessible platform for community nurses to learn, discuss and share clinical practice.

Hannah Brady Sawant



I am a senior lecturer with a background in district nursing, continuing healthcare (CHC) funding, palliative care and diabetes. I feel privileged to be able to influence the future district nursing workforce and love my job! I am passionate about innovation and encouraging district nurse students to reach their full potential. The JCN has been an integral part of my nursing career, with attendance at many JCN events and study days and the contemporary learning gained from reading each issue. The JCN published my first article and gave me the confidence to write more. A thirst for knowledge is fundamental in primary care, and this excellent free resource cannot be overstated. I am honoured to be part of the JCN editorial board.

Teresa Davies



I am a community nurse with a background in urgent community response. I am currently working as a senior lecturer and am passionate about raising the profile of community nursing (in all its forms) within pre-registration healthcare education. I am proud to be a Queen's Nurse and a non-medical prescriber and have a special interest in prevention of hospital admission, advanced physical assessment and multidisciplinary working. I am delighted to be joining the JCN editorial board and relish the opportunity to be a part of the ongoing conversation on developments in community nursing.

Abigail Brooks



As an advanced nurse practitioner focusing on chronic disease in Bristol, I am delighted to join the JCN editorial board. Sharing experience and knowledge within the community has become an important process with developments coming in nationally and internationally, and I am keen to be part of making the process easier and more accessible for clinical staff. I hope that my experience of community and primary care, which includes working for a festival charity providing medical cover in a field, a very different setting to that of a clinic, and as an expert witness for civil litigation, can contribute to JCN.

Wendy Smith

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In each issue of the *Journal of Community Nursing*, we investigate a topic affecting our readers. Here, Bethan Bridges, adult nurse lecturer, Cardiff University, looks at...

The untapped potential of the student nurse

With all the demands on the time of community nurses, being allocated a student can often be perceived as a mandate that does not bring any immediate benefit to the supervisor, assessor and wider team. The supervision of students in the community requires one-to-one observation, which can limit the nurse's feeling of personal autonomy. Students also require documentation to be completed to evidence learning and consideration of their individual learning needs, all of which take time. Although this role is a requirement of registered nurses, it is rarely given any protected time due to workload pressures.

Students can return from practice with reports of having had a great observational experience and the opportunity to absorb the knowledge and skills of busy qualified nurses. However, they also commonly feed back that there is a difference between the theory which they are taught in university and the practice that they are seeing in clinical areas. The author has particularly noted this with regards to wound care and aseptic non-touch technique (ANTT), with different approaches and adaptation of skills to suit different environments and patient needs. The knowledge-practice gap is well documented in the literature (Gassas, 2021), as is the negative response received by students who question this gap while in the clinical area. As a professional skill, education providers should encourage students to challenge practice, as this has numerous benefits both for them and healthcare, namely:



We must remember that student nurses are the future of the profession. As cheesy as this sounds, it is inherently true and an important concept for the community nursing workforce to remember. It is acknowledged that there are currently significant challenges in practice with increasing focus on care delivery at home, and limited investment and workforce to meet the demand. This overwhelm can make it hard to see how to effectively support student education, but it is essential for creating a sustainable workforce in the future. Representation matters — when students experience successful community placements, learn from community nurses, and engage in education beyond secondary care, they are more likely to consider it a viable career path. Without this exposure, community nursing risks being overlooked.

As mentioned within this article, community placements provide invaluable opportunities for students to develop autonomy, clinical decision-making, problem-solving, adaptability, and communication skills. Seeing the impact of community nursing first hand helps shift misconceptions and highlights its complexity and value. In my experience, student nurses bring fresh perspectives and up-to-date knowledge, allowing them to positively challenge practices and contribute to the continuous improvement of patient care.

Their curiosity and willingness to question can help ensure that care remains safe, effective, and evidence-based. None of us are above being questioned, and being open to this dialogue and encouraging this criticality builds student's confidence and competence too, ensuring that they enter the workforce prepared to deliver high-quality care closer to home. Ultimately, being open to supporting students within community settings strengthens the nursing profession — something that we all want and need for the future of healthcare.

Abigail Brooks

Senior lecturer in adult nursing, University of West London; Queen's Nurse



I have been a senior lecturer teaching pre-registration nursing for more than 20 years of my career and the Queen's Nursing Institute (QNI) advocates students to experience placements in all community settings, as there is no need for students to work in secondary care prior to working in community, primary or social care on qualifying. Students do need guidance on what to expect in the community and the difference they will experience, as visiting people at home 1:1 all day with a supervisor/assessor can be exhausting, for them and their supervisors/ assessors. However, student nurses really value the community experience, feeling involved and connected with one to one mentoring, but more importantly seeing how care in a person's home is really personalised (Meeley, 2021).

Accessing enough community placements for the number of students has been challenging for the longest time, and alternative approaches to primary care (<https://qni.org.uk/leeds-primary-care-student-leadership-placement/>), social care settings (<https://qni.org.uk/51302-2/>), and other community placements have contributed to widening the experience for students (<https://qni.org.uk/exploring-non-traditional-nursing-placements-my-experience-with-the-community-clinical-education-team/>, <https://qni.org.uk/my-experience-with-specialist-community-heart-failure-nurses/>) — with these experience showing how valuable students find community placements.

As these blogs show, the value of such placement leads to improving the understanding between settings and has affected direct recruitment of nurses into a role that they may not have known about before.

Amanda Young

Director of Nursing Programmes (innovation and policy), Queen's Nursing Institute (QNI)

Meeley RN (2021) Undergraduate student nurses' experience of their community placements. *Nurse Education Today* 106: 105054. Available online: www.sciencedirect.com/science/article/pii/S0260691721003117



► **Promotes evidence-based practice:**

- Challenging outdated or unsafe practices can lead to improvements in care by encouraging the use of current evidence-based guidelines
- It ensures that care delivery aligns with the latest research, standards, and protocols

► **Enhances patient safety:**

- Questioning practices that seem unsafe, unethical, or inefficient helps identify and address potential risks to patients
- It creates a culture of vigilance and accountability, reducing the likelihood of errors

► **Fosters critical thinking:**

- Encouraging students to critically evaluate and question practices sharpens their analytical and problem-solving skills
- This mindset helps them become proactive and reflective practitioners



It was great to read such a positive article from Bethan about student nurses; they have so much to offer in being creative and curious, supporting us all to develop practice. They also bring new learning, as sometimes keeping up with research is a challenge. Community nursing teams provide such a great educational experience, and students are exposed to services outside hospital settings.

I worked with the Health Education England placement expansion project with my local training hub, and capacity was always an issue. Placing students was like a jigsaw, sometimes with too many pieces.

Looking outside both community and secondary care to primary and social care was a great learning opportunity. As only a small amount of care is provided in the hospital, it's vital for rounded training for students to understand the whole of care provision. It's also great for future recruitment, in particular primary care.

Placement expansion with Collaborative Learning in Practice (CLiP) was trialled locally with year 3 students supporting year 1 and 2 students to increase capacity. In some areas, there were great results; however, workload didn't always allow for employees to provide the educational support needed.

Funding for supporting training needs to reflect the medical training model, where training practices have additional funding.

We all need to play a part in developing our future nurses, and using our experience is key to equipping all students who are the professionals of the future.

Wendie Smith

Advanced nurse practitioner, Bristol; Queen's Nurse

► Supports a culture of learning and improvement:

- A willingness to question and learn promotes a culture where innovation and improvement are welcomed
- It helps challenge the 'we've always done it this way' mentality, fostering continuous growth in healthcare

► Empowers students as future leaders:

- Encouraging students to voice concerns and suggestions builds confidence and advocacy skills
- These qualities are essential for leadership roles and interprofessional collaboration

► Encourages ethical practice:

- Nurses have a professional and ethical obligation to advocate for patients and ensure their care is of the highest standard
- Challenging inappropriate or suboptimal practices demonstrates integrity and adherence to ethical principles

► Prepares for real-world challenges:

- Healthcare environments are complex and ever-changing. By learning to challenge practice constructively during training, students are better prepared to navigate and influence the dynamic landscape of clinical practice.

The previously discussed demands on the time of community clinicians makes it hard, in the author's opinion, to release nurses for educational development and also means that qualified nurses have no time to read and apply the most recent evidenced-based care — potentially meaning that care being delivered is not up to date.

Furthermore, the benefits of hosting students is under appreciated and often treated with negativity in practice. However, if we could change the rhetoric there are so many benefits to hosting students in clinical areas.

ORGANISATIONAL BENEFITS

There are several ways that student nurse placements can benefit organisations, such as:

- **Future recruitment:** hosting students creates a pipeline for recruiting well-prepared and familiar staff after graduation. A positive student experience will ensure that students are well prepared to meet the demands of the clinical area once qualified
- **Skilled workforce:** students bring fresh knowledge from academic settings, helping to upskill and inspire the current workforce
- **Encourages a culture of learning:** students can be empowered to challenge practice, bring fresh ideas and encourage clinicians to think about their own practice. They can also ensure the links between academic institutions and clinical areas to foster growth and innovation
- **Supports evidence-based practice:** students bring the latest research knowledge into practice keeping clinical areas



The role of the community nurse is uniquely exciting and rewarding but also at times challenging. There is undoubtedly the opportunity to make a real difference to the individuals and patients we care for and also to have a positive benefit on patients, families and their communities, often over many years of interaction and practice within the community arena.

When I was asked to contribute to this article, I spoke to first- and third-year student nurses in both the mental health and adult health fields that I was teaching. These were ad hoc conversations with no prior agenda. The student nurses' responses about community nursing included revealing adjectives such as '... exciting, interesting, a slower pace, the way nursing is going, more of us will be nursing in the community in the future and it is where I plan to work...'. These sentiments were echoed more than once, even from student nurses who had originally planned to be working in inpatient settings.

However, community nursing is not without its challenges, and adding teaching and supporting student nurses adds to its complexity. Provision and change need to be accommodated within education, including introducing students to the community arena earlier and explaining how community nursing differs from inpatient settings. Such conversations should cover how you are becoming a guest in the individual's home and that a change of power balance is to be expected, as well as how competencies can be achieved in the community arena — all of which can help students to feel enabled, as the community setting can be unsettling for them initially.

Community practitioners need additional support, training and time, which needs to be protected, to support student nurses. This will ensure that they have an excellent community experience and may well encourage them to be future community practitioners. This may require changes to working patterns, skill reviews, and a review of resource allocation, including funding, training and support for practice supervisors.

Changes of emphasis within education and the practice arena would help to enhance the student nurses' experience and reduce some of their anxiety. Such actions would also improve the opportunity for community nurses, especially having the time to teach student nurses within the complex and challenging area of community nursing. Such steps could also contribute both to retention and recruitment within the community nursing arena.

Teresa Burdett
Principal academic, Bournemouth University



aligned with current evidence and standards.

PATIENT BENEFITS

Mentoring students in the community team can also provide benefits to patients, i.e:

- ▶ Increased hands-on assistance: supernumerary students can perform tasks under supervision, helping to ease workloads and improve care delivery. They are able to act as the second nurse in many situations reducing the load on the team
- ▶ Patient satisfaction: literature supports that patients appreciate contributing to the education of

future healthcare professionals and doing so provides them with a sense of involvement (Dijk et al, 2020)

- ▶ As said, students have access to university resources, including library and research access and national clinical skills guidelines, enabling them to bring up-to-date evidenced-based care into practice.

NURSE BENEFITS

The benefits to nurses from working alongside and supervising students should be noted, such as:

- ▶ Skill enhancement: acting as a supervisor/assessor to student nurses strengthens leadership, teaching and mentorship skills, which are essential for career advancement. The opportunity to advance communication skills through teaching and providing constructive feedback is valuable in any management role and also in direct patient care. Supervising a student allows nurses to enhance their critical thinking, through reflection on practice, honing their clinical reasoning skills
- ▶ Continuous learning: working with students allows supervisors to keep up-to-date with evidence-based practice and consider fresh perspectives. Having your practice scrutinised can be uncomfortable, however, the opportunity to learn from those challenges are far reaching. The field of nursing is constantly changing and, as said, students have access to the latest research and evidence
- ▶ Opportunities for career progression: active engagement with supervisory and assessment roles show commitment to professional development. The skills learnt open doors for promotion, management and leadership, as well as positions in education
- ▶ Job satisfaction: supervising students allows supervisors to shape the future of nursing by encouraging the desirable attitudes and behaviours to be developed during training, potentially creating the perfect

future colleague. There is also a huge sense of pride that comes from passing on your knowledge and skills and witnessing students grow in competence and confidence under your supervision

- ▶ Personal growth: supervision of students enables nurses to pass on their knowledge and skills, allowing them to recognise their expertise and grow in confidence. The supervision role provides opportunities to use new and underdeveloped skills, which when achieved, bring a huge sense of satisfaction. Balancing the student support role alongside clinical roles develops time management and adaptability skills
- ▶ Networking opportunities: acting as a supervisor/assessor involves collaboration with academic institutions and therefore broadens professional networks, bringing new opportunities to careers.

TEAM BENEFITS

Finally, there are overall advantages to the multidisciplinary team from supporting and supervising student nurses in the community setting:

- ▶ Enhanced collaboration: building an environment that is optimal for supporting students can provide a sense of collaboration to support learning collectively. The role modelling for team members should not just come from supervisors and assessors, but the whole team. Students are observing how the team works together and supports each other day to day and in challenging situations. This observation allows students to decide whether this is somewhere they would like to work in the future. We all know a well-staffed team is a much happier team
- ▶ Fresh perspective: if the team is open to it, students can question established practice and bring fresh ideas. These can help to focus clinical supervision, allowing the team to reflect and discuss, leading to innovations in practice. This can be encouraged by:

- Providing a safe environment: create a culture where questioning is not only allowed but encouraged, without fear of retaliation or judgment
- Having supportive supervisors: employers need to recognise the value of the student supervision role and provide time for supervisors to support students
- Education and training: teach students how to challenge practices respectfully and constructively
- Reflective practice: encourage a team approach to reflective practice using it for clinical supervision. Anyone can bring a challenge to the table.

By challenging practices, student nurses contribute to a healthcare environment that values growth, safety, and the wellbeing of patients and staff alike.

As a lecturer in nursing, the author is continuously challenged by her students. The sessions she delivers are evidenced-based and well considered underpinned by her experience and what the literature says. However, students continue to surprise her by asking questions that change her perception or introduce new methods of practice, which they have either witnessed as a student or through their personal experience and interests. This is one of the author's favourite things about being a nursing lecturer, as she can never assume that she is the most knowledgeable in the room, making her strive to be better. **JCN**

Acknowledgement

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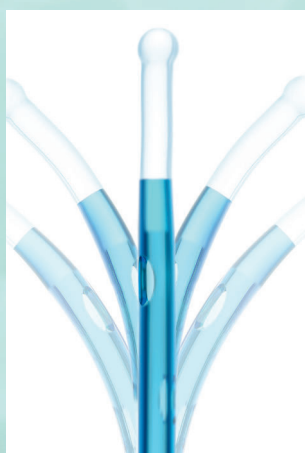
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Matthew Bradby, head of communications, Queen's Institute of Community Nursing (QICN)

In March 2025, The Queen's Nursing Institute (QNI) announced its new name, The Queen's Institute of Community Nursing (QICN).

The change of name highlights the organisation's commitment to promoting and supporting community nursing across England, Wales, and Northern Ireland.

The new name was granted by supplemental Royal Charter and is actually the fourth name of the charity since it was founded in 1887, in the reign of Queen Victoria. Nursing pioneer, Florence Nightingale, was instrumental in the creation of the charity, along with the philanthropist, William Rathbone, who had pioneered district nursing in Liverpool.

The rebranding includes a refreshed logo and an updated website which will serve as a central hub for resources, news, and opportunities for nurses working in all settings and fields of practice in the community, including primary care and adult social care. The new website home page is: www.qicn.org.uk. A more thorough refresh of the website will happen a little later this year.

Dr Crystal Oldman CBE, chief executive of the QICN, said:

Our new name more accurately reflects our mission and the vital role community nurses play in delivering high-quality

Rebranding reinforces the QNI's commitment to the community

patient care. This rebrand — an evolution not revolution — is a testament to our dedication to supporting and empowering community nurses and the individuals, carers, families and communities they serve. We hope you join us in celebrating this new milestone in the development of the organisation and we look forward to working together, as we continue to raise the profile of nursing in the community.

NEW CHIEF EXECUTIVE

The QICN has also announced the appointment of a new chief executive, who will succeed Dr Oldman in summer 2025.

Steph Lawrence has had a distinguished career as a nurse leader at regional and national level. Steph was previously chief nurse at Leeds Community Healthcare NHS Trust. She also spent three years working at the Care Quality Commission (CQC) as the national professional adviser for community services. Steph led the national trailblazer group for the district nurse apprenticeship standard, which is now being delivered in many English universities. She also co-chaired the clinical reference group for the National Community Nursing plan for several years.

Steph was born and has spent most of her working life in Yorkshire. She has been a nurse for more than 37 years with the last 22 years spent working in the community. As well as being a registered nurse for adults, she also holds qualifications in children's nursing, district nursing

and advanced practice and is a non-medical prescriber. In 2022, she received an MBE for services to district nursing.

NEW GARDENS AND HEALTH PROJECTS ANNOUNCED

The Queen's Institute of Community Nursing (QICN) has announced the latest group of nurse-led innovation projects.

The projects are all led by community nurses in various specialisms and will focus on the potential of gardens to improve the physical and/or mental health of a particular group of people. Each of the projects will benefit from up to £5000 in funding, and a year-long programme of support from the QICN.

The five projects are part of the National Garden Scheme (NGS) Elsie Wagg innovation scholarships, supported by the NGS, and are part of the QICN's wider community nurse innovation programme.

Dr Amanda Young, the QICN's director of nursing (innovation and policy) said:

The competition for this year's programme was very strong, with nearly 30 applications for the five funded places. This shows just how important this programme has become, and the appetite among community nurses to improve people's health in a sustainable and imaginative way. The QICN is perfectly placed to bring these nurses together and to nurture their ideas with a year-long programme of expert support.

The Elsie Wagg scholarships are named after the QICN council member whose inspiration led to the creation of the NGS in 1927.

The shortlisted projects were interviewed online by the QICN and the NGS, but most of the programme is delivered in person face-to-face: the QICN also organises site visits to all the projects during the year.

The launch workshop was held in London in March 2025. The gardens and health projects are being delivered alongside two nurse-led diabetes projects funded by the Burdett Trust, using the same overarching principles to achieve success. Final reports of all the projects will be presented early in 2026.

Project Summaries

The Circle Garden Haven

Leader, Kathy Pelc, Sutton Health and Care:

As we know, spending time in nature and in a garden, and with other people, has a positive impact on our physical and mental health. My project aims to bring mothers and their babies together in a group within the garden of the local library, where mothers are experiencing mild to moderate depression or anxiety. Through meeting weekly and developing the garden area it is hoped that this will bring about a positive change to their mental health and wellbeing. It will also

support the local environment and would be a haven for staff and the general public.

Twinwoods Sensory Garden

Leader, Simone Mingay, East London NHS Foundation Trust:

Outside wheelchair accessible space for our clients and staff. (Presently neither group can access being outside comfortably as there is nowhere to sit.) Our clients have high sensory needs; they will be able to experience a sensory pathway providing a range of smells, textures, colours and underfoot variation. We will create an area for workshops outdoors for art and nature projects. The workshops will aid health and well-being by providing access to fresh air, colour and a range of sensory experiences. A sense of achievement inducing increased well-being, will come from producing sustainable art for this space.

Using Nature to make Connections

Leader, Claire Norman, Ty Llidiard, Princess of Wales Hospital, Bridgend, Wales:

The project will bring together service users within the specialised services directorate to support their emotional health and wellbeing. The directorate consists of teams from early intervention psychosis, integrated autism service, eating disorder, perinatal and veterans service. Through

collaboration of these diverse groups, we will reduce feelings of isolation, promote skill development, ultimately boosting confidence and self-esteem. The refurbishment of the gardens within the hospital setting will provide a therapeutic space for all users, encouraging relaxation and social interaction. The aim is this will provide a sense of connection amongst participants.

Supporting Women with Horticulture

Leader, Emma Beniston, HMP Styal, Cheshire:

Within HMP Styal, over 90% of the population enter the prison with primary care level anxiety and depression. We have developed the social prescribing pathway to offer complementary and also alternative routes to prescribed medication where appropriate. The social prescribing pathway refers our women to a horticulture programme where they can grow home grown vegetables, take part in flower planting/arranging and other mindful activities with nature at the centre of the pathway, as we know how much nature can influence an individual's mental and as a result overall physical health. This will also support patients in prison experiencing menopause.

Gardening For Growth

Leader, Linda Antunes, Bridge House, Stockton-on-Tees:

We have numerous goals for this project, because we believe that it could be incredibly transformative for our residents. In the first instance, we hope to improve our residents' mental health, by reducing isolation, encouraging ownership, and increasing their exposure to nature. We also hope that by getting them involved in gardening, we can improve their physical health, because they will be doing both cardio and strength exercise. In addition to the health improvements for those directly involved in the project, we also hope to create outdoor spaces that will improve the health and wellbeing of future residents.



'Botanical Brothers' project, Newham, NGS Elsie Wagg scholarship, 2024.



Dr Andy Whittamore, GP and clinical lead, Asthma + Lung UK

Issues in asthma treatment and diagnosis: new guidelines

After a long wait, and years after updated international guidelines, the National Institute for Health and Care Excellence (NICE) has worked with the British Thoracic Society (BTS) and the Scottish Intercollegiate Guidelines Network (SIGN) to produce a unified guideline on asthma for the UK (NICE et al, 2024).

It comes at a time when seven out of ten people with asthma are not receiving the basic care they need to stay well, often resulting in their condition being uncontrolled and leaving them at risk of life-threatening asthma attacks. In fact, the number of asthma deaths has actually risen over the past decade (<https://ow.ly/zA1750V5ZRY>; <https://ow.ly/OycP50V5ZS0>; <https://ow.ly/TIe250V5ZSQ>).

To change this, it is vital that we improve awareness of the seriousness of asthma, and focus on supporting people to manage their condition themselves. Healthcare professionals also need to have the training, time and resources to understand each individual to ensure that they get the basic care they need.

Good asthma care can really help people get a handle on their condition, so that it has a minimum impact on their day-to-day lives.

The new guidance addresses some of these issues, bringing important changes that are relevant for every single clinician in contact

with people with asthma. It has the potential to make a real difference to the 7.2 million people in the UK living with asthma, offering clarity on how to diagnose and manage asthma, and a chance to refocus on what should be done at each step of the patient pathway.

Several recommendations will need time to filter through to the NHS. For example, funding mechanisms will need to catch up with these guidelines so that fractional exhaled nitric oxide (FeNO) testing and spirometry can be made uniformly available to patients. In addition, the current Quality and Outcomes Framework (QOF) rules on diagnosis are based on an older version of the guidelines.

KEY UPDATES AND HOW TO PUT THEM INTO PRACTICE

Diagnosis

The changes seen within this guideline are centred around taking, and documenting, a clinical history. This should outline any respiratory symptoms, their triggers and any risk factors for developing asthma. Alternative causes of the symptoms should also be explored. Anyone for whom asthma is being considered must be read-coded as having suspected asthma, to support future decision-making.

If asthma is suspected, the patient should have testing to confirm it. A single positive objective test is enough for diagnosis. Any negative test does not rule out asthma. Because of the variable nature of asthma, these tests are more likely to be positive in someone with asthma when they are symptomatic.

The guidelines therefore suggest performing these tests at acute presentations where asthma is suspected or as soon as possible after.

The first test should ideally be a test for eosinophilic inflammation. FeNO is now recommended as the first-line test for adults and children over five years, with blood eosinophil count an alternative option in adults. In the acute presentation, spirometry or peak flow with bronchodilator reversibility are options highlighted within the guideline.

If asthma is not confirmed by eosinophil count or FeNO level, measure bronchodilator reversibility (BDR) with spirometry.

Where spirometry is not available or it is delayed, measure peak expiratory flow (PEF) twice daily for two weeks looking for evidence of mean diurnal variability of 20%.

If asthma is not confirmed by eosinophil count, FeNO, BDR or PEF variability but still suspected on clinical grounds, children should have skin prick testing for house dust mite sensitisation or arrange a blood test for total immunoglobulin E (IgE) level and blood eosinophil count. In all ages, where tests are negative and asthma is suspected, refer for consideration of a bronchial challenge test. The exception to this is in children, where you can exclude asthma if there is no evidence of sensitisation to house dust mite on skin prick testing or if the total serum IgE is not raised.

Treatment

The main headline here is that patients diagnosed with asthma

should no longer be prescribed short-acting beta-agonists (SABAs) alone.

There are clear data that unopposed or excessive use of SABAs increase risk of asthma attacks and death (Levy et al, 2024). The new guidance makes it clear that no one should be prescribed a SABA without also being prescribed a regular inhaled corticosteroid (ICS).

Specifically, those over 12 with an initial diagnosis should be offered a low-dose ICS/formoterol combination inhaler as needed for symptom relief (anti-inflammatory reliever [AIR] therapy), or low-dose maintenance and reliever therapy (MART) if highly symptomatic.

Formoterol is a long-acting bronchodilator which works as rapidly as salbutamol and is as effective in treating acute symptoms. In a combination inhaler with an ICS, when used as a reliever inhaler, the ICS-formoterol relieves the acute symptoms while also addressing the underlying inflammation which causes the symptoms in the first place. This approach allows titration of the preventer medication in line with the variable nature of asthma. This reduces future symptoms and reduces risk, especially compared to previous approaches which titrate SABA use and enable untreated inflammation to escalate.

When an inhaler containing ICS-formoterol is prescribed to relieve symptoms, this is known as AIR therapy. When this inhaler is used for both maintenance and relief, this is known as MART. This guideline allows patients to self-titrate between AIR and MART. Most patients will require MART to treat underlying inflammation and keep on top of their symptoms. Patients with infrequent or seasonal symptoms may rotate between AIR therapy and MART. This is a major culture change in treatment approach from previous guidelines and it is essential that everyone in health and care understands it (including community pharmacies and acute care providers such as 111 and 999 services).

There are many different types

of inhaler with different drugs, doses and devices. This guideline supports the off-license use of an appropriately dosed inhaler as long as the patient can use it correctly. This provides greater flexibility for moving patients to a SABA-free regimen but does mean that prescribers, especially those signing prescriptions for non-prescribers, are comfortable with inhaler choices and off-license prescribing.

Review and monitoring

People with asthma should have an asthma review at least annually if well-controlled, more often if poorly controlled, and after every asthma exacerbation.

Pregnant women should have an asthma review early in pregnancy and in the postpartum period.

Asthma control should be checked at every asthma-related appointment. This means that all clinicians in contact with people with asthma need to be able to effectively perform all of these actions, not just those working in practice asthma clinics.

A check should include:

- ▶ Asthma control test (ACT), children's asthma control test or asthma control questionnaire
- ▶ Time off school or work
- ▶ Number of courses of oral steroids
- ▶ Number of emergency presentations with chest symptoms
- ▶ Reliever inhaler use, include checking the prescribing record
- ▶ Peak flow if this is part of someone's asthma action plan. However, having a measure of someone's peak flow when well can be a useful benchmark for acute episodes.

Assessing inflammation: a key part of the monitoring process

FeNO should now be considered within the annual review as well as before and after any change in therapy. A high FeNO level demonstrates untreated eosinophilic inflammation. This might be because of poor adherence to preventer medication, inadequate inhaler technique, or a need for a higher dose of inhaled steroids.

If FeNO is not raised in someone who has asthma-like symptoms, consider alternative causes for those symptoms rather than simply increasing the inhaler dose.

FeNO and eosinophil levels should be measured in anyone over 12 who is poorly controlled despite good adherence with a moderate dose MART inhaler. Raised levels of either should trigger a referral to a specialist asthma service to consider specialist treatments such as biologics.

Self-management advice

As well as a personalised written asthma action plan, adults, children and their carers should be offered:

- ▶ Education about their asthma and how to self-manage their symptoms
- ▶ Information about common triggers and how to address them, including indoor and outdoor pollution
- ▶ Smoking cessation advice and support.

Adolescents should also have specific advice about how their asthma may be affected by different occupational triggers. In addition, healthcare professionals should enquire about specific factors in their life that may impact on their self-management and use of inhaler.

Asthma + Lung UK has a new website to support people working in healthcare who are supporting people with respiratory conditions. For more information, visit: www.asthmaandlung.org.uk/healthcare-professionals. JCN

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Sian Wicks, CEO, ERIC

Back on track: tackling the problem of toilet training



With a quarter of children now starting school not toilet trained, ERIC, The Children's Bowel and Bladder Charity is launching an intervention to help reverse the trend, and is inviting families and healthcare professionals to hop aboard the Toilet Train.

Over the last century, the average age that children are being potty trained in the UK has risen from 12–18 months, to an average of around three or even four years today (Blum et al, 2004).

ERIC, The Children's Bowel & Bladder Charity, carried out research with the Association of Teachers and Lecturers in 2016 and the National Day Nursery Association in 2018. Both surveys showed that parents are toilet training their children later. Furthermore, research by Kindred Squared (2024) showed that one in four children in England and Wales are now starting school still wearing nappies.

School staff are diverting 2.5 hours a day, on average, away from teaching and towards supporting children who are not school ready. This has a knock-on effect on pupils, who lose around a third of learning time each day (Kindred Squared, 2025).

Support for children and parents is woefully lacking, and this is contributing to a situation where children are starting school underprepared, and where one in nine children in the UK lives with a bowel or bladder condition (Paediatric Continence Forum, 2024).

Later potty training increases the risk of developing wetting and soiling issues later, and also prevents the early identification of bladder and bowel problems. It also has a knock-on effect on other areas of health, education and social care:

- ▶ A staggering 25% of children start school still having frequent toileting accidents
- ▶ 90% of teachers have at least one child in their class who is not fully toilet trained
- ▶ Hospital admissions for childhood constipation have increased by 60% over the past decade (over 44,000 children last year)
- ▶ Good bowel and bladder education could reduce the incidence of issues like constipation by as much as 80% (Kindred Squared, 2025; NHS England, 2025).

In ERIC's experience, this trend has significant negative impacts for children, families, and society, namely:

- ▶ Health concerns: increased risk of urinary tract infections (UTIs) and constipation associated with prolonged nappy use
- ▶ Developmental delays: reduced independence and social confidence
- ▶ Emotional impact: children feeling different, social isolation
- ▶ Impact on education: lost teaching time for every child in reception year
- ▶ Environmental impact: nappies are a significant contributor to waste stream
- ▶ Economic burden: purchase and

disposal of nappies adds financial strain for families, nurseries, and Local Authorities.

Based on ERIC's working knowledge of the sector, key drivers of this delay include:

- ▶ Lack of support and training: early years practitioners do not receive education on potty training as part of their apprenticeship training, and many parents have reduced visits from a health visitor
- ▶ Cultural and societal changes: with an increase in dual income households, more children are in nursery from a younger age
- ▶ Equally, families with challenging living arrangements (split households, unsuitable housing, challenging lifestyles) struggle to focus
- ▶ Marketing influence: campaigns by the single-use nappy industry have promoted myths about 'readiness', encouraging later potty training.

There also appears to be a gulf between teachers and parents' expectations of what a child's developmental level should be before school. Almost half of teachers think parents should be more aware of their role in preparing their child for starting reception.

WHAT IS ERIC DOING?

Underfunding and unequal access to services has resulted in a situation where families are struggling to get the support they need. Families often find ERIC online or are signposted to

our services by early years settings. Demand for information and advice has never been higher.

Over the last five years, the volume of calls received by our helpline has increased by 215% (from 1900 calls in the year to September 2019, to 5987 calls in the year to September 2024).

ERIC believes that there is a significant opportunity for evidence-based intervention to help tackle these issues, and is working to convene and galvanise key influencers and decision-makers who have the power to enact change. It is only through working collaboratively that we can hope to make a positive impact on children's lives, so we are having conversations with key stakeholders to start making this happen.

ALL ABOARD THE TOILET TRAIN

ERIC also has a number of on-the-ground interventions to help families directly. Last year, an intervention campaign called All Aboard the Toilet Train was launched, which was aimed at families whose children were due to start school in September and were not yet toilet trained. Almost 3000 families signed up to receive advice and were successfully stewarded through the programme.

This year's campaign will be even bigger, with greater collaboration between the charity, local authority family hubs, schools and early years settings.

Following feedback from parents/carers and early years settings, this year's All Aboard the Toilet Train campaign is being launched earlier in April (as opposed to last year at

More information

Find out more at: <https://eric.org.uk/all-aboard-the-toilet-train-get-ready-for-school/>

Visit eric.org.uk for more information about its services and support.

Box 1

Five top toilet training tips for school

If you are supporting families whose children are getting ready to go to school, then them to remember the five Ps:

- **Prepare:** think about what you might need to take with you, like spare pants, trousers and wipes just in case. Visit the ERIC website for tips
- **Practice:** use loos away from home and try different types of flushes and hand dryers
- **Pants:** get your child to practice wearing their big kid pants and get used to pulling them up and down when they go to the loo
- **Plan:** try and get your child into a good toilet routine before you go to school
- **Praise:** give them a big clap whenever you try to use the loo by themselves. They deserve it!

the start of the summer holidays, which gave parents six weeks to get on top of toilet training), coinciding with primary school places being awarded. This means that parents and carers will have more time to start thinking about their children's toilet readiness and more opportunities to work with them over the coming months before they start school in the autumn.

These packs are also available for healthcare professionals to download and use with families they support.

They say it takes a village to raise a child; ERIC hopes that All Aboard the Toilet Train helps gather together that village of support that families need as they steer their children towards starting reception. **JCN**



How it works

Parents and children are invited to 'board the Toilet Train' by signing up to the charity's online support challenge that will help them prepare for school. They will receive information, advice and support via email over a six-week period to support them in their journey.

ERIC will also send free digital packs to early years settings and primary schools across the country which contain helpful PDF leaflets, advice sheets, and a video they can share with families to help get children toilet ready for school.

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Falls management in care settings and the community

Caroline Cosh

Falls can have a significant impact not only on the person who experiences them, but also their key, informal carers too. When waiting for long periods of time for help on hard, often cold floors, the side-effects can be dangerous and compromise health, wellbeing and dignity. Given that most major trauma patients are aged 60 years and over and experience a low mechanism of injury, careful management is required. With the right training and support, care teams can become competent and confident to manage falls. This article explores how proactive falls management strategies can significantly improve quality of life, alleviating societal and economic burden of falls-related complications.

KEYWORDS:

■ Fallen ■ Outcomes ■ Falls management ■ Prompt assessment

Although not inevitable, falls are common in older people due to age-related health changes. According to NHS data, one in three people over the age of 65 years and one in two people over the age of 80 years will fall at least once each year (NHS, 2025). Falls are estimated to cost the NHS more than £2.3 billion per year, with the human cost including distress, pain, injury, loss of confidence and independence, and mortality (National Institute for Health and Care Excellence [NICE], 2013).

The Office for National Statistics (ONS) 2021 consensus reported that the number of people aged 65 years and over has grown more considerably than any other age group since 2011, and it is predicted that by 2028 the number of people aged over 65 will have increased by 10%, and by 2043, by 32% (Age UK, 2023). The interplay between frailty, social problems and comorbidities increases the risk of falls (Cooper and Shenvi, 2017). Thus, it is crucial

'Falls are estimated to cost the NHS more than £2.3 billion per year, with the human cost including distress, pain, injury, loss of confidence and independence, and mortality.'

to understand the challenges of managing the growing ageing population for effective and safe management.

In 2021, the ONS consensus data reported that 82.1% of care home residents were aged 65 and over and almost 74% were aged 80 years and over. This means that 27.4% of people living in care homes aged over 65 and 37% of those aged over 80 years will fall annually. This equates to a huge number of falls annually within both care homes and local communities where older people reside in their own homes.

AMBULANCE TRIAGE

In February 2024, 763,141 999 calls were answered by ambulance services, averaging 26,315 per day, higher than the average for 2023–2024 (National Statistics, 2024).

Increasing demand and hospital handover delays are just two factors which have increased ambulance response times. In order to triage the most appropriate response, ensuring that patients in need receive the fastest emergency service, a set of pre-triage questions are used to screen calls. There are four categories with target response times, with category allocated being dependent on urgency, as determined by the triage process.

The fallen patient is likely to be triaged as requiring a category 3 (urgent) or category 4 (less-urgent) ambulance response. Category 3 calls have a 90th percentile response target of two hours and category 4 calls a 90th percentile response target of three hours (NHS England, 2018). *Table 1* shows the categories of calls.

WHAT DOES THIS MEAN FOR THE FALLEN PATIENT?

NICE (2013) states that when a person falls it is important that they are assessed and examined promptly to see if they are injured. Wait times of two to three hours do not provide prompt examination. This means that uninjured patients may spend long periods of time on the floor. This increases the risk of pressure ulcers, hypothermia, dehydration and pneumonia, all of which may result

Practice point

After a fall, elderly people may experience a decline in functional ability, making it difficult to maintain independence and perform activities of daily living. Indeed, falls often result in a cycle of reduced activity, muscle weakness, and further fall risk, all of which can contribute to frailty.

Caroline Cosh, owner and managing director, Clifton Homecare Limited; paramedic

in complications (Jones, 2023). Long lies can also cause rhabdomyolysis; the rapid destruction of skeletal muscle tissue which leads to myoglobin leaking into the blood stream. Myoglobin is the protein that stores oxygen in the muscles. Too much myoglobin can result in acute kidney injury and life-threatening electrolyte imbalances.

In addition to NICE guidelines, the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014: Regulation 12, Safe care and treatment states:

The intention is to prevent people from receiving unsafe care and treatment and prevent avoidable harm or risk of harm. Providers must assess the risks to people's health and safety during any care or treatment and make sure staff have the qualifications, competence, skills and experience to keep people safe.

Given these risks and regulatory requirements, in the author's clinical opinion, there is a definite need for proactive, prompt falls management, reducing the incidence and impact of avoidable harm.

WHAT IS THE ALTERNATIVE?

Care provider compliance and regulatory governance continue to increase. Care providers are inspected by the Care Quality Commission (CQC), local authorities and the NHS, in addition to being answerable to the Health and Safety Executive (HSE). Understandably, this often causes risk averse processes and procedures. In the author's clinical experience, litigation concerns and risk avoidance can mean that patient outcomes are compromised when the default for falls management is to call 999.

In *Going further for winter: Community-based falls response*, NHS England (2022) outlined key principles and requirements to improve community-based falls response services, which would (Table 2):

- ▶ Enhance response times, reducing the incidence of long lies
- ▶ Improve system efficiency, ensuring ambulance capacity for where it is most needed.

Table 1: Ambulance response programme review (NHS England, 2018)

Category	Description	Sub-description	Average response target	90th percentile response target
1	Life-threatening	Time critical life-threatening event needing immediate intervention or resuscitation	7 minutes	15 minutes
2	Emergency	Potentially serious conditions that may require rapid assessment and urgent on-scene intervention and/or urgent transport	18 minutes	40 minutes
3	Urgent	An urgent problem (not immediately life-threatening) that needs treatment to relieve suffering and transport or assessment and management at the scene with referral where needed within a clinically appropriate timeframe	None (mean indicator or 60 minutes)	2 hours
4	Less-urgent	Problems that are less urgent but require assessment and possibly transport within a clinically appropriate timeframe	None	3 hours

Table 2: Community-based falls responses (NHS England, 2022)

Level of fall	Description	Community-based response considered appropriate
1	No known injury	Responder services, fire and rescue services, community first responders, St John's ambulance services and NHS volunteers
2	Minor injury/illness	Urgent responders, rapid response teams, multidisciplinary teams
3	Serious injury/illness	Emergency ambulances

This information provides context for the level of skill and competence deemed necessary by NHS England for assessing the fallen patient. For level 1 falls, where the patient is considered to be uninjured, non-clinical teams trained in falls response and assessment can provide appropriate, often more timely assessment and management. In addition to non-clinical community-based teams, competent, confident care teams could help stop unnecessary ambulance service demands if trained to manage falls, which would optimise patient outcomes while freeing up ambulances for those most in need. However, care teams would require suitable training, processes, and support to equip them with the framework, knowledge and skills necessary for safe and effective management.

NECESSARY CAUTION

Historically, major trauma was usually associated with working age patients who had experienced a high mechanism of injury. Mechanism of injury refers to the force or trauma

impacting the body, which plays a significant part in the severity of injury sustained. Examples would be road traffic collisions, pedestrian versus car or fall from a height. This association started to change when the Trauma Audit and Research Network revealed in 2017 that most major trauma patients were aged over 60 years and had experienced a low mechanism of injury (Banerjee et al, 2017). This was further supported by the Office for Health Improvement and Disparities (OHID) in 2021 when they reported that fragility fractures can result from low-level and low-energy trauma. The World Health Organization (WHO, 2024) has now quantified this as trauma from standing height or less. Major trauma in patients aged over 65 years is now referred to as 'silver trauma' (Chowdhury, 2020).

These latest findings mean that careful consideration, ensuring evidence-based practice and robust processes for falls management are essential. High risk patients and/or conditions must be identified; for example, patients taking anticoagulant medications and



patients with osteoporosis. The Joint Royal College of Ambulance Liaison Committee (JRCALC, 2024; <https://jrccalc.org.uk/guidelines/>) states that thorough and careful physical examination is required along with a high index of suspicion when assessing the fallen. Furthermore, regular monitoring and observation post fall is equally as important as the initial assessment process to identify delayed symptom onset and complications. Although this may be easier to manage in care home settings as opposed to the community, additional care visits and use of family or friends could help ensure regular, ongoing monitoring to safeguard the patient.

NEXT STEPS

Given the staffing, financial and capacity constraints impacting both the NHS and patients, in the author's clinical opinion, it would be beneficial for health and social care to work together to train, develop and support non-clinical social care teams to assess the fallen patient and assist them off the floor. NHS England's (2022) community falls response approach confirms non-clinical teams can be effectively trained to respond safely and provide prompt assessment.

Considering that cognitive impairment, behavioural challenges and poor mental health often affect social care service users, it would be prudent for care teams who know them well to lead on triage and assessment. There are many apps and processes already in place in social care settings, enabling their care teams to manage falls independently, but in the author's clinical opinion, a unified, evidence-based, robust approach would provide a beneficial

'Prompt management of fallen patients also demonstrates person-centred, responsive care provision, which is essential when evidencing regulatory compliance.'

national impact. For example, involving healthcare professionals, particularly paramedics, could be extremely helpful, strengthening relationships and partnership working. In the author's clinical experience, paramedics develop knowledge and skills to manage situations and patients that qualifications alone cannot prepare you for. Transferring some of that skill to frontline care teams would have significant benefits on competence and confidence, enabling them to manage situations involving a fallen service user safely. Given delegated healthcare activities are being embedded within social care practice in order to improve patient outcomes, falls management fits alongside this well.

Prompt management of fallen patients also demonstrates person-centred, responsive care provision, which is essential when evidencing regulatory compliance. However, social care has struggled with recruitment and retention for many years. *The state of the adult social care sector and workforce in England* executive summary (Skills for Care, 2024) reports that there were 131,000 vacant posts in 2023–2024. The document also confirms that learning and development supports retention within social care. So, increasing opportunities for care teams to learn additional skills not only enhances continuity of care for patients, but can

also improve retention of social care staff. Indeed, improved continuity increases care standards, providing effective and responsive care.

THE CLIFTON HEALTHCARE PROCESS

Caroline Cosh, a Health and Care Professions Council (HCPC) paramedic, owner and managing director of Clifton Homecare Limited created a falls policy when founding the homecare company in 2013. The policy has since expanded to include baseline observations and the National Early Warning Score (NEWS) 2 and has undergone an innovation validation assessment at the University of Central Lancashire. There is ongoing monitoring of the Clifton Healthcare process, evaluating safety and effectiveness and necessary adjustments are made as required. However, the assessment concluded that, 'The Clifton Healthcare process is an excellent use of skilled staff, trained appropriately to high standards, using a systematic approach to meet the needs, wants, and wishes of a specific group of service users'.

The procedure includes a primary patient survey, ensuring immediate life-threatening presentations are ruled out first. Once this has been completed, the staff member completes a secondary, head-to-toe survey, following a step-by-step process. The process refers the user to call 111, 999 or the patient's GP, if findings cause concern. In these situations, the patient is not assisted off the floor or moved. Instead, an ambulance is called and the findings reported to the ambulance control centre. When leaving patients at home following a fall, the process includes safety netting advice, i.e. ensuring that regular checks are made by family or the care team. This means that any delayed concerns are followed up and medical advice sought appropriately.

CONCLUSIONS

Undoubtedly, improved, proactive and prompt community-based falls management would lessen the burden on the NHS through reduced

ambulance call outs and responses, reduced costs and less complications caused by long lies. Falls management should not just lie with the ambulance service, especially when patients are uninjured. Increasing ambulance demand means uninjured fallen patients will wait between two to three hours on a floor, resulting in high risk complications such as rhabdomyolysis. Given the correct training, support and robust processes in place, non-clinical care teams can be trained to assess the fallen patient safely. Processes should take into account silver trauma and have appropriate escalation plans in place to respond to findings from the assessor having a high index of suspicion.

Prompt assessment and management of the fallen patient complements person-centred care and maximises health outcomes. Further research into adopting this as recommended national policy and improved partnership working would benefit not only patients, but also care provision in general, with the potential for learning and development to retain social care staff. **JCN**

KEY POINTS

- Considering frailty, social problems and comorbidities increase falls risk (Cooper and Shenvi, 2017), the rise in the ageing population creates challenges which we need to understand to enable effective and safe management.
- NICE (2013) states that when a person falls it is important that they are assessed and examined promptly to see if they are injured.
- For level 1 falls, where the patient is deemed to be uninjured, non-clinical teams trained in falls response and assessment can provide appropriate, often more timely assessment and management.
- Major trauma in patients aged over 65 years is now referred to as 'silver trauma' (Chowdhury, 2020).

An elderly gentleman fell off his mobility scooter in a greenhouse. The senior domiciliary care assistant promptly attended, followed the Clifton Healthcare process, assessed the gentleman and assisted him off the floor using an emergency lifting cushion. The gentleman was uninjured and was not outside for a long period of time. His injuries were limited due to not experiencing a long lie on an external, cold, hard surface. He did not experience any complications as a result of the fall and was monitored for a period of time afterwards. In addition, the gentleman was incredibly pleased not to have to wait for the ambulance service to respond.

Patient story

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Idiopathic pulmonary fibrosis: an overview

Margaret Perry

Pulmonary fibrosis (PF) is a long-term chronic condition, which is more common in older adults. It is a progressive disease limited to the lungs and presents with several features which have variable degrees of severity. PF is a highly complex disease with many different types, of which idiopathic pulmonary fibrosis (IPF) is the most common (American Lung Association, 2024). Idiopathic pulmonary fibrosis is one of the most aggressive forms of PF, characterised by chronic, progressive fibrosis associated with inexorable decline in lung function, progressive respiratory failure, and high mortality (Barratt et al, 2018). The prognosis is often poor and the vague symptoms can make diagnosis challenging for clinicians. This article focuses predominantly on IPF to give an insight into this complex condition with the aim of improving confidence in recognition of the disease. With increased knowledge, it is hoped that quality of life can be improved for patients suffering with this unpleasant condition.

KEYWORDS:

■ Pulmonary fibrosis ■ Idiopathic pulmonary fibrosis ■ Symptoms
■ Diagnosis ■ Treatment

PREVALENCE RATES

Precise estimates of the incidence and prevalence of idiopathic pulmonary fibrosis (IPF, the commonest form of pulmonary fibrosis [PF]) are difficult to determine and appear to vary considerably between countries for reasons which remain unclear (Munchel and Shea, 2021). The incidence of IPF worldwide is estimated to be 10.7 cases per 100,000 person years for males and 7.4 cases per 100,000 person years for females, with two-thirds of those diagnosed being over the age of 60 at the time of diagnosis (Zisman et al, 2005).

In the UK, the median age of presentation is approximately 70 years, and prevalence is around 15 to 25 cases per 100,000 people, with an increased prevalence among older adults (Knott, 2020). Overall, the number of people affected by IPF appears to be increasing, which is thought to be the result of a

complex interplay between ageing, host susceptibility (i.e. genetics and epigenetics), and environmental factors, including viral infections, passive smoking, and air pollution (Sack and Raghu, 2019). However, the specific relationships between these factors and how they impact on disease development remains unclear (Munchel and Shea, 2021).

PATHOPHYSIOLOGY

Pulmonary fibrosis is a form of interstitial lung disease that causes scarring in the lungs. The interstitial tissues are made up of cells which form the space between the blood vessels and other structures within the lungs. Damage to these tissues leads to the formation of fibrotic tissue. It was previously thought that the condition was caused by a generalised inflammation, which progressed to widespread fibrosis (Homer et al, 2011). This theory has now been discounted because anti-inflammatory drugs have been found to have no impact on preventing disease progression.

Although the underlying pathophysiology remains poorly understood, it is currently believed that IPF, which this paper focuses on, occurs when endogenous or environmental stimuli disrupt the homeostasis of alveolar epithelial cells, resulting in diffuse epithelial cell activation and abnormal epithelial cell repair (Verma et al, 2007).

Once an epithelial injury has occurred, there is an activation of fibroblasts and dysregulated repair of the alveolar epithelium, which can lead to increased matrix deposition in the lung interstitial tissues. This causes exaggerated narrowing of the airways, scarring, and destruction of lung architecture, leading to the development of IPF (Shioya et al, 2018).

RISK FACTORS

Multiple risk factors have been studied, which have been identified as being both intrinsic (non-modifiable) and extrinsic (modifiable), with an additional risk associated with certain comorbid conditions (see below).

Intrinsic factors

The following intrinsic factors have been identified (Zaman and Lee, 2018):

- **Genetics:** this area remains unclear, but it is now thought that an autosomal dominant trait may

Red Flags

- Several forms of PF exist, of which IPF is the most common
- IPF is a debilitating, chronic condition
- It is more common in males and increases in prevalence with older age
- Mean age of presentation in the UK is approximately 70.

Margaret Perry, locum advanced nurse practitioner

Table 1: Additional risk factors for IPF (Zamon and Lee, 2018; Park et al, 2021)

Risk factor	Additional information
Farming and agriculture workers	Regular contact with livestock
Livestock feeds	Linked to increased risk
Chronic viral infection	Epstein Barr virus and cytomegalovirus have been found in the lung tissue of patients with IPF
Pesticides	Regular use of pesticides is associated with increased prevalence of IPF
Pigeon breeding	Linked to increased risk

account for approximately 70% of cases (Zisman et al, 2005)

- ▶ **Ageing:** the incidence of IPF increases with older age, with most cases being diagnosed between the fifth and seventh decades of life
- ▶ **Gender:** globally, males account for approximately 70% of cases of IPF, which is thought to be attributed to inhaled exposure, such as occupational exposure and cigarette smoking (Zaman and Le, 2018)
- ▶ **Lung microbiome:** the lungs were once thought to be sterile, however in recent years it has become evident that this is not the case. Although the lungs were known to harbour microbes in acute infections and chronic suppurative diseases, such as bronchiectasis and cystic fibrosis (CF), microbial communities in the healthy lung have only been recently described (Charlson et al, 2011). However, in health, the lung possesses exceedingly low microbial biomass, and the nature of lung microbes differs markedly in quantity and dynamics from that of other body habitats which also harbour microbiomes, such as the gut, skin, mouth, and vagina (Whiteside et al, 2021). While this area is still under investigation, it is thought that among patients with IPF, those with a greater bacterial burden may have worse survival rates (Zaman and Lee, 2018).

Practice point

Familial IPF is defined as IPF occurring in two or more relatives who share common ancestry, while those with no known family history are classified as having sporadic IPF (Kropski et al, 2017).

Extrinsic factors

The following extrinsic factors have been identified (Zamon and Lee, 2018):

- ▶ **Smoking and environmental exposure:** several environmental exposures have been associated with increased risk for both PF and IPF, with occupational disease caused by exposure to hazardous materials such as asbestos or silica (American Lung Association, 2024). Cigarette smoking seems to be the most strongly associated factor in both sporadic IPF and familial PF (Taskar and Coultas, 2006).

Comorbidities

Certain comorbidities also put people at greater risk of developing IPF, including:

- ▶ **Diabetes:** the association between diabetes and IPF has been of interest for many years and recent epidemiological research conducted across populations with different genetic backgrounds has suggested that diabetes is an independent risk factor for IPF, with the prevalence of IPF found in patients with diabetes estimated to be 10–42% (Wang et al, 2020)
- ▶ **Obstructive sleep apnoea (OSA):** the prevalence of OSA is continuously increasing in patients with IPF and, for the first time, the recent IPF guidelines recognise OSA as an important associated comorbidity that can affect patient's survival (Schiza et al, 2015)
- ▶ **Pulmonary hypertension:** this is raised blood pressure in the blood vessels that transport blood to the lungs and is reported to be common in patients with IPF (Luppi et al, 2021)
- ▶ **Gastroesophageal reflux disease (GORD):** GORD has been

investigated and in a study by Reynolds et al (2023) was found to increase the risk of IPF, but there was no evidence that IPF increased the risk of GORD

- ▶ **Anxiety and depression:** the chronic and progressive nature of symptoms of IPF have a significant impact on morbidity and mortality. Specifically, worsening dyspnoea, declining pulmonary function, and hypoxemia are characteristic features of IPF progression, which have been shown to correlate with depression and anxiety (Luppi et al, 2021).

Additional risk factors are shown in Table 1, with known causes shown in Table 2.

SIGNS AND SYMPTOMS

Diagnosis of IPF is often difficult because early symptoms are vague and non-specific and can easily be mistaken for other more common conditions. Despite increased awareness of the disease, the delay between onset of symptoms and diagnosis is estimated to be around two years (Hoyer et al, 2019).

The first symptoms are a gradual increase in shortness of breath, which may or may not be accompanied by a dry cough. Both patients and healthcare professionals may attribute this to ageing, smoking habits, or to more common cardiovascular or respiratory diseases (Hoyer et al, 2019). Finger or toe nail clubbing (a painless swelling at the base of the nails) occurs in about half of all cases (Hazell, 2023). Weight loss and tiredness are also possible symptoms.

Red Flags

- Vague, non-specific symptoms make diagnosis difficult
- There is often a delay between first presentation and confirming the diagnosis of around two years
- Early symptoms of dry cough and breathlessness are often mistaken for other more common diseases.

Table 2: Other causes of PF (Hazell, 2023)

Condition	Additional information
Occupational interstitial lung disease	Lung disease caused by inhalation of dust at work. The commonest type is pneumoconiosis in coal workers. Other forms include asbestosis or silicosis. There is often a long delay between contact with causative substance and onset of symptoms
Hypersensitivity pneumonitis	Caused by a reaction to something inhaled which causes inflammation then scarring over time. Examples include bird fancier's lung (caused by breathing in particles from bird faeces or feathers), and farmer's lung (caused by breathing in mould found on hay and straw)
Autoimmune diseases	Rheumatoid arthritis, scleroderma and Sjogren's syndrome are examples. When the disease is active, the immune system can attack the lungs, causing inflammation and, over time, fibrosis
Medication induced	Certain medications such as methotrexate, amiodarone and certain chemotherapy drugs may cause PF as an adverse effect
Sarcoidosis	Nodules, known as granulomas, develop at various sites but frequently in the lungs and can lead to inflammation and scarring

EXAMINATION AND INVESTIGATIONS

Initial assessment of IPF should include a detailed history of symptoms and their duration and information relating to past medical history, occupational history, medications, and duration of symptoms, and whether any current symptoms are felt to have worsened. Bloods can be taken in the primary care setting, including full blood count (FBC), erythrocyte sedimentation rate (ESR), C-reactive protein (CRP) and autoantibodies (to detect antibodies characteristic of several autoimmune diseases).

Physical examination may find bilateral inspiratory crackles on auscultation and the presence of finger clubbing (Patel et al, 2023).

Other investigations include:

- ▶ **Chest X-ray:** this will show scarring of the lungs suggestive of IPF
- ▶ **Lung function testing:** if spirometry is available, this will often show a restrictive pattern with reduced forced vital capacity (FVC) and reduced forced expiratory volume in 1s (FEV1) (Glass et al, 2022)
- ▶ **High resolution chest computed tomography (HRCT):** this will show patchy bibasilar honeycombing. This is the appearance of variably sized cysts in a background of densely scarred lung tissue (Umphress, 2017). If the diagnosis remains

uncertain, bronchoalveolar lavage (which allows a sample to be collected from the lungs) or lung biopsy can be undertaken.

DIFFERENTIAL DIAGNOSIS

IPF shares symptoms with other forms of PF as well as some other diseases, namely:

- ▶ **Sarcoidosis:** this is a rare condition involving the development of granulomas, which can potentially develop in any organ of the body but most frequently occur in the lungs and lymph nodes. Symptoms overlap with those of IPF, with the patient developing a cough and shortness of breath
- ▶ **Asbestosis:** this can be difficult to differentiate because of shared radiological features. However, fibrotic foci (found on chest X-ray), are a pathologic hallmark of IPF and are infrequent in asbestosis, while the presence of mild fibrosis of the visceral pleura on a chest X-ray is a characteristic finding in asbestosis, but rarely seen in IPF (Spagnola et al, 2012)
- ▶ **Connective tissue disease:** this may be suspected in patients with symptoms below the age of 50, as IPF is rare in this age group. It is advisable that patients, especially females in this age range, are screened for connective tissue disease (e.g. Raynaud's), since patients without clinical or serologic features at presentation may subsequently manifest overt features of an underlying

condition that was subclinical at the time of first presentation (Spagnola et al, 2012)

- ▶ **Familial pulmonary fibrosis:** familial forms of IPF (affecting two or more members of the same family) have been reported. However, this is rare, affecting less than 5% of IPF cases (Raghu et al, 2011)
- ▶ **Hypersensitivity pneumonitis (HP):** this condition shares similar non-specific symptoms to IPF, such as dyspnoea, cough, and malaise, but history is useful as a guide to suspecting this disease. The most common causes of HP are exposure to avian antigens, occurring in pigeon breeders or those who keep birds as pets at home (Kouranos et al, 2017).

Table 3 gives some guidance of radiological findings to support a differential diagnosis.

TREATMENT

There is no cure and treatment aims to reduce symptoms and improve quality of life. Non-pharmacological therapy for IPF consists of the following:

- ▶ **Supplemental oxygen administration:** used in patients suffering with resting or exertional hypoxia
- ▶ **Pulmonary rehabilitation (PR):** to help preserve and possibly improve exercise tolerance (Munchel and Shea, 2021). Typical PR programmes include exercise training, nutritional advice, occupational therapy, education, and psychosocial counselling. Vainshelboim et al (2014) reported that exercise-based PR improved exercise tolerance, functional capacity, leg strength, pulmonary

Red Flags

- Shared symptoms with other conditions suggest several possible alternative diagnoses
- Several investigations are needed to determine an accurate diagnosis
- If the cause remains uncertain then bronchiolar lavage or lung biopsy may be needed.

Table 3: Radiological and histological features suggestive of a lung disease other than IPF (Spagnola et al, 2012)

Features	Hypersensitivity pneumonitis	Connective tissue disease	Asbestosis	Sarcoidosis
	Areas of decreased lung attenuation (a radiologic finding which is non-specific)	Bronchiectasis away from fibrotic areas	Plaques and/or significant pleural thickening	Fibrosis and linear opacities (morphological changes seen in IPF) and traction bronchiectasis (irreversible dilation of bronchi and bronchioles seen within areas of PF)
Radiological	Centrilobular nodules with a predominance in the upper lobe	Signs of pulmonary hypertension, which is disproportionate to the extent of fibrosis There may be pleural or pericardial effusion and oesophagus or bone abnormalities	The radiographic appearance of asbestosis is non-specific, but the presence of findings such as pleural thickening and plaques is suggestive of asbestosis as the cause	Conglomerate masses of fibrosis in the posterior part of the lungs
Histological	Cellular interstitial pneumonia Multinucleated giant cells or granulomas situated round the bronchioles	Extensive pleuritis Dense perivascular collagen	Pleural abnormalities Asbestosis bodies Bronchial wall fibrosis	Non-caseating granulomas (areas of chronic inflammation which do not have a central area of necrosis), with a characteristic para-lymphatic distribution

function, dyspnoea and quality of life in patients with IPF

- ▶ Influenza and pneumococcal vaccinations
- ▶ **Encouraging smoking cessation if applicable:** cigarette smoking can worsen symptoms and increases the risk of lung cancer, chronic obstructive pulmonary disease (COPD) and heart disease
- ▶ Physiotherapy may be helpful
- ▶ Healthy diet and weight reduction if needed.

Medical management

Following intense research, there are now approved drug treatments for IPF which have been shown to slow lung function deterioration and improve clinical outcomes (Sofia et al, 2023). Further research is currently underway to identify more options with a view to developing better tolerated drugs. *Table 4* shows the currently available drugs.

PROGNOSIS

Prognosis is extremely difficult to predict because of the variability in the rates of disease progression between patients. Some patients will have a rapidly deteriorating disease, while others will progress much more slowly with a steady decline over several years. For many patients, there is a progressive worsening of shortness of breath and the eventual development of respiratory failure, with average survival only three to five years after diagnosis (Munchel and Shea, 2021). Prognosis is

particularly poor in patients with pre-existing IPF who develop an acute exacerbation or deterioration in their condition over a very short period of time (Raghu et al, 2008).

An acute exacerbation has been defined as a clinically significant deterioration with worsening respiratory symptoms and increased dyspnoea, which develops within less than one month with no obvious cause (Leuschner and Behr, 2017). These patients often have no evidence of an identifiable cause such as infection, cardiovascular or thrombotic disease (Raghu et al, 2008). Acute exacerbations of IPF can lead to hospitalisation for respiratory failure with a precipitous decline in lung function (Munchel and Shea, 2021). The mortality of hospitalised cases is approximately 50% and even patients who survive hospitalisation continue to have a poor prognosis, with approximately half of all IPF-related deaths occurring after a non-elective respiratory hospitalisation (Munchel and Shea, 2021).

Management of comorbidities by specialists is equally important. Oldham and Collard (2017) promote aggressive management of comorbidities to improve quality of life and potentially improve survival rates because, if left untreated, they can be the cause of deterioration of the underlying IPF. In patients with advanced disease, lung transplantation is the only treatment which offers the opportunity for

prolonged survival, as it has been shown to reduce the risk of death at five years (Raghu et al, 2011).

CONCLUSION

IPF is a devastating diagnosis for any patient and carries with it the risk of progressive deterioration and a poor prognosis. Early symptoms are non-specific and can easily be mistaken for other conditions with similar symptoms. For these reasons, diagnosis is often challenging for clinicians and can lead to a delay in making an accurate diagnosis.

Recent years have seen the arrival of new medications and with future research it is hoped that the number of available options for patients will increase further. This article has given nurses and non-medical prescribers an insight into this often fatal disease and aims to enable them to have an increased awareness of this condition so that they will have a high index of suspicion when assessing patients, and may be instrumental in getting an earlier diagnosis and treatment, which can impact on quality of life and hopefully survival rates. **JCN**

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Table 4: Antifibrotic agents used in IPF (National Institute for Health and Care Excellence [NICE], 2016; 2018)

Drug	Additional information	Adverse effects
Pirfenidone	Thought to have immunosuppressant and anti-inflammatory effects Recommended as an option for patients with FVC between 50% and 80% of predicted	Serious liver disease has been reported within the first year following initiation, including two cases with a fatal outcome. Alanine aminotransferase (ALT) and aspartate aminotransferase (AST) and bilirubin should be checked before commencement, then monthly for six months and three monthly thereafter
Nintedanab	Administered orally and is recommended for patients with FVC between 50% and 80% of predicted. Thought to achieve its effects by blocking the signalling pathways involved in the development of fibrotic processes	Multiple adverse effects including abdominal pain, alopecia, and loss of appetite Should be stopped if disease progresses (a decline in FVC of 10% or more in a 12-month period)

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Tension location: putting theory into practice

Tammy Temple

Many ostomates experience leaks at some points in their lives. However, some experience frequent leaks, which lead to physical complications such as sore skin, bleeding and pain, as well as having a negative impact on their emotional wellbeing and quality of life. Worrying about leaks can result in reduced sleep, social isolation and low mood — all of which can be emotionally exhausting and stressful. Effective stoma management is essential to prevent leaks and maintain peristomal skin integrity, such as the use of convex base plates. There are five characteristics of convexity which when applied correctly can reduce leaks and improve skin health, namely: depth, compressibility, flexibility, tension location and slope. These characteristics work together to achieve the desired outcome. However, tension location can be used in a different method to flatten large creases and dips. This helps to promote skin integrity and improve patient comfort and confidence in managing their stoma, as this article describes.

KEYWORDS:

■ Leaks ■ Compression ■ Tension location ■ Improvement

Stoma care can be difficult to manage both for the ostomate and clinician supporting their care. One of the challenges which ostomates frequently encounter are leaks to their pouch. This can happen for a number of reasons, such as poorly fitted appliances, poorly spouted and situated stomas, as well as issues with output consistency and also user error, such as fitting the pouch incorrectly (Association of Stoma Care Nurses 2013). Some of these problems can be managed simply with education and support. However, poorly fitting appliances and difficulties with the stoma can be more complicated, requiring different and more challenging management.

Convexity in stoma care is often used as a solution to poorly spouted ileostomies or urostomies and retracted colostomies (McKenzie and Ingram, 2001). There are different uses of convexity, which work in a variety of ways to prevent and reduce leaks, for example:

- ▶ **To help stoma protrude:** for stomas that are recessed, sitting in a crease, or flush with the surface, the gentle pressure exerted by the convex surface helps the stoma to protrude outwards, which helps with better drainage, reducing the risk of leaks and skin irritation
- ▶ **To flatten uneven skin surfaces:** skin folds, scars and uneven skin surfaces can prevent the stoma from getting a good seal with a flat barrier. Pushing down/ flattening uneven areas, creates a more uniform surface for attachment, thus improving the seal

(Hoeflok et al, 2013).

The different features of convexity can help to reduce leaks by creating a skin barrier around the

stoma, providing a secure fit and encouraging a flat stoma to protrude. Achieving a secure fit depends on five characteristics which, when applied correctly, can produce the desired outcome. These are known as the five characteristics of convexity, namely:

- ▶ **Compressibility:** the capacity of the convex dome to be displaced or flattened
- ▶ **Flexibility:** how easily the convex skin barrier can bend
- ▶ **Slope:** angle from the base of the convex skin barrier to the apex of the dome
- ▶ **Depth:** depth of the convex skin barrier is defined as the measurement from the apex of the dome to the base
- ▶ **Tension location:** the position in which the convex dome exerts downward and outward forces on the peristomal topography (Cobb et al, 2021).

This article focuses on tension location and the success this method has had with ostomates who were experiencing leaks that the author has reviewed.

STOMA LEAKS AND COMPLICATIONS

Leaks are commonly experienced by ostomates and can have both physical and psychological implications (Erwin-Toth et al, 2012). As many as 76% of ostomates experience a leak under the base plate once a month, with 65% of these experiencing a leak

Practice point

Convexity in ostomy products refers to the shape of the base plate, which is curved outward (convex) rather than flat and can apply gentle pressure to the skin around the stoma, helping to ensure a secure fit.

onto clothing at least once in a year (Down et al, 2021).

Experiencing leaks has a negative impact on ostomates as they cause sore skin, bleeding and pain, and if not managed appropriately can lead to more severe complications such as ulceration (Jordan and Christian, 2013). There is also a small risk of infections to the skin with an incidence of around 6%. Infection may occur in ostomates with immunosuppression due to chemotherapy. Infections can be fungal, such as candida, folliculitis and less commonly viral infections. Ostomates with a urostomy may also experience an increase in urinary tract infections due to the shortened urinary tract system (Burch, 2008).

Ostomates also worry about odour. While a well-fitting pouch should only release an odour when emptying or draining which a simple air freshener can resolve, ostomates experiencing a leak onto their clothing will worry about odours (Pringle and Swan, 2001).

Leaks causing soreness and damaged skin have a financial burden to the NHS. Patients with peristomal skin complications are more likely to be readmitted to hospital and more than one-third of stoma nurse visits are skin related (Jemec and Nybaek, 2008).

Ostomates who worry about experiencing a leak are also more likely to change their pouches more frequently, with a recent study showing up to half of respondents changing more frequently to reduce the risk of experiencing a leak (Jeppersen et al, 2022).

These issues not only affect the ostomate's wellbeing, but also have a financial impact on the NHS as initially they can lead to longer hospital stays and more frequent input from healthcare professionals, as well as increased product ordering due to leaks.

There are several postoperative complications ostomates may experience including retraction of the stoma, parastomal hernia, prolapse

and peristomal skin complications (PSCs) (D'Ambrosio et al, 2023). While attention is given to surgical complications, data about PSCs are still limited, despite their high incidence and being a common skin problem after ostomy surgery (D'Ambrosio et al, 2022).

However, getting the right pouch to fit an ostomate's particular body shape and stoma location can reduce the incidence of leaks, and this is where the five characteristics of convexity are applied (Bird, 2017).

As said, frequent leaks can have an impact on an ostomate's quality of life. A study in 2019 found that most people living with a stoma worried about leakage to some degree. Only 8% did not worry at all, while 39% reported worrying about leakage to be high or very high (Jeppersen et al, 2022). Worrying about leaks can result in ostomates frequently changing the pouch when it may not be necessary, and causing them to constantly check the pouch, which can be both emotionally exhausting and stressful. Indeed, such hypervigilance can lead to their setting alarms at night to wake to check their pouch. The impact of leaks can also lead to embarrassment and social isolation, as people are afraid of experiencing a leak when out (Cakir and Ozbayir, 2018). As a clinician, the author has reviewed patients who have stopped working, going on holiday, visiting family members for fear of experiencing a leak in their home, and even avoiding basic tasks such as shopping for fear of having a leak in the supermarket.

Such psychological and emotional factors underpin the need to reduce the frequency of leaks for ostomates, which, in the author's clinical experience, is where the use of convexity and its five characteristics can be successfully implemented. As said, this paper specifically focuses on tension location.

TENSION LOCATION

Tension location is one of the methods of convexity which the author has used in clinical consultations. The tension location

theory focuses on body profiles, reviewing an ostomate in different positions such as sitting, bending and lying. By evaluating various positions, different contours, such as deep creases when sitting and bending, can be assessed. Assessing a stoma in this manner allows the clinician to select a wider convex area which can provide greater tension away from the stoma helping to flatten skin folds, and therefore creating a secure seal (Cobb et al, 2021)

Applying tension location in practice

The author has applied this method with several patients who had previously tried different products, levels of convexity, and different accessories such as seals, paste and flange extenders — all of which increase prescription costs and also make the process of changing a pouch more time-consuming for the ostomate while not always being successful in reducing leaks.

Tension location is a different way of thinking about how to apply convexity. Traditionally, when using convexity in clinical practice, the base plate with the smallest cut size to match the stoma is used, as this provides the most protrusion. Conversely, the tension location method uses a wider base plate around the stoma to offer a level of convexity to protrude the stoma, while also providing a wider plateau to flatten surrounding creases (Cobb et al, 2021).

Patient stories

The author, having attended a study day discussing this method, while understanding the theory was not sure how to apply it in practice. However, a lady presented at clinic whose stoma was situated in her lower abdomen and she was constantly experiencing leaks. When reviewing her lying down, her stoma had a good spout and the surrounding surface was flat. However, when she sat up on the couch she had a significant crease across the location of the stoma due to the positional change. She was wearing a convex pouch with a small area of convexity and a seal and was experiencing problems. Thus,

a change of convexity size with a wider base plate was discussed and the author explained to the patient how this might flatten the creases on movement, reducing the risk of leaks. Initially, the patient was unsure if this would help, but was happy to try and the following day she called to say that she had slept all night without a leak — the first time in three years. This consultation was a 'lightbulb moment' for the author, as by applying theory in practice, this case cemented the education with the results being better than expected.

Later that week, the author reviewed another patient in clinic who had reduced mobility and used a wheelchair. She experienced several leaks in a day and said that one day while out with friends she had had to buy four new outfits due to frequent leakage.

Having gained consent to examine the patient she lay on the couch without her pouch for assessment. The stoma was measured to ensure that the cut size was correct, as this can contribute to frequent leaks, but it was appropriate. When lying down again she had a flat body profile and her stoma had a good spout. However, the peristomal skin was red and excoriated, which caused her pain when the area was cleaned. On being asked to sit up, there was a large horizontal crease due to a skin fold. Following this assessment, the author again felt that applying the tension location theory would help achieve a secure seal.

Patient feedback

The following are a few comments which the author has received from patients:

'I hadn't had a full night's sleep since surgery.'

'Now I don't leak any more and my pain has gone as I had such sore skin.'

'I've had the confidence to buy a white dress.'

And, perhaps the most rewarding: 'I can wear a suit to my wedding.'

Thus, the author discussed the option of trying a base plate with a larger surface area of convexity, explaining to the patient how this may flatten the crease on movement and bending and help to reduce leaks, as the tension of the convexity was applying pressure in a wider area. The patient was happy to try this alternative and when fitted in clinic with the new pouch, it appeared to achieve a more secure fit. She felt comfortable with the new product and was hopeful that this would work.

Three days later the patient contacted the author to say that she had not experienced any leaks and that she had spent a day out in her chair, which was when she usually experienced the most problems. She was delighted as it was such a positive result in such a short space of time.

On speaking with her a month later, she said that she no longer had leaks and output on her skin for long periods of time and as a result of this her pain had resolved. She was gaining confidence and was going out more, feeling happy and confident that her pouch would not leak.

Due to such outcomes, the author has continued to apply this method of convexity to other patients. Admittedly, not every review has been a success, but there have been more positive than negative outcomes.

CONCLUSION

The worry of experiencing frequent leaks can have a devastating effect on an ostomate's quality of life leading to anxiety, loss of confidence, social isolation, and even depression. As clinicians, it can sometimes be challenging trying to work out how to prevent them, as every stoma is unique in shape, size and location. While leaks cannot be prevented for everyone, adopting a different review process and looking at convexity holistically with a fresh view can be beneficial and lead to positive outcomes. **JCN**

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Understanding wound malodour: patient and clinician perspectives

Kirsty Mahoney

Wound malodour is often an unpleasant side-effect experienced by patients with hard-to-heal wounds. The impact on mental and physical wellbeing is profound and can result in embarrassment, social isolation, depression and nausea. This list is not exhaustive and understanding the effect of malodour on an individual should be considered during holistic patient assessment. This article presents the findings of two surveys which aimed to gain a deeper understanding of the impact that malodour has on individuals and also the challenges experienced by healthcare professionals (HCPs) when treating patients with malodorous wounds. The patient survey was completed by 29 people, of which 76% (n=22) experienced wound malodour. The HCPs survey was completed by 789 respondents and challenges highlighted included lack of training and education, limited access to appropriate dressings and managing patient expectations.

KEYWORDS:

- Wound malodour ■ Malodour assessment ■ Quality of life
- Challenges of wound malodour ■ Dressing selection

Hard-to-heal wounds present a significant challenge both financially for healthcare organisations and personally for individuals who suffer from them (Black and Berke, 2020; Guest et al, 2020). Many of these wounds are accompanied by distressing symptoms, such as pain, excessive exudate, and malodour, all of which can significantly affect a patient's quality of life (Samala and Davis, 2015; Gethin 2023a; Probst and Saini, 2024). Patients experiencing malodour often resign themselves to living with the condition, which negatively impacts on many aspects of mental and psychological wellbeing, and may include nausea, depression, embarrassment, and social isolation (Gethin, 2023a).

'Patients experiencing malodour often resign themselves to living with the condition, which negatively impacts on many aspects of mental and psychological wellbeing... '

Causes of malodour are complex and multifactorial, with infection being the most common factor (Black and Berke, 2020). Other contributors include the presence of devitalised tissue (e.g. slough and necrosis), fungating/malignant wounds (MFWs), certain wound dressings (e.g. hydrocolloids), and poor general hygiene (Pramod, 2025).

Despite its impact, managing wound malodour remains challenging for healthcare professionals (HCPs) due to inconsistencies in odour assessment, lack of standardised treatment protocols, and limited evidence-

based guidance in the literature (Gethin et al, 2023a; 2023b). Effective management begins with comprehensive patient assessment to identify barriers to healing and establish a diagnosis to guide care planning (Marshall, 2022; Pramod, 2025).

Assessing wound malodour is particularly difficult due to its subjective nature and the absence of a standardised assessment tool (Akhmetova et al, 2016). Malodour perception may also vary between patients and clinicians (Gethin et al, 2023b), and some individuals — including HCPs and patients — may experience anosmia (loss of smell) due to conditions such as post-Covid-19 effects or certain medications (Li and Lui, 2023). Patients may also become desensitised to the smell over time (Fleck, 2006).

Several grading and classification scales are available for assessing malodour, including the visual analogue scale, Teler[®] Scale and the Haig and Baker Scale (Akhmetova et al, 2016). The visual analogue scale and the Haig and Baker Scale are relatively simple to use, whereas the Teler[®] Scale involves a more detailed two-part assessment — one evaluating odour strength and the other assessing its impact on the individual (Browne et al, 2004; Fletcher, 2008). However, odour assessment scales are not commonly used in clinical practice. A survey by Gethin et al (2014) involving 1,444 HCPs found that only 12% assessed wound odour, primarily using descriptive terms, while just 4.5% of nurses employed a formal odour evaluation scale.

Additionally, there is limited guidance on validated treatment

options for managing wound malodour (Gethin et al, 2023b), often leading to a trial-and-error approach that can result in suboptimal patient outcomes (Gethin et al, 2014). Effective treatment should prioritise identifying and addressing the underlying cause along with managing patient concerns and expectations (Black and Berke, 2022).

There is limited research on the impact of wound malodour on individuals and the management challenges faced by HCPs. This article presents findings from two surveys conducted with both patients and HCPs, aiming to explore the complex challenges associated with experiencing or treating wound malodour. The survey results offer valuable insights into patients' lived experiences and the daily impact of malodour on their lives. Additionally, the findings highlight areas in clinical practice that may require improvement to better support HCPs in managing this issue effectively.

METHOD

Richardson Healthcare, in partnership with JCN, conducted two surveys to explore the impact of malodour on individuals with wounds, as well as the challenges HCPs face and their confidence in managing wound malodour.

Survey one, the patient survey, targeted members of the In This Together (ITT) community, a forum supporting individuals living with wounds or requiring compression. ITT members were invited to participate via an e-newsletter link. This survey included seven multiple-choice questions, allowing participants to select the most appropriate responses. Survey two, the HCP survey, consisted of eight questions, with opted-in users of the *Journal of Community Nursing* (JCN), *Journal of General Practice Nursing* (GPN) and *Wound Care Today* (WCT) websites invited to participate through an e-newsletter link. To provide deeper insights, both individuals with wounds and HCPs were also invited to share free-text summaries of their experiences and challenges related to wound

malodour. Both surveys were available from 04/2/25–24/2/25.

RESULTS

A total of 29 individuals who had experienced wound malodour completed survey one and 789 HCPs survey two. However, it should be noted that not all respondents to the surveys answered all questions so numbers (n) of respondents may vary according to the question.

Survey one — patient survey Does your wound smell or have you ever had an odorous wound?

Over 76% (n=22) of respondents indicated that they currently have or have had a wound that was malodorous.

Where is your wound located?

Five respondents (17%) chose not to indicate the position of their wound. The majority of respondents (54%, n=14) indicated that their wound was present on the leg. Other wound locations included the foot (12%, n=3), stomach (12%, n=3). The ear, ankle, bottom and rectum represented 3% (n=1) respectively of wound locations.

How does the smell impact on your life?

Five respondents chose not to answer this question. Malodour affected various aspects of the respondents' quality of life, with embarrassment being the most common impact (29%, n=7). Depression, self-isolation, and resistance to treatment were reported by 12.5% (n=3), while nausea and anxiety were experienced by 8% (n=2). One respondent indicated that wound malodour affected friends and family. Additionally, another respondent indicated that the malodour had resulted in a lack of confidence in clinicians.

What is the most distressing symptom that you experienced with your wound?

Three respondents chose not to answer this question. Pain was identified as the most distressing symptom, affecting 46% (n=12) of respondents. Odour was also a significant concern, reported by 27%

(n=7). Other distressing symptoms included leakage (15%, n=4), frequent dressing changes (8%, n=2), and lack of information (4%, n=1).

Do you feel comfortable speaking with your clinician about the smell?

Four respondents chose not to answer this question. Most of the respondents (68%, n=17) indicated that they felt confident in speaking to their clinician about the odour from their wounds. However, there were 32% (n=8) who did not feel confident.

Do you think your clinician is dealing with the smell effectively?

Two respondents chose not to answer this question. The majority (70%, n=19) felt that their clinicians managed wound odour effectively. However, 30% of respondents believed that their wound malodour was not adequately addressed.

Do you think your overall experience of care would improve if your clinician got rid of the smell?

Three respondents chose not to answer this question. Many (62%, n=16) stated that their overall wound care experience would improve if their clinician could eliminate wound malodour. However, 38% (n=10) felt it would not significantly impact their overall experience. Two respondents indicated that they did not see a clinician to manage their wound, this may imply that these respondents were self-managing their wounds.

Survey 2 — healthcare professional survey

What percentage of your current caseload has a malodorous wound?

Just over half of the respondents (51%, n=402) reported that malodour was present in less than 20% of their caseload. Meanwhile, 26% (n=209) noted that it affected more than 20% of cases, and 16% (n=130) indicated it could be present in over 40%. Additionally, 5% (n=38) estimated that malodour affected more than 60% of their caseload, while a small proportion (1%, n=10) believed that it could impact up to 80%.

Do you know the causes of malodour?

The majority of HCPs indicated that they were aware of the causes of

Table 1: Common themes in challenges when trying to manage malodorous wounds

Theme	HCP comments
Dressings	▶ Poor availability and access to appropriate dressings ▶ Not enough choice of products ▶ Many dressings did not have the ability to manage the malodour effectively ▶ Products available did not manage the combination of symptoms that were present within the wounds, such as high volume of exudate, odour and infection ▶ Leakage of malodorous exudate onto bandages
The patient	▶ Managing patient comfort was considered both a challenge and a priority ▶ Respondents believed that embarrassment, social isolation, distress and poor quality of life was experienced by patients with malodorous wounds ▶ Patient compliance with treatment ▶ Managing patient expectations
Knowledge	▶ Lack of knowledge when assessing the cause of wound odour ▶ Poor understanding of what is the most appropriate product that could assist in odour management
Wound types	▶ Leg ulcers and fungating wounds were cited as being particularly difficult to manage when considering odour
Effects of malodour	▶ Wound malodour made some respondents feel 'physically sick' ▶ Hiding their response to the odour to the patient was sometimes a challenge ▶ Effects of malodour on other patients or relatives

malodour (71%, n=558). However, 25% (n=194) had limited awareness of malodour and 5% (n=37) did not know what caused wound odour.

Do you receive any training in managing malodour?

This question had 787 responses. Limited training on malodour was reported by 44% (n=345) of respondents, while 24% (n=191) had received no training at all. Additionally, only 32% (251) of respondents stated that they had received adequate training on wound odour.

How challenging do you find managing malodour?

This question received 788 responses. Only a small minority found wound malodour not challenging (9%, n=69), and for most respondents malodour was either moderately challenging (39%, n=304) or slightly challenging (37%, n=291). Additionally, there were some respondents that found malodour management either very challenging (14%, n=107) or extremely challenging (2%, n=17). HCPs had the opportunity to elaborate on the challenges they faced through a free-text response, with 46% (n=359) choosing to provide comments.

Common themes and key insights from their responses are summarised in *Table 1*.

Do you feel comfortable speaking to your patients about malodour?

This question received 785 responses. The majority of respondents (64%, n=500) felt comfortable discussing malodour with patients, while 28% (n=223) indicated that they sometimes felt uncomfortable addressing the topic. Respondents had the opportunity to express their thoughts around why they found speaking about malodour uncomfortable in a free text option of which 23% (n=185) chose to express their views. The respondents' opinions revealed recurring themes, including:

- ▶ It was hard to discuss with the patient if the patient was not aware of the odour
- ▶ Difficult to discuss malodour in palliative patients
- ▶ It was considered 'a hard to discuss', 'sensitive' or 'taboo' subject to address with patients
- ▶ Respondents were concerned about 'upsetting', causing 'embarrassment' or that it may affect a patient's 'self-esteem'
- ▶ Some patients may not have the capacity to understand that they

had wound malodour due to disease processes such as dementia

- ▶ Lack of knowledge, training, experience and confidence was indicated by some respondents.

In order of severity please grade the impact of wound complications on patients

This question received 775 responses. HCPs identified pain as the wound complication that impacted most on patients (47%, n=364), followed by malodour as the second most distressing symptom (20%, n=154). Infection (19%, n=143) and excessive exudate (15%, n=114) were reported as the least impactful.

What is your first-choice dressing category for managing malodour?

This question received 788 responses. Many of the respondents (43%, n=340) indicated that antimicrobial dressings were their preferred choice for managing wound malodour, followed by carbon dressings, used by 40% (n=316). Absorbent dressings were chosen by 8% (n=65), while scented dressings were the least popular option (1%, n=7). Additionally, 8% (n=60) had no specific dressing preference.

What challenges do you experience with the dressings currently available for malodour?

This question received 786 responses. Limited choice of dressings was cited as the most problematic challenge experienced by respondents (44%, n=342). Availability of dressings was also problematic for 27% (n=210) of respondents. Some other challenges cited were absorption (15%, n=116), sizes (5%, n=39) and dressing retention (3%, n=26). Respondents had the opportunity to share additional challenges through free-text responses, with 5% (n=40) choosing to do so. Some of the consistent trends that were observed included:

- ▶ Cost of dressing
- ▶ Lack of conformability to limb or body shape
- ▶ Limited availability or no availability on local formulary or from suppliers

- ▶ Dressings available for malodour in area of practice are ineffective
- ▶ Limited clinician knowledge.

DISCUSSION

Malodour was reported by 76% of patients in the survey, with HCPs identifying it as the second most significant factor impacting patients, after pain. Similarly, patients ranked malodour as one of the most distressing symptoms, alongside dressing leakage, frequent dressing changes, and lack of information. These findings align with previous studies by Pramod (2024) and Gethin et al (2014).

The effect of malodour on quality of life has been previously explored (Gethin et al, 2023a), with this survey echoing similar findings. Embarrassment was the most reported impact, followed by social isolation, resistance to treatment, nausea, and anxiety, further highlighting the profound effect which malodour can have on individuals. Furthermore, Gethin et al (2023a) established that patients often accept malodour as an unavoidable part of living with a chronic, non-healing wound and develop their own strategies to manage it. These include increasing the frequency of dressing changes, changing clothes and bed sheets more often, and using deodorants, incense, or candles to mask the smell.

When discussing malodour with HCPs, 68% of patients (n=17) felt confident in raising concerns, whereas 32% (n=8) did not feel comfortable doing so. Additionally, 30% (n=8) believed that their wound odour was not being managed effectively.

Most HCPs expressed confidence in discussing malodour with patients; however, 28% (n=223) lacked confidence in certain situations, particularly when caring for palliative patients due to concerns about causing distress, embarrassment, or their own lack of knowledge and training. Some HCPs believed malodour was a difficult to discuss or taboo subject. Moreover, 44% (n=345) reported receiving limited training, while 24% (n=191) had no



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training at all. Gethin et al (2023a) emphasised the urgent need for HCPs to recognise, assess, and better understand how patients experience wound odour and how it impacts on an individual.

There was only a minority of HCPs (9%, n=69) who reported that they found malodour management unchallenging, with the majority finding it either slightly or moderately challenging. Commonly cited challenges (*Table 1*) included:

- ▶ Lack of training and education
- ▶ Limited knowledge among HCPs
- ▶ Cost and accessibility of appropriate dressings
- ▶ Ineffectiveness of dressings in managing symptoms
- ▶ Patient compliance and expectation management.

The HCP survey focused exclusively on topical treatments,

without exploring other malodour management strategies such as wound cleansing and debridement. Further research into additional odour reducing techniques would be valuable. The survey also did not explore any detail on the rationale behind why HCPs selected a particular type of dressing. An understanding of this in clinical practice would be beneficial to develop further insight into this area. Results of the current survey, however, revealed that antimicrobial dressings were the most used option for managing malodour (43%, n=340), followed by carbon dressings (40%, n=316). Conversely, a recent systematic review on topical treatments for malodour (Gethin et al, 2023b) highlighted a lack of research in this area, with no standardised or consistent outcome measures reported for these products. Further guidance on appropriate

management options for malodour and introduction of a standardised approach into clinical practice would assist in improving clinical outcomes for patients.

These findings highlight the need for improved education, standardised assessment tools, and better access to effective treatment options to enhance malodour management and patient care. Using an objective odour assessment tool, such as the Teler® Scale, could provide a more structured approach to evaluating and defining malodour (World Union of Wound Healing Societies [WUWHS], 2019) and assist HCPs in understanding how living with malodour can affect individual quality of life.

LIMITATIONS

Both surveys were distributed online, limiting participation to individuals who are computer-literate and able to complete an online survey, potentially restricting access to a broader population. This may be the reason for the low response rate in the patient survey (n=29). The patient survey was distributed via registered members of In This Together, meaning only those within their database had access, which may not reflect the wider population who experience wound malodour. Similarly, the HCP survey was shared through the JCN, GPN and WCT websites, restricting participation to its members and excluding a broader range of healthcare professionals, such as GPs.

Despite the recognised challenges of low response rates and selection bias in surveys (Eysenbach, 2005), the HCP survey received enough responses to draw meaningful conclusions about the experiences of treating patients with malodour and the challenges encountered in clinical practice. Additionally, although the patient survey had a smaller sample size, it still provided valuable insight into the lived experience of individuals with malodorous wounds.

CONCLUSIONS

The surveys highlight the significant

impact of wound malodour on quality of life, with embarrassment, distress, and emotional challenges being key concerns. While many patients felt confident discussing odour with clinicians, a notable proportion did not or felt their concerns were unmet. While most HCPs believed that they were confident in diagnosing the causes of malodour, many had received limited or no training in its assessment and management. Additionally, several challenges were expressed by HCPs, especially regarding access to knowledge and training, cost of dressings, availability and access to effective dressings, and managing patient expectations.

Standardising odour assessment and treatment protocols is crucial for improving care. Further research is needed to develop reliable tools and evidence-based guidelines. These findings underscore the need for better clinician-patient communication, enhanced management strategies, and greater support to address both the physical and psychological effects of wound malodour. **JCN**

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HCPs' attitudes regarding current wound care treatments

Kirsty Mahoney

Hard-to-heal wounds present a significant challenge in healthcare, requiring a comprehensive understanding of the wound healing process and effective management strategies. A survey was conducted by the *Journal of Community Nursing* among its registered online members to explore the current opinions and challenges faced by healthcare professionals (HCPs) who are involved in delivering wound care, including opinions on advanced wound therapies. The survey, which consisted of 14 questions, highlighted some interesting findings including several challenges experienced when treating patients with wounds. Results revealed that 69% (n=311) of participants indicated a lack of time and resources as the primary barrier. Patient compliance (67%, n=303), limited access to advanced therapies (47%, n=211), insufficient training (37%), and cost pressures (32%, n=145) were also significant concerns. Despite these challenges, most respondents (63%, n=281) felt 'somewhat satisfied' with their ability to manage wounds, but found the process frustrating due to the difficulties that they encountered.

KEYWORDS:

- Hard-to-heal wounds ■ Wound recurrence ■ Healing times
- Challenges in wound care ■ Advanced wound care products

Wounds that fail to heal or show significant progress after four weeks, despite optimal treatment, have traditionally been classified as 'chronic' wounds (Doughty and Sparks-DeFries, 2016; Murphy et al, 2020). However, more recently, it has been suggested that the term 'chronic wound' be replaced with 'hard to heal', emphasising the possibility of overcoming barriers to healing and shifting the perspective towards a more optimistic outlook for wounds that are slow to heal (Murphy et al, 2020). Several factors can contribute to impaired healing (Table 1), and effective management requires clinicians to conduct holistic assessment, identifying and addressing underlying barriers to healing whenever possible (Wounds

UK, 2018). Failure to do so can lead to unwarranted variations in care and increased reliance on non-evidence-based practices, further exacerbating the burden of hard-to-heal wounds (Gray et al, 2018).

The significant economic burden of hard-to-heal wounds is well documented (Wounds UK, 2018; Guest et al, 2020). A study by Guest et al (2020) estimated that approximately 3.8 million wounds are treated annually in the UK, with an associated cost of £8.2 billion per year. Notably, 81% of these wounds are managed in community settings, placing substantial demand on resources such as district nurse visits, practice nurse appointments, and costs associated with wound dressings. Additionally, the study found that the healing rate for chronic wounds was around 59% when no infection was present. This economic burden is expected to rise in the coming years due to an ageing

population with increasingly complex comorbidities (Guest et al, 2020).

The burden of hard-to-heal wounds extends beyond financial and resource constraints. Patients with non-healing wounds often experience a significant decline in quality of life, facing challenges such as sleep disturbance, pain, mental health issues, and social isolation. This list is not exhaustive and each patient with a wound will have a different experience — an important consideration when developing an individualised plan of care (Wounds UK, 2018).

Factors contributing to chronicity include:

- ▶ Failure to conduct accurate clinical assessment and reach a correct diagnosis
 - ▶ Failure to treat underlying comorbidities that contribute to poor healing
 - ▶ Lack of engagement with the multidisciplinary team (MDT) to assist in managing complex care (e.g. vascular specialists, dieticians, physiotherapists, psychologists, tissue viability nurses)
 - ▶ Patient compliance
 - ▶ Use of non-evidence based practice
- (Gray et al, 2018; Wounds UK, 2018; Guest et al, 2020).

Additionally, limited access to wound care training and education can contribute to suboptimal care, ultimately leading to poorer patient outcomes (Grothier, 2018; Wounds UK, 2018; Atkin, 2020).

The potential of a wound to become chronic or hard to heal should be identified via holistic assessment (Wounds UK, 2018). For these patients, access to appropriate advanced therapies is gaining

great interest with the possibility of increasing healing potential (European Wound Management Association [EWMA], 2008; Piaggese et al, 2018). Advanced wound therapies, such as negative pressure wound therapy (NPWT), oxygen therapy, electrical stimulation, medications, growth factors, and cell-based therapies (among others), may initially appear more costly (EWMA, 2008). However, if they contribute to faster healing rates, they could prove to be more cost-effective in the long run (EWMA, 2008; Piaggese et al, 2018). Ongoing research continues to assess their efficacy, cost-effectiveness, and optimal use in clinical practice to ensure that they are applied appropriately and deliver the best patient outcomes (Piaggese et al, 2018).

This article discusses the findings of a survey to healthcare professionals (HCPs) to establish their current perspectives on wound care provision in their field of practice and identify some of the challenges that are faced in clinical practice. It also highlights their views and use and acceptability of advanced wound therapies.

AIM

A survey was conducted to gain a deeper insight into the challenges and attitudes of HCPs when treating hard-to-heal wounds, and to determine opinions of advanced wound therapies.

METHOD

The survey consisted of 14 questions (13 had fixed answers with one having an opened-ended option), and opted-in users of the *Journal of Community Nursing* (JCN) website were invited to take part via an e-newsletter link. The survey was available between 8–22 January, 2025. Results were collated automatically using survey software and cross-referenced to data gathered in excel.

RESULTS

Over the period of the survey (two weeks), a total of 451 HCPs responded. However, it should be noted that not everyone answered

Table 1: Factors that can contribute to poor wound healing (adapted from Wounds UK, 2018; Atkin, 2022; Grey and Patel, 2022)

Patient factors	Wound factors
Age	Devitalised tissue, e.g. slough/necrosis
Obesity	Size and position of wound
Smoking	Presence of infection
Malnutrition	Poor blood supply
Medication, e.g. steroids/immunosuppressants	Duration of wound
Comorbidities, e.g. diabetes, rheumatoid arthritis	Recurrence of wound
Poor mobility	Increases risk of pressure ulceration, reduced blood supply and leg oedema
Psycho/social issues, e.g. mental health issues, substance misuse, non-concordance with treatment	Mental health issues, substance misuse, non-concordance with treatment can contribute to poor healing

all 14 questions so numbers (n) of respondents may vary according to the question (Table 2). Responses to the questions are now presented.

Primary role in wound care

Participants were asked to describe their current role or job position. The most common role was general nurse (29%, n=129). Specialist nurses, including district and practice nurses, accounted for 26% (n=119), while tissue viability nurses (TVNs) made up 14% (n=65). Healthcare assistants comprised 6% (n=26), and physicians represented 1% (n=5). Additionally, 23% (n=106) of participants selected 'other' as their job role, which included various nursing positions such as nursing associates, student nurses, nurse practitioners, dermatology nurses, palliative care nurses, and homeless practitioners. The survey also included responses from podiatrists and foot health specialists, highlighting the diverse range of disciplines and healthcare settings represented.

Number of years working in wound care

A significant portion of respondents had over 10 years' experience of delivering wound care (49%, n=222), while 28% (n=127) had been working in the field for one to five years, suggesting a considerable level of expertise among the clinicians surveyed. Additionally, 18% (n=79) had six to 10 years of experience, and a smaller group (5%, n=21) had less than one year's experience.

Primary place of work

The majority of respondents worked in community care (41%, n=187), with acute care represented by 30% (n=135). 11% (n=50) worked within long-term care, which included nursing homes, and 17% (n=79) worked in other areas of healthcare.

Most common types of wounds encountered in practice

Pressure ulcers were the most frequently encountered wound type, reported by 67% (n=305) of respondents. Venous leg ulcers followed closely at 63% (n=284), while surgical wounds were seen by 60% (n=271). Diabetic foot ulcers were reported by 52% (n=237), and arterial ulcers by 34% (n=154). Additionally, 18% (n=83) of respondents commonly encountered other wound types, including traumatic wounds, skin tears, malignant fungating wounds, and self-harm wounds.

Primary treatment goal when managing chronic wounds

The primary treatment goal reported by most respondents (82%, n=371) was a combination of achieving complete wound healing through tissue regeneration and closure, while also managing symptoms such as exudate control, maintaining skin health, reducing odour, and improving quality of life. A smaller proportion (9%, n=42) focused solely on achieving complete wound healing, while 6% prioritised symptom management as their main goal.

Table 2: Questions and number of respondents for each

Question	Number of respondents
What is your primary role in wound care?	450
How many years have you been working in wound care?	449
In which type of setting do you primarily work?	451
What are the most common types of wounds you encounter in your practice (select all that apply)?	451
When managing chronic wounds, which of the following best reflects your primary treatment goal in practice?	450
What percentage of the wounds you manage do not appear to improve or heal over time?	443
For wounds that do heal, how often do you observe recurrence?	440
How would you rate your job satisfaction in managing these wounds considering the challenges of slow or non-healing wounds?	443
How important is time to healing in your approach to wound care?	447
What are the top three challenges you face in delivering effective wound care?	451
How often do you use advanced wound care products or technologies (e.g. negative pressure wound therapy, bioengineered skin substitutes)?	448
How open are you to adopting new wound care technologies or methods (e.g. fat-derived stem cells, AI-based wound assessment tools)?	448
What factors would encourage you to adopt new wound care innovations?	450
If a single-treatment therapy were available that could heal most wounds within six weeks, how would it impact your perspective on chronic wound management?	336

Percentage of wounds that did not appear to improve or heal

A high proportion of respondents (63%, n=281) reported that 0–25% of the wounds that they managed did not heal or improve over time. A slightly lower proportion (23%, n=101) indicated that 25–50% of wounds failed to heal or improve. A minority (10%, n=46) stated that 50–70% of their managed wounds did not heal, while 3% (n=15) reported that 75–100% of wounds failed to show improvement or heal over time.

Recurrence observed in wounds that healed

Recurrence was most commonly reported in up to 25% of wounds, as indicated by 56% (n=241) of respondents. For 25–50% of wounds, recurrence was reported by 34% (n=148). Additionally, 8% (n=36) experienced recurrence in 50–75% of wounds, while 2% of respondents

reported recurrence in 75–100% of wounds.

Job satisfaction considering the challenges faced when managing hard-to-heal wounds

Many of the respondents (63%, n=281) indicated that they were somewhat satisfied with the management of hard-to-heal wounds, acknowledging that while they handled the challenges well, the process could sometimes be frustrating. Meanwhile, 28% (n=123) reported feeling confident and fulfilled in their role, expressing job satisfaction despite the challenges. A smaller percentage found that the challenges arising in caring for people with hard-to-heal wounds made their job less rewarding (8%, n=27), while 2% (n=11) stated that these challenges had a negative impact on their overall job satisfaction.

Importance of time to healing in respondents' approach to wound care

Half of the respondents (50%, n=223) believed that healing time was very important and a key factor in their approach to wound management, although not the sole focus. Meanwhile, 31% considered healing time to be extremely important and a top priority. Additionally, 21% (n=93) stated that while healing time was somewhat important, other factors were equally significant. Only 2% (n=8) indicated that healing time was neither important, nor a primary consideration.

Top three challenges faced when delivering effective wound care

An overwhelming 69% (n=311) of respondents identified lack of time and resources as the primary challenge to delivering effective wound care. Patient compliance was also a significant concern, cited by 67% (n=303). Additionally, 47% (n=211) highlighted limited access to advanced therapies, while 37% (n=169) reported insufficient training and education as a challenge. Cost pressures were also a factor, noted by 32% (n=145) of respondents. Additionally, 11% (n=50) indicated that there were other challenges such as patients at the end of life, communication with other HCPs, and poor availability of appropriate dressings, which proved challenging to delivery of effective care.

Use of advanced wound care products or technologies

Some respondents (39%, n=176) indicated that they occasionally used advanced wound care products in selected cases. Meanwhile, 27% (n=120) reported rarely using them, and 21% (n=93) stated that they never used advanced products. Only a small percentage (13%, n=59) frequently incorporated advanced wound care products into their practice.

Openness to adopt new wound care technologies or methods

There were 45% (n=200) of respondents who were very open to adopting new wound care technologies, 27% (n=120) were

somewhat open and 25% (n=110) were neutral. A small proportion were either somewhat resistant (4%, n=16) or very resistant (0.45%, n=2) to adopting new wound care technologies.

Factors which would encourage adoption of new wound care innovations

The leading factor encouraging participants to adopt new wound care innovations was strong evidence of clinical efficacy, cited by 88% (n=396) of respondents. Training and education were also highly valued, with 82% (n=370) considering them important. Other key factors included ease of use (69%, n=312), cost-effectiveness (68%, n=306), and support from management (66%, n=298). In contrast, patient demand was only considered important by 34% (n=153) of respondents.

Impact on chronic wound management if a single-treatment therapy could heal wounds within six weeks

This question allowed respondents to provide free-text responses about the potential impact of a single-treatment therapy capable of healing most wounds within six weeks. While 5% (n=17) were sceptical, doubting whether such a treatment could exist or effectively aid in chronic wound management, the overwhelming majority (95%, n=319) believed it would be highly beneficial. Many described it as 'amazing', 'brilliant', and a 'game changer', emphasising its potential to significantly improve patient outcomes, reduce nursing visits, and lower overall healthcare costs.

DISCUSSION

The majority of respondents worked within the community setting (41%), which is not surprising since most wound care is thought to be delivered in the community (Guest et al, 2020).

The most common wound types encountered by respondents was similar to other studies exploring wound aetiologies (Gray et al, 2018; Guest et al, 2020), and included pressure ulcer, venous leg ulcers and diabetic foot wounds. These wounds

are also the most commonly cited wounds linked to chronicity, usually as a consequence of underlying pathological processes (Pignet et al, 2024). While issues surrounding non healing of chronic wounds have been previously discussed, for some patients, due to their complexity, wound healing may not be an appropriate outcome and understanding what is important to them and managing symptoms becomes the priority, rather than healing (EWMA, 2008). This was reflective in respondents' responses where just 10% indicated that wound healing was the only primary goal. Most respondents (82%) felt that their primary goal was a balance between achieving complete wound healing and managing symptoms such as exudate volume, skin health maintenance, odour reduction, and improving the individual's quality of life. This is a crucial consideration, as HCPs' goals may differ from those of patients (Trouth, 2024). Aligning care with patient priorities fosters co-production and enhances compliance, which can ultimately influence the healing process (Trouth, 2024), and is also a key component of true evidence-based practice.

Healing rates among respondents varied, with 63% reporting that only 0–25% of wounds failed to heal, while 37% indicated that 25–100% of treated wounds did not heal over time. Further investigation is needed to determine whether this is associated with specific wound types, the role of the respondent (e.g. end-of-life settings would aim for symptom control), or other factors that may influence healing. Similar findings however were reported in a study by Guest et al (2020), which found that only 59% of chronic wounds without infection healed within the study period, dropping to 45% when infection was suspected.

Recurrence rates were reported in less than 25% of patients by 56% of respondents; however, 44% experienced high recurrence rates. While this survey did not investigate which wound types were most prone to recurrence, Rosenblum et al (2017) highlighted that recurrence within six months of healing remains a

significant issue, affecting 40% of leg ulcers and diabetic foot wounds — a possible effect of the underlying condition for which there is no cure.

Respondents indicated that they faced several challenges when trying to deliver effective wound care, with 69% citing a lack of time and resources as the primary barrier. Patient compliance (67%), limited access to advanced therapies (47%), insufficient training (37%), and cost pressures (32%) were also a significant concern. Atkin (2020) emphasised that wound care places a significant demand on NHS resources, yet is often overlooked and does not always receive the recognition or support needed for effective management. Grothier (2018) indicated that evidence-based clinical guidance in wound care often could not be implemented due to lack of resources leading to frustration in HCPs trying to deliver effective wound care. Additionally, wound care education is frequently deprioritised in the face of resource challenges, such as staff shortages (Grothier, 2018; Atkin, 2020).

Given the substantial financial pressures on the NHS, it is more crucial than ever to implement strategies that promote cost-effective, evidence-based care (Gray et al, 2018). Grothier (2018) also identified patient concordance as a significant challenge in wound care. Overcoming non-concordance can be difficult, but may be improved through a patient-centred approach that emphasises engagement and education (Grothier, 2018; Wounds UK, 2018).

Despite the challenges, most respondents (63%) felt somewhat satisfied or very satisfied (28%) with their ability to manage hard-to-heal wounds, although some found the process frustrating.

Use of advanced wound care products varied, with 39% of clinicians using them occasionally, while 27% rarely use them, and 21% never do. Only 13% frequently incorporate these products into their practice. The adoption of new wound care innovations is primarily driven by strong clinical

evidence (as indicated by 88% of the survey respondents) and training and education (82% of the survey respondents). Other influencing factors include ease of use (69%), cost-effectiveness (68%), and management support (66%), while patient demand plays a lesser role (34%). Anecdotally, access to advanced wound care products may be influenced by knowledge and expertise of the clinician and availability and cost of the product. AI technologies, such as digital wound solutions that assist in assessment, have gained interest in the past few years and certainly can contribute to increasing the accuracy of wound assessment and diagnosis (Piaggese et al, 2018), if their validity and reliability is established.

If a single-treatment therapy capable of healing most wounds within six weeks was available, 95% of respondents believed it would be a game-changer, improving patient outcomes, reducing nursing visits, and lowering healthcare costs. There was great interest shown by respondents to know if such a therapy existed and many wanted to know more about the therapy and the evidence that supported its use in clinical practice.

LIMITATIONS

The survey was distributed through the JCN to its members, which may have excluded other HCPs who treat wounds but do not have access to the JCN site. Thus, the findings potentially may not represent the views of the broader healthcare population. Nevertheless, the respondents comprised a diverse range of healthcare professionals from various healthcare settings, providing a good overview of wound care provision across different clinical environments. A further limitation was that answers were not stratified according to professions, which could have given further insight into job-specific challenges and opinions.

Some survey questions required participants to estimate figures, such as the recurrence rate of wounds or the proportion of wounds that fail to heal or improve over time. This introduces a degree of

subjectivity and the possibility of recall bias. Future research could involve collecting this data directly from caseload managers for greater accuracy, although this approach would be more time-consuming and may require ethical approval.

Despite these limitations, the survey provided a convenient and accessible method for engaging a large number of participants. It offered valuable insights into current wound management practices and highlighted key challenges faced by a wide range of HCPs working in wound care today.

CONCLUSION

The findings of the survey reported here provide a window into the views of and challenges faced by HCPs working in wound care, which are in alignment with published papers on the burden of wound care (Guest et al, 2020). Many HCPs reported significant challenges in delivering evidence-based care, including resource constraints, limited access to training and advanced wound therapies, patient non-compliance, and financial pressures. Despite these difficulties, many HCPs expressed high job satisfaction. Recurrence and non-healing were commonly encountered, with many lacking access to advanced wound care products or technologies but expressing a willingness to adopt them if they were readily available and training was provided. Addressing the challenges of hard-to-heal wounds requires a shift towards evidence-based practice, enhanced clinician education, and early intervention strategies to improve healing rates, reduce healthcare costs, and enhance patient quality of life. **JCN**

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Purple urine bag syndrome: what community nurses should know

Linda Nazarko

Purple urine bag syndrome (PUBS) is reported to be a rare condition that occurs in people who have catheters, chronic constipation and bacterial urinary tract infection (UTI). While in most cases it is harmless, the purple colour of the urine (a result of the breakdown of tryptophan, an amino acid found in food, in the intestines by gut bacteria) can be alarming. The priority is to address any underlying infection and maintain good catheter hygiene. Much of the literature focuses on symptomatic treatment. This paper, based on a case history, uses a more holistic approach to explain what PUBS is, why it occurs, and how it can be treated.

KEYWORDS:

■ Urinary catheterisation ■ Catheter-associated urinary tract infection (CAUTI) ■ Medication review

Purple urine bag syndrome (PUBS) is a condition in which the urine drainage system turns purple due to a reaction involving tryptophan metabolism and certain bacteria (Pandey et al, 2018).

It is reported to be uncommon (Vallejo-Manzur et al, 2005). However, a brief literature search by the author found 400 case reports, so it may be that it is under-recognised in clinical practice. Indeed, there are reports that it can occur in almost 10% of people who have long-term catheters and live in long-term care (Lin et al, 2008).

Risk factors associated with PUBS are being an older female — 70.7% of people with PUBS are women and

'... it is a common misconception that PUBS causes discolouration of the urine, whereas, as said, it is the urine drainage system that is discoloured or changes colour.'

have an average age of 78 (Sabanis et al, 2019). Almost half of cases, 45.1%, have a long-term urinary catheter, and most, 90.1%, have chronic constipation (Sabanis et al, 2019). Urinary tract infection (UTI) that leads to alkaline urine affects 91.3% of cases. Most incidents, 76.1%, are reported to be bedridden patients, 42.8% have dementia and 14.1% have chronic renal failure (Sabanis et al, 2019; Worku, 2019). Table 1 outlines risk factors and possible causes.

WHY DOES PUBS DEVELOP?

Tryptophan is an amino acid that is found in food. It helps keep nitrogen levels in balance and also helps make serotonin, a hormone that regulates mood, sleep patterns, and appetite, which also converts into melatonin,

a hormone that helps to regulate the body clock, i.e. sleep-wake cycles.

Tryptophan is found in both plant and animal proteins. Animal-based proteins like meat, poultry, fish, eggs, cheese, and yoghurt are called complete proteins because they have all nine of the essential amino acids, including tryptophan (Sheik, 2024). Some plant-based proteins, such as quinoa, soy, and buckwheat, are also complete proteins that have tryptophan (Sheik, 2024). Other foods high in tryptophan include prunes, bananas, apples and chocolate. Tryptophan is converted into indole (indigo and indirubin pigments) in the gut. Constipation leads to increased gut transit time, which results in an increase in tryptophan and indigo and indirubin pigments (Jappi and Hadi, 2023).

Indole is absorbed and reaches the liver through the portal vein (Tennoune et al, 2022). The liver conjugates indole to produce indoxyl sulphate, which is secreted into the urine. Certain bacteria in urine produce phosphatases and sulphatases, which convert indole to indoxyl. Indoxyl is then oxidised to indigo (blue pigment) and indirubin (red pigment). These pigments react with the catheter, catheter tubing and the plastic urine bag to cause the purple discolouration seen in PUBS (Bhattarai et al, 2013). Figure 1 illustrates the process.

INFECTION AND PUBS

PUBS develops in the presence of infected urine and a high urinary pH. Common bacteria that produce an alkaline environment are *Providencia*, *Klebsiella*, *Proteus*, and *Enterobacteriaceae* (Shaeriya et al, 2021). Chong (2020) points out that it is a common misconception that PUBS causes discolouration of the

Table 1: Identified risk factors for PUBS (based on Sabanis et al, 2019; Worku, 2019)

Risk factor	Possible causes
Increased tryptophan in diet	Increased substrate for metabolism, i.e. more food to fuel the transformation into indole, the pigment producing substances
Female gender	Increased risk of UTI
Severe constipation	Impaired indoxyl sulphate clearance
High bacterial load	Often causes alkaline urine
Chronic indwelling urinary catheter	
Renal failure	

urine, whereas, as said, it is the urine drainage system that is discoloured or changes colour. A search of 23 papers published in 2018–2019 found that only 26% correctly noted that the urine is not coloured purple (Chong, 2020). Urine is usually of normal colour, or it may be a muddy brown.

TREATMENT AND MANAGEMENT OF PUBS

It is important to be clear what is being treated. Is the clinician proposing to treat the phenomena of a discoloured urine bag, asymptomatic bacteriuria, or a symptomatic catheter-associated UTI (CAUTI).

Adults with indwelling urinary catheters are at increased risk of developing CAUTIs (Nicolle, 2014). The urinary catheter provides a portal of entry into the bladder. Bacteria can enter the bladder during catheter insertion, through the catheter lumen and along the catheter urethral interface. Infection risks rise the longer a catheter remains in place because the bladder becomes colonised with bacteria. The urine becomes cloudy and malodorous and urine dipstick testing is positive to leucocytes and nitrates. If urine is cultured, a mixed growth of bacteria is often found. In the absence of clinical symptoms of UTI, the presence of bacteria in the urine is known as asymptomatic bacteriuria and antibiotic treatment is not required (National Institute for Health and Care Excellence [NICE], 2018).

The presence of a urinary catheter enables bacteria to form a biofilm. This is a sticky, slimy layer that protects bacteria from

both antimicrobial agents and the person's natural immune response (Trautner and Darouiche, 2004; Rubi et al, 2022). When a bladder fills and empties normally, bacteria are flushed away. However, this protection is lost when a person has a urinary catheter on continuous drainage (Rubi et al, 2022).

Some of the literature details administration of intravenous (IV) antibiotics. However, it is unclear if this is for symptomatic CAUTI or asymptomatic bacteriuria (Al Montasir and Al Mustaque, 2013).

Popovic et al (2023) describe a case of an older lady living at home and receiving community caregiver support. The lady had been immobile for some time following a pathological spinal fracture, due to malignant disease

that was in remission. She had a history of constipation and a long-term catheter. Popovic et al (2023) carried out a thorough physical examination and found her overall clinical presentation unremarkable. Caregivers reported mild confusion and the patient was slightly dehydrated. She was treated initially with fosfomycin — it was considered that she had an infection as she was reported to be mildly confused — an antibiotic that is highly effective in the treatment of multidrug-resistant bacteria, including *Proteus mirabilis* (Banerjee et al, 2017), and increased fluids. Popovic et al (2023) argue that PUBS should be treated in asymptomatic patients, as it is indicative of a heavy bacterial burden that could develop into a serious health threat to the patient. In this patient, caregivers reported PUBS but did not seek medical advice for 14 days as they considered that this might have been caused by consumption of beetroot or rosehip tea. Indeed, medical staff were only consulted when caregivers noted mild confusion.

Many clinicians have a differing view. Kwarciak et al (2024) state that intensive antibiotic treatment is usually not recommended. PUBS is almost always asymptomatic

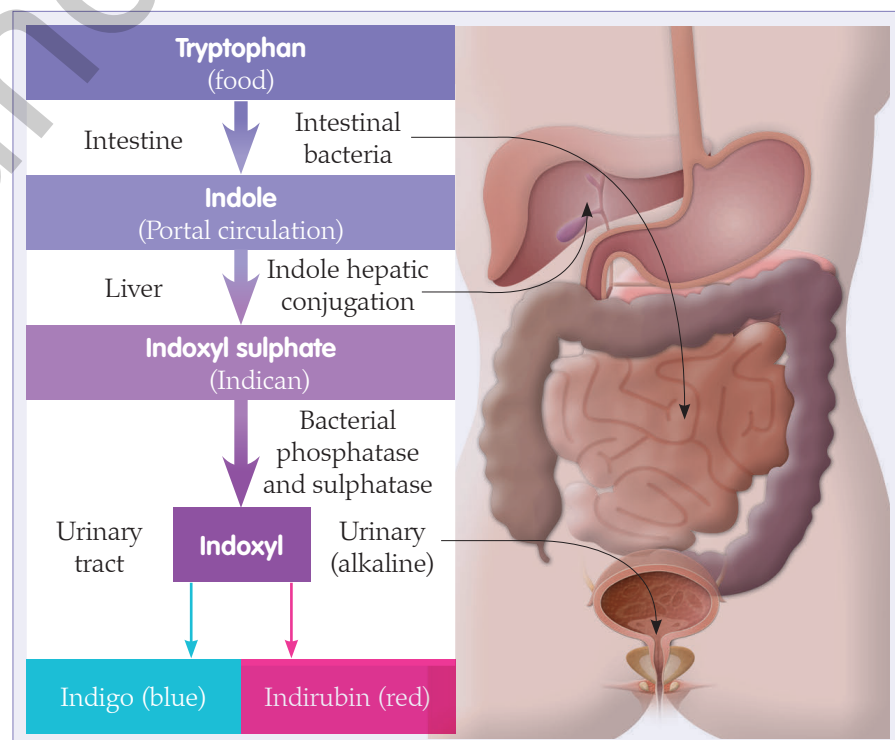


Figure 1.
How PUBS develops.

Mrs Emma Williams is an 82-year-old lady who is resident in a nursing home. She has moderate vascular dementia, hypertension and left-sided weakness following a stroke some years ago. She is doubly incontinent, has had an indwelling urinary catheter since she entered the home some years ago, and uses an incontinence pad. Her catheter, tubing and catheter bag are deep purple and nursing home staff are alarmed. This is known as purple urine bag syndrome (PUBS).

Patient story

literature (cited) recommends that the catheter is changed. The aim is to reduce the bacterial burden in those with asymptomatic bacteriuria and to enable effective treatment if the person has a symptomatic UTI. Changing the urinary catheter removes the bacteria laden biofilm that lives on the catheter (Jappi and Hadi, 2023; Kalsi et al, 2017). Kalsi et al (2017) reviewed published cases, which appear to have been people admitted to hospital. In some cases the review notes documented that the catheter had been changed, but in others it was unclear. The point Kalsi et al (2017) were making is that if the person has what is considered to be a severe infection, the catheter (with its biofilm) is going to impede treatment and should be changed.

Lin et al (2008) recommend removing urinary catheters if at all possible. They also suggest that:

- ▶ Organisations should reduce the use of catheters
- ▶ Minimise duration of use
- ▶ Improve catheter care.

PATIENT STORY

When Mrs Williams developed PUBS she appeared well and at her normal functional baseline. A thorough physical assessment was carried out, bloods were checked for inflammatory markers, and renal function and a medication review was carried out.

Physical assessment was unremarkable. Mrs Williams had a body mass index (BMI) of 17 and was known to the community dietitians. Care home staff reported that she had a poor appetite.

Blood results indicated that Mrs Williams was mildly dehydrated. Care home staff reported that it was difficult to get her to drink, especially in the afternoon as 'she's exhausted by tea time'.

Her medical records gave no indication of the reason for urinary catheterisation. Mrs Williams' daughter said that she was catheterised when she was admitted to hospital following her stroke.

and harmless (Hadano et al, 2012), and is not evidence of a UTI. It can also be difficult to elucidate some infective symptoms because the older person may have dementia (Kalsi et al, 2017). Simple steps, such as checking the National Early Warning Score (NEWS2) (Royal College of Physicians [RCP], 2017), asking caregivers if there has been any change in clinical condition, and checking bloods for indications of infection, such as elevated white cell count, can be helpful in the author's clinical opinion.

Indications for antibiotic therapy include symptomatic UTI, sepsis, signs of infection, or if the PUBS occurs in an immunosuppressed patient. Awareness of this condition is needed to avoid unnecessary investigation and antibiotic use (Worku, 2019). There are no clinical benefits in treating asymptomatic bacteriuria (Zalmanovici Trestioreanu et al, 2015). Indeed, inappropriately treating asymptomatic bacteriuria as an infection exposes the individual to a number of hazards. For example, antibiotic use affects the microbiome, and can decrease natural immunity and increase the risk of infections such as *Clostridium difficile* (Amon and Sanderson, 2017). Antibiotic use can also lead to antibiotic resistance, which can affect not only the individual, but also the general population (Zalmanovici Trestioreanu et al, 2015).

INDICATIONS FOR CATHETERISATION

Indwelling urinary catheters are a focus for infection. Over 124,000 people in the UK have long-term indwelling catheters (Gage et al,

'Most long-term catheters are originally inserted in hospital, but documentation regarding the reasons for indwelling catheterisation is often absent.'

2017; Nazarko, 2024). Most long-term catheters are originally inserted in hospital, but documentation regarding the reasons for indwelling catheterisation is often absent (Rasanathan and Wang, 2020). Long-term catheterisation can be fraught with problems — between 50–70% of people who have long-term catheters experience problems with their catheters (Youssef et al, 2023). Commonly reported problems include bladder pain, catheter leakage, blockage and UTI (Khan et al, 2007; Youssef et al, 2023). These complications have a major impact both on the person's quality of life and the health service. Gage et al (2024) found that in a year:

- ▶ 63% of people with long-term catheters required GP input
- ▶ 43% contacted out-of-hours services
- ▶ 33% required additional community nurse support
- ▶ 15% attended accident and emergency
- ▶ 13.6% were admitted because of problems related to their catheter.

Furthermore, around 30–50% of urinary catheters are inserted without a robust clinical indication (Shackley et al, 2017; Almeida et al, 2020).

When a UTI is identified, the

Medication review revealed that she was on omeprazole, a proton pump inhibitor (PPI), for many years. Her medical records did not provide information about why it was initially prescribed. Mrs Williams had no recorded history of gastrointestinal bleeding, oesophagitis, or any other licensed indication. In up to 70~% of cases, PPIs may be inappropriately prescribed (Gomm et al, 2016). Generally, PPIs are given for eight weeks unless there are indications, such as prophylaxis in patients with a history of non-steroidal anti-inflammatory drug (NSAID)-associated gastroduodenal lesions who require continued NSAID treatment (British National Formulary [BNF], 2024a). Long-term use of PPIs is associated with declining renal function (Hatakeyama et al, 2021), and can be hazardous (Savarino et al, 2018).

Reported adverse events include osteoporosis-related fractures, infections, including *C. difficile*, besides poor absorption of vitamins and minerals such as vitamin B12, magnesium, and iron. There are also reports of increased risk of dementia, pneumonia, myocardial infarction, and stroke (Chinzon et al, 2022).

Mrs Williams was also taking co-codamol 30/500mg two tablets four times a day and had been taking these for years. Co-codamol can cause constipation, drowsiness and nausea (BNF, 2024b). Mrs Williams was prescribed two senna tablets each evening to treat constipation.

Treatment options were discussed with Mrs Williams, her daughter, staff caring for her and her GP. A trial without catheter (TWOC)

was successfully carried out and urinary incontinence managed with incontinence pads. The omeprazole and co-codamol were discontinued. Mrs Williams became more alert and food and fluid intake improved. She was less constipated and senna was discontinued, although she still required lactulose.

DISCUSSION

There is a lack of specific guidelines regarding PUBS, but this may well be because it is rare or unusual. However, relevant guidelines and a body of knowledge relating to medication, the risks and benefits of indwelling urinary catheters and bacteriuria are available. In the author's clinical opinion, these can be used in a holistic way to provide the best possible care for people who develop PUBS.

Nurses working at advanced level can support general practitioners (GPs) and care home staff in caring for vulnerable people with complex care needs. They have a higher level of skills than care home staff and more time than GPs, in the author's clinical experience. Some nurse practitioners do this work routinely, while others deal only with acute problems. This may be because of a lack of confidence or concerns that GPs may consider the nurse to be interfering. Older people can benefit a great deal from holistic overviews — something that needs to be developed in primary care. **JCN**

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KEY POINTS

- Purple urine bag syndrome (PUBS) is a rare condition in which the urine drainage system turns purple due to a reaction involving tryptophan metabolism and certain bacteria.
- Adults with indwelling urinary catheters are at increased risk of CAUTIs. The urinary catheter provides a portal of entry into the bladder.
- Infection risks rise the longer the catheter remains in place because the bladder becomes colonised with bacteria.
- Treatment involves prescribing antibiotics if there are clinical signs of infection, changing the urinary catheter and treating constipation.
- Holistic treatment, including reviewing the need for a urinary catheter and medication, can improve a person's quality of life.
- By supporting GPs and care home staff, nurses working at advanced level can improve quality of life for vulnerable people with complex care needs.

Practice point

PUBS is a rare and striking clinical condition in which the urine in a catheterised patient turns purple or bluish in colour, which can alarm both patients and carers. However, although this colour change may be concerning, it is typically harmless if managed appropriately.

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Revalidation Alert

Having read this article, reflect on:

- Why purple urine bag syndrome (PUBS) can occur
- Risk factors for PUBS
- The clinical implications of the condition of PUBS
- Management options which should be put in place.

✓ Then, upload the article to the free JCN revalidation e-portfolio as evidence of your continued learning: www.jcn.co.uk/revalidation

Mental health first aid: a role for community nurses

Victoria Sharman

This article explores the development of mental health first aid (MHFA) training and how the principles of first aid can be applied with a person experiencing mental health distress. MHFA was designed to reduce mental health stigma and improve the public's awareness, but is suitable for nurses to complete to enhance their first aid response to both physical and mental health situations. This article seeks to encourage nurses to undertake MHFA training.

KEYWORDS:

- Mental health first aid ■ Community nursing ■ Inequalities
- Nursing role

Mental health first aid (MHFA) is a training course to support participants to confidently respond to a person in mental health distress (Zilnyk, 2010). MHFA was developed in Australia in 2001 by a nurse educator, Betty Kitchner, and her husband, researcher Professor Anthony Jorm. After discussing Anthony's participation at a national depression workshop they realised that physical health first aid courses typically did not address mental health distress and emergencies (Kitchner and Jorm, 2002; MHFA International 2024a).

'MHFA was designed as a mental health awareness programme to teach the public how to support a person experiencing a mental health concern.'

During their spare time they started to develop a course and drew on Betty's experience of teaching first aid and her personal experiences of depression and discrimination in the workplace (MHFA International 2024a). Kitchner and Jorm (2002) were concerned about the stigma attached to mental health, that the public would not recognise mental health problems or have the knowledge and confidence to respond.

MHFA was designed as a mental health awareness programme to teach the public how to support a person experiencing a mental health concern (Jorm and Kitchner, 2011). The pilot MHFA course was delivered in Canberra in 2001 and the initial research found that the course did increase awareness of mental health concerns and concluded that the training principles of first aid could be applied to MHFA (Kitchner and Jorm, 2002).

Nurses will be familiar with the primary survey DR ABC response to undertake an assessment for physical health first aid (St John Ambulance, 2024a). For MHFA the action plan to follow is the acronym ALGEE (Jorm and Kitchner, 2011). *Table 1* shows the DR ABC and ALGEE response to use if it is safe for the first aider to proceed. Using ALGEE provides a structure to engage with the person, listen to their concerns and identify help. The person may need to access mental health support through NHS 111, their GP or attendance to a mental health urgent care centre. Community signposting could also be suggested, which is detailed in *Box 1*.

In 2003, Scotland was the first country to facilitate MHFA training outside of Australia with support from Betty Kitchner (Terry, 2009). The MHFA programme was adapted to ensure cultural relevance to Scotland (Terry, 2009). MHFA training was then introduced into England and Wales in 2007 and 2008 respectively (Terry, 2009). MHFA training is now facilitated worldwide and MHFA International reports that seven million people have received training which is delivered by 67,000 instructors across 29 countries. MHFA International (2024b) has a goal that 'everyone has the MHFA skills to support people with mental health problems'.

Practice point

Just as physical first aid helps in emergencies before medical professionals arrive, mental health first aid provides immediate emotional support to someone experiencing a mental health crisis or emotional distress. It aims to stabilise the individual, reduce stress, and guide them toward professional help if necessary.

Victoria Sharman, practice development lead, Cambridgeshire and Peterborough NHS Foundation Trust; Queen's Nurse

The prevalence of mental health concerns makes it likely that the public will meet someone who needs support (Terry, 2009). One in six adults (age 16+) have experienced a common mental health disorder and around 20% of children, aged seven to 16, have a probable mental health condition (Baker and Kirk-Wade, 2024).

An example of using MHFA was recently seen in the news when American musician Jon Bon Jovi supported a woman to move to safety from the ledge of a bridge and seek help. Jon Bon Jovi had been on the bridge filming a music video and he and another person spoke to the woman and supported her during a mental health crisis. It was reported that Jon Bon Jovi had received training on speaking to people in crisis (Sky News, 2024).

EVIDENCE-BASED PRACTICE

Since the implementation of MHFA, research studies have taken place on its effectiveness. Reviews of MHFA studies have found that there is strong evidence that MHFA is effective at improving participants' knowledge, attitudes, and confidence to provide support (Wong et al, 2015; Maslowski et al, 2019). After completing MHFA training, Atanda

Table 1: Action plans for physical and mental health first aid

Primary response using DR ABC (St John Ambulance, 2024a)	MHFA action plan — ALGEE (John and Kitchner, 2011)
Check for D anger	A pproach the person, assess and assist with any crisis
Check for a R esponse	L isten non-judgementally
Open A irway	G ive support and information
Check B reathing	E ncourage the person to get appropriate professional help
Check C irculation	E ncourage other supports

et al (2020) found that 68–88% of participants had used their skills, demonstrating the benefit of the course. However, there is an evidence gap on understanding the impact of MHFA on the recipient so further research is needed (Wong et al, 2015; Maslowski et al, 2019).

Within healthcare, Kelly and Birks (2017) designed a MHFA course for nursing and midwifery undergraduate students and found improvement in attitudes towards mental health concerns. The study recommended that MHFA is part of pre-registration training for all healthcare professionals (Kelly and Birks, 2017). Davies et al (2018) delivered a MHFA course to medical students. The medical students reported increased confidence to respond to a MHFA situation,

improved awareness towards mental health concerns, and that MHFA was beneficial to support their own and colleagues' needs throughout their medical training. Maindonald et al (2020) delivered a patient co-produced MHFA course which included an e-learning package, followed by face-to-face experience learning on MHFA to non-mental health staff. The course evaluation indicated improvements in mental health knowledge, confidence, communication skills and empathy (Maindonald et al, 2020).

MHFA LIMITATIONS AND CONCERNS

MHFA has not been universally accepted as criticisms have been expressed. DeFehr (2016) reported concerns that MHFA medicalises distress by labelling it as a mental health problem, whereas distress can be a normal reaction to challenging situations. However, the aim of MHFA is not to diagnose or commence treatment but to provide an initial helpful response (Kelly and Birks, 2017). Bovopoulos et al (2018) support the introduction of MHF aiders in the workplace and recommend that organisations develop policy to explain confidentiality and signposting requirements for MHF aiders. Mantzios et al (2020) support the aims of MHFA, but caution that MHF aiders should not be seen as a solution to the shortage of staff working within NHS mental health services.

MHFA AND STRATEGY

There have been key strategies that support the expansion of MHFA within the UK. 'No health without mental health' reported the need

Box 1 Community signposting resources

- Samaritans — provide listening support without judgement. www.samaritans.org/
- Shout — free, confidential, mental health text crisis support. <https://giveusashout.org/>
- BAYO — mental health and wellbeing support for the black community. www.bayo.uk/
- Muslim Community Helpline — listening and emotional support. <https://muslimcommunityhelpline.org.uk/>
- Nightline — facilitated by students to support other college/university students. <https://nightline.ac.uk/listening-services/>
- Papyrus HOPELINEUK — for people aged under 35 who are experiencing suicidal thoughts. www.papyrus-uk.org/?gad_source=1&gclid=EAIaIQobChMlrrtft_2DiQMVtoBQBh188xrOEAAAYASAAEgLUU_D_BwE
- C.A.L.L — community advice and listening line for mental health if living in Wales. www.callhelpline.org.uk/
- Switchboard — LGBTQIA+ support available on 0800 0119 100 or through the website: <https://switchboard.lgbt/>

to ensure parity of esteem between mental health and physical health by improving awareness of mental health concerns and reducing stigma (Department of Health [DH], 2011). The Mental Health Crisis Care Concordat was agreed in 2014 and stated that people experiencing mental health distress should experience a whole systems approach (DH, 2014) — meaning that all healthcare professionals need to be able to respond effectively. In 2018, the Health and Safety Executive recommended that employers appoint MHF aiders within the workplace (Health and Safety Executive, 2018).

The Suicide Prevention Strategy regards suicide prevention as everyone's business and highlights the importance of training to develop confidence and skills to prevent suicide (Department of Health and Social Care, 2023). The stigma of mental health concerns has led to suicide being regarded as a taboo issue (Calaminus, 2013). To challenge this position, on World Suicide Prevention Day, 10 September, the 2024–2026 theme 'changing the narrative on suicide' was launched (World Health Organization [WHO], 2024). By undertaking MHFA, nurses will be supporting these strategies by having conversations to support distress and prevent suicide.

MHFA COURSES

The original MHFA course was nine hours and delivered face-to-face for three hours over three weeks (Kitchner and Jorm, 2002). Following MHFA course feedback this was increased to 12 hours (Kitchner and Jorm, 2008). MHFA England now offers online courses consisting of e-learning and four live training sessions across two weeks (MHFA England, 2024). Since the growing awareness of the benefits of MHFA other organisations such as St John Ambulance have developed their own courses to enable first aiders to be able to respond to a person experiencing a mental health crisis by meeting both their mental and physical health needs (St John Ambulance, 2024b). The Zero Suicide

Alliance provide free online training to support the development of skills and confidence to have what could be a lifesaving conversation (Zero Suicide Alliance, 2024). Courses on suicide awareness and autism, and support for university students and veterans are also available (Zero Suicide Alliance, 2024). PAPYRUS also provide training as part of their prevention of young suicide strategy (PAPYRUS, 2024). MHFA courses have also been adapted to support adolescents, older people, cultural groups (Richardson et al, 2023), and within the workplace (Bovopoulos et al, 2018). Course delivery is now offered virtually or as an e-learning package. MHFA courses typically cover the following:

- ▶ Introduction to MHFA
- ▶ Learning about mental health and mental ill health
- ▶ Understanding mental health concerns, including depression, anxiety, eating disorders, substance misuse and psychosis
- ▶ Understanding the impact of stigma of mental health concerns
- ▶ Understanding urgent mental health concerns such as panic attacks, self-harm, suicidal thoughts, traumatic events, severe effects of drug and alcohol and severe effects of psychosis

- ▶ Learning how to respond, communicate, encourage seeking support and signposting (MHFA International, 2024b).

Box 2 shares the experiences of staff at Hertfordshire Partnership University NHS Foundation Trust as to why they undertook MHFA training and what they learnt.

MHFA AND COMMUNICATION

MHFA is a communication tool that can be used in a crisis. Hopkins and Niemic (2007) found that mental health service users in a crisis wanted four things:

1. To be listened to
2. Not to be judged
3. For the person to be calm
4. For the person to be friendly.

These four components can guide nurses on how to respond in a crisis. As it can be difficult to know what to say to someone who appears distressed, the Samaritans launched a conversation campaign called 'Small Talk Saves Lives' (Samaritans, 2024). The Samaritans suggest asking a simple question such as 'where can I get a coffee?' or making an observation about the weather is enough to get the conversation

Box 2 MHFA training reflections

Why I undertook MHFA training?

Becoming a MHF aider was about being a part of a positive culture, reducing stigma and encouraging more open and honest conversations where people feel safe to talk freely, look out for each other, and offer support to one another.

Liz Hill, senior dialectical behavioural therapist

I became a MHF aider because, having previously done a traditional first aid course, it felt like a MHFA course would be at least as valuable to me and others. Mental health issues are often less visible than physical ones, but of course they are often experienced as more uncomfortable. In our day-to-day life, why would we leave someone to be in distress if there was something positive we could do about it, with relatively little training?

Jon Walmsley, non-executive director

What I learnt on the MHFA course?

The MHFA course helped me identify different experiences that leave people in a vulnerable state and often don't feel comfortable addressing. I learnt how I could make someone feel comfortable in sharing how they felt and gaining their trust.

Suki Sangha, executive personal assistant

I learnt how to frame my response in a structured way. To remember that I am a signposter — not a fixer.

Debbi Knight, support, time, and recovery worker

started (Samaritans, 2024). Once the conversation has started, nurses can draw on their skills to build rapport, and communicate effectively through active listening and using open questions. Ferlick (2023) reminds us that during a crisis the person's reasoning is likely to be reduced so instead of trying to reason with them we should suggest gentle requests, spoken slowly and use simple language. Ferlick (2023) suggests using pauses when talking, tolerating silence, having an open body posture and using soft, intermittent eye contact.

IMPLICATIONS FOR COMMUNITY NURSING PRACTICE

MHFA is intended to be used by everyone. However, the author has observed that MHFA training is not routinely undertaken by nurses. Bonnar (2015) advocated that supporting patients' mental health issues is a role for all nurses. Nurses, midwives, and nursing associates are required to meet the standard to 'always offer help if an emergency arises in your practice setting or anywhere else' (Nursing and Midwifery Council [NMC], 2018: 16). While this standard is further explained as within the professional's knowledge and competence (NMC, 2018), if mental health is to have the same parity as physical health problems, all nurses should complete MHFA training. By undertaking MHFA training as continued professional development (CPD), nurses are also meeting other NMC standards to prioritise people by listening to concerns and responding with kindness, compassion, and respect that promotes their professionalism (NMC, 2018), as well as promoting health and being able to assess signs of mental and emotional distress (NMC, 2024).

For people experiencing severe mental illness, their life expectancy is reduced by 15–20 years due to preventable physical health problems (Public Health England [PHE], 2018). While patients with long-term physical health conditions are more likely to experience mental health concerns (PHE, 2016). Due to these

circumstances, nurses working in primary and community care are likely to work with patients that have or will develop mental health problems (Chadwick and McGlynn, 2021), thus undertaking MHFA training will enhance patient care.

Due to the mental health pressures experienced in nursing, nurses may need to use MHFA communication skills while at work if they observe that a colleague is distressed. Ford (2023) stated that a survey found that 40% of nurses reported their mental health and wellbeing as 'bad' or 'very bad'. Contributing factors were identified as concerns about staffing levels, patient safety, and their personal finances due to increased costs of living (Ford, 2023). The Royal College of Nursing (RCN, 2024) reported that a 76% increase of staff seeking support due to experiencing suicidal thoughts occurred within the first half of that year.

Nurses working in community settings often witness the impact of social determinants of health such as reduced education and employment opportunities, poor housing, poverty, racism, and discrimination (Garnowski, 2024). These challenges can impact nurses' health and wellbeing (Wakefield et al, 2021), so as well supporting patients, families or members of the public, nurses may need to draw on MHFA skills to support their colleagues.

SELF-CARE

When people are distressed, nurses will try to respond in helpful ways such as using MHFA skills. However, nurses can become stressed by the person's distress (Riley, 2011). Mantzios et al (2020) recommend that MHF aiders need to ensure that their needs are met after being exposed to distress. Following a mental health crisis intervention, nurses should give themselves time to process what has happened and talk about how they are feeling with someone trusted (Samaritans, 2024). Nurses could speak to their line manager, colleague, a professional nurse advocate, employee support assistance or their union.

CONCLUSION

MHFA training is appropriate for nurses working in primary and community care as it is likely that they will encounter a patient, relative, member of public or colleague who could benefit from support. Undertaking MHFA training can contribute to nurses' professional development by improving their knowledge of mental health concerns and provide guidance on how to respond to a person experiencing mental health distress with confidence. MHFA builds on nurses' existing communication skills to engage a person in distress and identify supportive services. By completing MHFA, primary and community nurses are making a commitment to support the strategy that mental health receives the same recognition and value as physical health. JCN

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Parkinson's disease at end of life: a guide for community nurses

Victoria Bartlett

Parkinson's disease at the end of life can present unique challenges both for patients and those caring for them. This article offers a guide for community nurses to understand the complexities of Parkinson's disease and the importance of managing end-of-life care. Parkinson's disease progresses differently for each individual and, as it advances, symptom control, especially regarding pain, motor difficulties and non-motor symptoms can become increasingly difficult. Nurses play a critical role in managing these challenges, ensuring that patients receive optimal care tailored to their needs. This includes advance care planning, where nurses can facilitate discussions and provide psychosocial support to both patients and their families. Coordinating with an interdisciplinary team of healthcare professionals ensures a holistic approach to care, addressing physical, emotional, and spiritual needs. These key aspects are explored here, highlighting the crucial role that community nurses play in delivering compassionate, effective care at this complex stage of the disease.

KEYWORDS:

■ Parkinson's disease ■ End of life ■ Key symptoms
■ Interdisciplinary collaboration

Parkinson's disease is a chronic and progressive neurological disorder that primarily affects movement. It is caused by the degeneration of nerve cells in a part of the brain called the substantia nigra, which leads to a decrease in the production of dopamine, a neurotransmitter that plays a crucial role in coordinating smooth and controlled muscle movements (Zhou et al, 2023).

Understanding end-of-life care for patients with Parkinson's disease is critical because of the unique and complex symptoms that emerge in its advanced stages. Parkinson's, a progressive neurodegenerative disorder, affects both motor and non-motor functions, resulting in a range of physical, cognitive, and emotional challenges that can be especially demanding in late-stage

'In 1817 James Parkinson described the condition that now bears his name in an essay named 'The Shaking Palsy'.

disease management (Chaudhuri et al, 2006). Symptoms like severe rigidity, impaired swallowing (dysphagia), cognitive decline, and autonomic dysfunction can lead to significant discomfort and risks, such as malnutrition, respiratory issues, and heightened risk of infections like pneumonia (Müller et al, 2001). Nurses play a central role in managing these symptoms to maintain quality of life and provide comfort.

The relevance of specialised nursing care is underscored by the unpredictable progression of Parkinson's, requiring adjustments in medication and non-drug interventions to manage symptoms while minimising side-effects.

In the author's clinical experience, nurses are vital in end-of-life care for patients with Parkinson's disease, providing compassionate, personalised support that extends beyond symptom management. Their role includes:

- ▶ **Pain and symptom management:** nurses help manage complex symptoms through careful observation and tailored interventions, providing both pharmacological and non-pharmacological support
- ▶ **Communication and advance care planning:** nurses facilitate open communication with patients and families, guiding advance care planning and helping clarify preferences for end-of-life decisions, such as resuscitation and feeding options. Advance care planning also helps patients to maintain a sense of control
- 3. **Psychosocial support:** nurses offer emotional support to both patients and families, addressing anxiety, depression, and existential concerns, such as reduced independence or control over situations. These can be present at any time during the disease trajectory (Simpson et al, 2021), and are common in advanced Parkinson's disease
- ▶ **Coordination with the interdisciplinary team:** nurses act as liaisons within a broader team of healthcare providers (doctors, social workers, speech therapists), ensuring all aspects of the patient's care are integrated and patient-centred.

Through these roles, nurses not only provide essential physical care, but also foster a sense of dignity, respect, and comfort for patients at the end of life, helping them experience the highest quality of life possible in their remaining time.

Victoria Bartlett, director of patient care, controlled drugs accountable officer and CQC registered manager, Rowcroft Hospice; member of the QNI Executive Community Nurse Network

OVERVIEW OF PARKINSON'S DISEASE AND ITS PROGRESSION

The symptoms of Parkinson's disease can vary from person to person but generally include:

- ▶ **Motor symptoms:**
 - Tremor: shaking, usually beginning in the hands or fingers. A common type is a 'resting tremor', which occurs when the affected limb is at rest and subsides with movement
 - Bradykinesia: slowness of movement, making everyday tasks more difficult and time-consuming
 - Muscle rigidity: stiffness in the muscles, which can limit the range of motion and cause discomfort or pain
 - Postural instability: problems with balance and coordination, leading to an increased risk of falls.

(National Institute for Health and Care Excellence [NICE], 2017).

There are also a number of non-motor symptoms of Parkinson's disease. These encompass a range of symptoms beyond motor ones (Chaudhuri et al, 2006; Kalia and Lang, 2015), and can affect various systems and significantly impact patient quality of life. They include, but are not limited to:

- ▶ Cognitive impairment (memory issues, slowed thinking, dementia in later stages)
- ▶ Mood disorders (depression, anxiety, and apathy)
- ▶ Sleep disturbances (insomnia, sleep behaviour disorders)
- ▶ Autonomic dysfunction (constipation, urinary issues, blood pressure fluctuations)
- ▶ Sensory symptoms (pain, tingling, or numbness)
- ▶ Fatigue and loss of sense of smell (Chadhuri et al, 2006; Kali and Lang, 2015).

These symptoms are increasingly recognised as having a vital impact upon quality of life and thus should be recognised when supporting people with Parkinson's disease (Carroll et al, 2021).

It is important to be clear about

end-of-life and palliative care. Palliative care is a specialist form of care for people living with serious, chronic, or life-limiting illnesses. It can focus upon symptom relief and stress of the illness, regardless of the stage of the disease or the need for other therapies. The World Health Organization (WHO, 2020) identifies one of the key facts of palliative care as the challenges associated with life-threatening illness, whether physical, psychological, social or spiritual. The primary goal is to improve quality of life for both the patient and their family. Palliative care can be offered alongside curative treatments. It is provided by different professions and services, not just within the NHS. Hospices in the UK play a key part in this, most of which are charities so they may not always have the capacity to meet the needs of all those who may benefit from their expertise.

End-of-life care is a specific part of palliative care that focuses on the final weeks, days, or hours of a person's life. It is provided when it is clear that a person is nearing death, and the focus shifts entirely to comfort care rather than curative treatment.

Parkinson's disease progression is frequently evaluated using the Hoehn and Yahr scale, a five-stage framework that categorises disease severity based on motor symptoms and independence levels. This was developed by Hoehn and Yahr (1967) to capture a more comprehensive picture of disease impact. In the author's experience, nurses often use the Unified Parkinson's Disease Rating Scale (UPDRS) (Goetz et al, 2008) alongside Hoehn and Yahr. This combination helps assess both motor and non-motor symptoms, providing valuable insights for care planning, particularly as the disease reaches its advanced stages. In late-stage Parkinson's disease, patients can experience severe motor and cognitive symptoms that require highly individualised and often complex palliative care. This is when advance care planning and complex assessment skills are key. Merlane and Armstrong (2020) advocate the nurse's role in using skilled communication.

Early and mid-stages of Parkinson's disease

Stage 1

At this stage, symptoms are often mild and typically affect only one side of the body. Symptoms such as a slight tremor, minor postural changes, and some stiffness may be present, but they generally do not interfere with daily activities.

Stage 2

Symptoms often begin to affect both sides of the body. Patients experience increased tremors and rigidity, but they can still complete daily activities independently.

Stage 3

This stage marks a significant shift, where balance issues and slower movement can become pronounced and falls become more frequent. Patients often require support to complete daily tasks, although they may still manage independently with some safety measures.

Advanced Parkinson's disease (late stages)

Stage 4

At this stage, the impact on both motor and non-motor functions can become increasingly severe, namely:

- ▶ **Motor decline:** patients experience pronounced rigidity, bradykinesia (slowness of movement), and instability, often requiring the use of mobility aids such as walkers or wheelchairs to move safely
- ▶ **Cognitive impairment:** memory loss, confusion, and difficulties in planning become prominent, and dementia is common. Parkinson's disease dementia may significantly impact communication and safety
- ▶ **Swallowing difficulties (dysphagia):** this can lead to malnutrition and dehydration. The risk of aspiration (inhaling food or fluids into the lungs) increases, heightening the likelihood of respiratory infections, particularly aspiration pneumonia
- ▶ **Autonomic dysfunction:** patients experience issues with blood pressure regulation (orthostatic hypotension), bladder and bowel function, and excessive sweating, which often complicate daily care.

Stage 5

This is the most debilitating stage, where patients experience profound motor and cognitive decline and are typically bedridden or require full-time assistance. Symptoms include:

- ▶ Complete motor dependence: severe rigidity and weakness make it difficult to move independently, and patients often need comprehensive assistance with all activities of daily living
- ▶ Severe cognitive decline: memory loss, confusion, and personality changes are common, and advanced Parkinson's disease dementia can lead to the need for specialised, round-the-clock care
- ▶ End-of-life complications: patients in this stage face heightened risks of infections, respiratory distress, and blood pressure fluctuations, making the coordination of palliative care essential.

IMPORTANCE OF END-OF-LIFE CARE AND RELATED MEASURES

In the author's clinical experience, the Hoehn and Yahr scale, supplemented by other tools, provides a structured understanding of Parkinson's disease progression, allowing healthcare providers to anticipate the unique challenges patients face in late stages.

By understanding the advanced stages of Parkinson's disease, healthcare providers can work within a multidisciplinary framework to address complex physical and emotional needs, helping patients experience a dignified and comfortable end of life, as advocated as a key aspect of advance care planning (Merlane and Armstrong, 2020).

End of life in Parkinson's disease can profoundly affect the person's quality of life, with a complex mix of motor and non-motor symptoms that call for specialised and personalised care. Severe motor impairment, cognitive decline, autonomic dysfunction, and swallowing difficulties create daily obstacles that compromise independence, safety, and overall well-being. In advanced stages, managing these symptoms requires a tailored approach that blends medical, emotional, and

physical care, carefully addressing each patient's unique needs. Individualised interventions such as precise medication adjustments, tailored nutritional support, and adaptive equipment are crucial to managing symptoms, enhancing comfort and supporting quality of life for both patients and their families (NICE, 2017).

KEY SYMPTOMS AND CHALLENGES AT END OF LIFE

With the likely decline in motor and cognitive functions, it is vital to address rigidity, tremors, falls, and dementia-related complications. Pain and discomfort also need to be considered, as pain can be a non-motor symptom of Parkinson's disease. The cause could be related to rigidity, bradykinesia and involuntary movements, which may become more problematic with time (although there are other causes of pain, which can relate to other conditions). Comprehensive assessment will enable the most effective exploration of symptom control (Parkinson's UK, 2020a) to help explore medications such as analgesia and Parkinson's disease treatments, which may need to be considered in late stage Parkinson's disease.

In advanced Parkinson's disease, dysphagia can be a common and serious issue that heightens the risk of malnutrition and aspiration pneumonia. As the disease progresses, muscles involved in swallowing become increasingly compromised, leading to challenges in safely consuming food and fluids. These difficulties not only impact nutrition, but also pose risks for aspiration, where food or liquids enter the lungs, causing potentially life-threatening respiratory complications. According to NICE (2017) and Parkinson's UK (2020a), a proactive approach involving speech and language therapists (SLTs) is essential for assessing swallowing function and planning interventions to ensure safe eating practices. Decisions about nutritional support, including the possibility of feeding tubes, require a careful and compassionate approach, often involving multidisciplinary input

and discussions with the patient and family. While some may opt for feeding tubes to maintain nutrition, others may choose comfort measures, prioritising quality of life over invasive procedures in the end-of-life phase (NICE, 2017).

Furthermore, in advanced Parkinson's disease, respiratory and autonomic dysfunctions can be prevalent and can significantly impact patient safety and quality of life. Respiratory complications, such as weakened respiratory muscles, restrict airflow and impair effective coughing, raising the risk of pneumonia — a leading cause of hospitalisation and mortality among Parkinson's disease patients (NICE, 2017; Parkinson's UK, 2020a).

Autonomic issues, including orthostatic hypotension (a significant drop in blood pressure upon standing), can further complicate care, as they can cause dizziness, falls, and fainting. These symptoms are caused by the impact of Parkinson's disease on the autonomic nervous system, which regulates blood pressure, heart rate, and digestion. NICE (2017) guidelines recommend an interdisciplinary approach to manage these challenges, incorporating pharmacological treatments, physiotherapy, and occupational therapy to improve mobility and safety while adjusting medications that might exacerbate hypotension (NICE, 2017; Parkinson's UK, 2020a). Tailored, comprehensive care is essential to manage these complex symptoms and effectively reduce associated risks for those in advanced stages of Parkinson's disease.

PSYCHOSIS AND HALLUCINATIONS

Psychosis, including delusions and hallucinations in Parkinson's disease, is highlighted by Chadhuri et al (2006) demonstrating the significance of these distressing non-motor symptoms. Addressing these symptoms can be complex, but a thorough approach begins with screening for underlying causes, such as urinary or respiratory infections, which are known to impact on psychosis (Hogg et al, 2022). If

no other causes are identified, a comprehensive medication review is essential to assess whether the hallucinations or psychosis may be side-effects or interactions related to the patient's treatment regimen. Following assessment, a holistic approach to symptom management can guide further treatment, aiming to reduce distress and improve quality of life for patients and their caregivers (Seppi et al, 2019; Cummings et al, 2020).

SYMPTOM MANAGEMENT STRATEGIES

Medication considerations

Parkinson's disease medications, particularly levodopa, can be central to symptom management but often may require adjustment as the disease progresses to be end of life. Nurses should collaborate closely with the clinical team to balance symptom relief. NICE guidelines recommend regular reviews of medication regimens to account for changes in metabolism and swallowing function, as many patients experience difficulty swallowing pills in advanced stages (NICE, 2017). This might include transitioning to other formulations to maintain efficacy such as transdermal patches or other formulations if appropriate (NICE, 2017; Parkinson's UK, 2020a).

Any changes made should involve the team supporting the patient, with their individualistic needs at the centre of the decision. One of the many tools which can be helpful in this is the Parkinson's Excellence Network dose calculator (Parkinson's Excellence Network, 2024).

When the individual is unable to take medication orally

When patients with Parkinson's disease become unable to take their medication orally, nurses play a crucial role in ensuring continuous and effective management of their symptoms. One of the primary strategies involves use of alternative medication delivery methods, such as dispersible preparations in thickened fluids, enteral tubes, transdermal patches, or subcutaneous injections.

Nurses can utilise tools like the Parkinson's disease MedCalc and the OPTIMAL calculator to convert oral medications to appropriate alternative forms, and ensure accurate dosing and administration. These calculators are particularly useful in hospital settings where timely and precise medication management is critical to prevent complications such as neuroleptic malignant syndrome (NMS), a potentially life-threatening condition characterised by fever, muscle rigidity, and autonomic dysfunction (British Geriatrics Society [BGS], 2023).

'Anxiety, confusion, and cognitive decline are common in advanced Parkinson's disease and managing these symptoms requires a compassionate approach.'

In addition to medication management, nurses should adhere to local protocols and guidelines, such as those provided by NICE (2017), which offer comprehensive recommendations on the pharmacological and non-pharmacological management of Parkinson's disease. These protocols emphasise the importance of multidisciplinary collaboration, regular monitoring, and patient-centred care. Nurses should also be vigilant about the risk of NMS, especially during medication changes or interruptions. In the author's clinical experience, early recognition and prompt intervention are essential to mitigate the risks associated with this syndrome. By leveraging these tools and adhering to established protocols, nurses can significantly enhance the quality of care for patients who are unable to take their medication orally.

Pain management

Parkinson's disease-related pain can be both musculoskeletal and neuropathic, requiring a combined approach. Pharmacological treatments might include non-opioid analgesics and, when appropriate, low-dose opioids, especially when pain becomes more intense. Non-

pharmacological interventions, such as massage, heat therapy, and gentle stretching, can also provide relief. Research from Parkinson's UK suggests that a multi-modal approach to pain, including mindfulness and distraction techniques, can be beneficial for patients experiencing chronic discomfort (Parkinson's UK, 2020a, b).

Supporting mobility and comfort

Maintaining patient mobility and comfort at end of life can positively impact quality of life. Positioning and regular turning help prevent pressure ulcers, while fall prevention measures, such as bed rails and appropriate footwear, can reduce injury risks (Heyn et al, 2023). Nurses can help reposition patients with care to avoid strain on weakened muscles, and physical therapy recommendations may guide safe exercises to promote circulation and prevent stiffness (NICE, 2017). Additionally, ensuring that support surfaces and aids, such as cushions or specialised mattresses, are used effectively is essential for minimising pain and maintaining comfort.

Managing anxiety and cognitive decline

Anxiety, confusion, and cognitive decline are common in advanced Parkinson's disease and managing these symptoms requires a compassionate approach. Techniques like maintaining a calm environment, reducing sensory overload, and using reassurance can ease anxiety. Cognitive support strategies, such as familiar objects, routine maintenance, and gentle communication, are also valuable. NICE guidelines advocate for minimal use of sedative medications, suggesting that non-drug interventions should be prioritised where possible (NICE, 2017). These guidelines detail the types of medications that are advocated.

In the author's clinical experience, by implementing these symptom management strategies, nurses can provide Parkinson's disease patients with a comprehensive, compassionate approach that aligns with best practice and considers the unique needs of those nearing end of life.

ADVANCE CARE PLANNING AND ETHICAL CONSIDERATIONS

Ideally, advance care planning should take place well before the end-of-life stage, allowing individuals to express their preferences and priorities for future care (Harrison-Dening, 2022). This approach is strongly supported by NICE (2017), the European Parkinson's disease Association (EPDA, 2016), Parkinson's UK, and Hospice UK, as it fosters meaningful discussions between individuals, their families, and healthcare providers. Through advance care planning, individuals can articulate their preferences on matters such as their desired place of care, specific treatments they would like to receive or avoid, and any other personal wishes or values that should guide their care as their condition progresses (EPDA, 2016; NICE, 2017; Parkinson's UK, 2020a, b).

COMMUNICATION AND EMOTIONAL SUPPORT

Due to the progressive nature of Parkinson's disease, both unpaid and paid carers play a vital and often long-term role in supporting individuals throughout the disease course, particularly at the end of life. In the author's clinical experience, it is crucial to recognise the unique contributions and expertise that carers bring, as they are often attuned to the individual's health patterns and can detect subtle changes in symptoms that may signal the need for additional support. NICE emphasises the importance of supporting carers, including providing them with information and emotional support to enhance quality of care (NICE, 2017). Additionally, assessment tools such as the Integrated Palliative care Outcome Scale (IPOS) carer version can help identify the carer's needs and connect them with supportive services that ease the caregiving burden (Kane et al, 2015).

Supporting carers is a priority in the UK, given their substantial and often long-term commitment. Carers UK advocates for tailored support services, recognising that many carers need emotional and practical support

due to the significant mental and physical toll of caregiving over time. In particular, bereavement support is recognised as an essential aspect of end-of-life care, providing comfort to families before and after a patient's death (Carers UK, 2020).

'... it is crucial to recognise the unique contributions and expertise that carers bring, as they are often attuned to the individual's health patterns and can detect subtle changes in symptoms that may signal the need for additional support.'

For patients and families affected by Parkinson's disease, psychosocial support is critical, as the emotional and cognitive challenges can be profound. Nurses play a key role in offering emotional support by listening actively, validating feelings, and creating a safe space for patients and families to express concerns. Effective communication strategies, including simple language, visual aids, and gestures are especially important for patients with cognitive or speech difficulties (Bloem et al, 2021). Nurses also provide essential education for family caregivers, offering practical caregiving advice, self-care encouragement, and resources for grief counselling to help families manage the challenges of caregiving and bereavement.

INTERDISCIPLINARY COLLABORATION AND RESOURCES

As said, the interdisciplinary team plays a crucial role in providing comprehensive end-of-life care for people with Parkinson's disease, with nurses often serving as the key coordinators. This collaborative approach ensures that all aspects of a patient's care needs are addressed holistically. Physicians manage complex symptom control and medication adjustments, while social workers provide vital emotional support and help families navigate available resources and advance

care planning. Speech therapists are essential in managing dysphagia and communication difficulties that often worsen in late-stage Parkinson's, helping to maintain quality of life and prevent complications (Heyn et al, 2023). Occupational therapists contribute by adapting the environment and suggesting techniques to maintain independence and dignity for as long as possible. The nurse's role is central in synthesising information from all team members, ensuring consistent communication, and providing direct patient care.

This team-based approach enables better symptom management, reduces hospital admissions, and helps fulfil the patient's wishes for their end-of-life care (Merlane and Armstrong, 2020).

In the author's clinical experience, regular team meetings and clear communication channels are essential to ensure that care remains coordinated and responsive to the rapidly changing needs of both the patient and their family caregivers.

CONCLUSION

Nurses play a vital role in delivering compassionate, person-centred, end-of-life care to people with Parkinson's disease. This role encompasses four vital areas:

- ▶ Effective symptom management, particularly during periods when oral medication becomes challenging
- ▶ Coordination of interdisciplinary care to ensure comprehensive support
- ▶ Facilitation of advance care planning discussions
- ▶ Ongoing patient and family advocacy.

Furthermore, the nurse's position within the interdisciplinary team is crucial for ensuring seamless care delivery, with careful attention to protocols such as the Parkinson's medication calculator and alternative administration routes when oral medication becomes impossible. Essential resources, including Parkinson's UK and NICE guidelines, provide evidence-based frameworks for delivering high-quality care. In

addition, nurses should actively engage in continuous professional development (CPD), utilising the wealth of educational opportunities available through organisations such as Parkinson's UK to enhance their knowledge and skills in managing complex neurological conditions at the end of life. This commitment to ongoing learning and advocacy helps to ensure that patients receive optimal care that aligns with their wishes and maintains their dignity throughout their journey.

Box 1 lists key resources for nurses caring for people with Parkinson's disease. **JCN**

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Box 1

Resources

- ▶ Parkinson's UK: www.parkinsons.org.uk/professionals/
- ▶ Parkinson's Excellence Network: www.parkinsons.org.uk/professionals/parkinsons-excellence-network
- ▶ Cure Parkinson's: <https://cureparkinsons.org.uk/>
- ▶ Parkinson's Disease Nurse Specialist Association: www.pdnsa.org/
- ▶ NICE Guidelines (NG71): www.nice.org.uk/guidance/ng71
- ▶ Unified Parkinson's Disease Rating Scale: www.movementdisorders.org/MDS/MDS-Rating-Scales/MDS-Unified-Parkinsons-Disease-Rating-Scale-MDS-UPDRS.htm
- ▶ Non-Motor Symptoms Questionnaire Non-Motor Symptoms Scale for Parkinson's disease (NMSS): www.movementdisorders.org/MDS/MDS-Rating-Scales/Non-Motor-Symptoms-Scale-for-Parkinsons-Disease-NMSS.htm
- ▶ Parkinson's Disease Questionnaire (PDQ-39): www.parkinsons.org.uk/professionals/resources/parkinsons-disease-questionnaire-pdq-39
- ▶ OPTIMAL Calculator: www.parkinsonscalculator.com/
- ▶ Parkinson's UK Learning Hub: www.parkinsons.org.uk/professionals/learning-hub
- ▶ European Parkinson's Disease Association
- ▶ Parkinson's UK Nurse Specialist Helpline: 0808 800 0303

Short exploration of the psychological stresses of type 2 diabetes

Rona Dury

Diabetes in the UK has topped five million, of which 90% of those diagnosed have type 2 diabetes (Wise, 2023). These figures have demonstrated an increase of 148,951 from those recorded in 2020–22, with an estimate that potentially a further 2.4 million people are at high risk of developing type 2 diabetes (Diabetes UK, 2023). The National Diabetes Inpatient Audit has shown that 18% of all hospital beds on any one day are occupied by people who have a diagnosis of type 2 diabetes (NHS Digital, 2020). Apart from healthcare costs attributed to age, financial costs of managing diabetes by the National Health Service is around £10 billion a year (NHS England, 2022), with late recognition of the condition being a contributory factor to rising costs (Diabetes UK, 2023). Those people with late recognition or poorly managed diabetes are at risk of developing cardiovascular diseases, which are the most prevalent cause of mortality and morbidity among people with type 1 and 2 diabetes (Orasanu and Plutzky, 2009; Ma et al, 2022). Achievement of good glycaemic control is fundamental to the prevention of complications due to diabetes — although worldwide it is recognised that only 50% of those with diabetes achieve good glycaemic control (Pastakia et al, 2017).

KEYWORDS:

■ Type 2 diabetes ■ Management ■ Psychological stresses

The current increase and management of diabetes prompted NHS England (2020–21) to provide transformational funding of £44 million, with a view to addressing some of the issues associated with diabetes and reducing the number of amputations due to poor diabetes management, as highlighted in the National Diabetes Foot Care Report (Office for Health Improvement and Disparities, 2022; 2023). Type 2 diabetes is an ever-growing national and international concern. However, despite recognition of the impact of the disease, the condition continues to increase (Hicks, 2015). In addition, type 2 diabetes has substantial

‘Community nursing has been described as an ideal area of accessibility to support people with diabetes, with over 80% of type 2 diabetes being managed in primary care.’

socioeconomic implications; its treatment accounts for around 10% of the annual NHS budget, around £10 billion per annum (NHS England, 2022). It is therefore essential that effective support for people with type 2 diabetes is achieved.

The increase in obesity in the UK is closely linked to the rise of type 2 diabetes. According to a government report (Baker, 2023), 63.8% of adults over the age of 18 are classified as obese. These figures show a rise, albeit slight, from the 2020–21 figure of 63.3% (Department of

Health and Social Care, 2023). People who develop type 2 diabetes under the age of 40 are more likely to experience rapid deterioration in pancreatic function and have a greater incidence of adverse outcomes (Magliano et al, 2020).

Community nursing has been described as an ideal area of accessibility to support people with diabetes, with over 80% of type 2 diabetes being managed in primary care (Davidson, 2010). In particular, the multidisciplinary aspect of the community nursing team is an essential component in providing holistic care and helping people living with diabetes and related comorbidities through support and education (Alshammari et al, 2021).

The aim of diabetes education is to provide knowledge and assistance to people regarding managing their overall diabetic health. This includes supporting patients to develop an understanding of monitoring their blood glucose levels and related medication requirements. However, National Institute for Health and Care Excellence guidelines (NICE, 2017) have altered the recommendations surrounding regular blood glucose monitoring (BGM) in type 2 diabetes, advising that BGM need not be done on a regular basis unless the person is insulin dependent, subject to hypoglycaemia, or on medication that may induce hypoglycaemia. NICE (2017) also recommends supporting individualised care by promoting general education of a person's condition, such as adhering to an appropriate diet, maintaining exercise patterns and taking prescribed medication with the objective of preventing future complications of conditions associated with type 2 diabetes (Schmidt et al, 2018). This includes addressing lifestyle issues

to improve health (Lynch et al, 2019). Increasing a person's knowledge of their condition can not only help to improve their health, but also assist in achieving personal goals (Powers et al, 2015; Schulman-Green et al, 2016).

Previous models of diabetes care provision were developed and implemented when early-onset type 2 diabetes cases were infrequent. However, the increase in numbers of those with type 2 diabetes has called for differing strategies to manage this health burden (Misra et al, 2023).

Evidence suggests that adopting a Making Every Contact Count (MECC) approach, an initiative proposed by Public Health England (PHE) in 2016, promotes a person-centred perspective. Such an approach is designed to increase motivation levels in a person to self-manage their condition (Aveyard, 2012). MECC involves investing time with a patient during routine health and care interactions, such as a nursing review (Anderson et al, 2017). However, evidence from reviews of MECC have highlighted some barriers to its implementation, including a lack of time and resources to plan and implement MECC. Also, concerns have been raised by nurses who feel that they are not fully prepared for the advanced roles in diabetic care, which require training and the additional capacity to implement MECC (Alshammari et al, 2021). Furthermore, there is no consistent or standard training for MECC implementation (Haighton et al, 2021; Parchment et al, 2023), which has resulted in trusts adopting differing forms (Chisholm et al, 2019). A better understanding of the overall cost-effectiveness and benefits to the patient have as yet to be fully explored (Atkins et al, 2017).

In the author's clinical opinion, the complex issue of poor diabetes control is not always fully addressed by health education and motivational strategies alone. Such strategies do not necessarily help or reduce concerns that may be adding to an individual's anxiety levels and affecting their diabetic self-management. A study by Siegel



et al (2018) identified that only about 3% of adults meet most of the type 2 diabetes risk-reduction goals. Indeed, socioeconomics and financial constraints have been identified as contributing to a person's inability to access diabetes support and clinical requirements (Meisters et al, 2024), which has an impact on self-management. Areas of increased social deprivation tend to have higher numbers of type 2 diabetics (Adu et al, 2019; Misra et al, 2023). Furthermore, the UK government's initiative to tackle obesity — a contributory factor to type 2 diabetes — identified that the poorest 10% of the population would need to spend 75% of their income to meet the NHS's Eatwell guidelines (Marmot et al, 2020).

The issue of poor eating habits which are not in line with appropriate dietary recommendations that affect diabetic self-management are complex, including psychosocial stress and negative emotions (Wheatley and Whitaker, 2019). Emotional eating can have an effect on dietary choices, with palatability of foods to provide a greater feeling of reward and satiety influencing choice (Campbell et al, 2017; Kontinen, 2020), e.g. foods which are high in fats and carbohydrates, but with reduced nutritional content. Eating foods from these groups can add to feelings of guilt caused by subsequent weight gain and reinforce the cycle of weight gain and emotional stress (McKay et al, 2021).

Another reason for selecting this type of food in response to an emotional state may reflect food availability and accessibility, or food poverty, the outcome of which can result in poor eating habits due to the affordability of food available (Campbell et al, 2017; Poti et al, 2017). Food insecurity is driven by various issues, including lack of financial security, i.e. unemployment, household debt and weaknesses in the state benefits system (Lambie-Mumford and Loopstra, 2020). There are currently around 1,200 Trussell Trust food banks spread over the UK and in 2018–9 they distributed over 1.5 million food parcels to 290,000 people — evidence of the extent of food poverty in the UK (Caplan, 2020).

DIABETIC DISTRESS

As well as physical effects, type 2 diabetes has a substantial emotional impact upon people and has been associated with a greater risk of comorbid depression, which can hamper a person's quality of life and that of their family (Ghosh and Chatterjeel, 2013; Speight et al, 2020). This has been identified as 'diabetic distress', which is a component of the diabetic condition and has been recognised as a barrier to a person self-managing their diabetes (Batais et al, 2021). Diabetic distress has been described as a condition encompassing a range of negative emotions, including:

- ▶ Worry
- ▶ Frustration

- ▶ Anger
 - ▶ Emotional burnout
 - ▶ Feelings of guilt or shame due to physical inactivity leading to obesity
- (Snoek et al, 2015).

All these emotions can add to a person's anxiety levels, leading to feeling overwhelmed by what is needed to manage their diabetes (Snoek et al, 2015; Schmidt et al, 2018). Stress, be it physical or mental, can have an impact on blood glucose levels by affecting the hormonal response and reducing the process of absorption of glucose from the muscles and adipose tissues, resulting in hyperglycaemia (Sharma et al, 2022).

Depression is considered to be separate from diabetic distress and is characterised by feelings of sadness, anhedonia or the inability to feel pleasure in normal pleasurable experiences, as well as appetite changes, disrupted sleep and, in some cases, thoughts of suicide (Remes et al, 2021). However, there can be an overlap in the symptoms of diabetic distress and depression, as demonstrated in a study by Lopez et al (2014), which identified that 4.5% of patients who were screened had both depression and diabetic distress.

Diabetic distress is attributed to the daily challenges of living with diabetes, particularly affecting women with type 2 diabetes (Perrin et al, 2017). It has also been identified as being greater in younger people who have a shorter duration of diabetes, as opposed to older people with a longer experience of the condition (Fisher et al, 2015; Shamshirgaran et al, 2017). There are in excess of 122,780 people with type 2 diabetes under 40 years in the UK, and over 1,500 of them are under the age of 19 (NHS Digital, 2023).

Those people who demonstrate poor motivational skills, a component of diabetic distress, struggle to manage their symptoms. This may be due to the significant lifestyle changes a diabetic person may be required to make, or difficulties in comprehending

instructions from healthcare professionals (Sharkiya, 2023). Some of the advice provided to manage their condition may be complex and difficult to understand, especially for those without an understanding of the medical implications of poor diabetic control. This may lead them to feel that they are being judged by healthcare professionals as to their ability to self-manage, i.e. a burden of guilt in not achieving glycaemic control (Todalabagi et al, 2020). Furthermore, health education does not always cover the effects of not adhering to diet and exercise — important aspects to prevent relapse of a person's condition (Linmans et al, 2015).

A study by Ribu et al (2019) explored how individuals with diabetes adapt to and manage their condition and found different categories of self-management behaviours. While some struggled with diabetic self-management, others actually 'gave up' the struggle. Ribu et al (2019) identified that conducive environmental factors, such as living in areas of low pollution with green spaces and areas to walk, as well as a person's ability to adapt to changes in their diabetic management are elements in successfully self-managing diabetes. Positive factors for diabetic self-management include a person's health status, types of resources available, personal knowledge, and access to health resources (Schulman-Green et al, 2016).

CONCLUSION

The goal should be for community nurses to be empowered to support diabetes self-management. They play a crucial role in diabetes care, especially as they often work closely with patients in their homes and communities. Providing nurses with the skills, resources and access to a multidisciplinary team (MDT) means that they can provide tailored, effective support to help patients with diabetes take an active part in managing their health (Xiao and O'Neill, 2017).

It is important that care is not solely focused on treatment and

management, but also includes diabetes prevention and health promotion as part of the ethos of healthcare provision (Sharkiya, 2023).

Primary care has been tasked with providing both routine and more complex diabetes care (Hawthorne et al, 2012). In the UK, there are a significant number of younger people now living with type 2 diabetes — 4% of the total number, any of whom are under the age of 40. While this may only be a small proportion of the overall numbers diagnosed, the effects of the condition are often more severe (Tancredi et al, 2015; Misra et al, 2023).

There are varying principles of effective self-care, including following a healthy diet, taking exercise, adherence to medication, monitoring glucose level, problem-solving, reducing risks and healthy coping. However, effectiveness of health education activities are affected by an individual's acceptance of their disease. This involves nurses recognising those diabetic patients who are struggling to manage their condition and the support required.

The increase in numbers of patients with type 2 diabetes has changed the dynamics of managing this condition (Misra et al, 2023). It is therefore essential that community nurses, who are often one of the first points of contact in supporting the diabetic patient, have the knowledge and skills to manage the demands of the increase in these patients on their caseloads (Nikitara, 2019; O'Flynn, 2022). **JCN**

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- KEY POINTS**
- The aim of diabetes education is to provide knowledge and assistance to people regarding managing their overall diabetic health.
 - The multidisciplinary aspect of the community nursing team is an essential component in providing holistic care and helping people living with diabetes and related comorbidities through support and education.
 - Areas of increased social deprivation tend to have higher numbers of type 2 diabetics.
 - The issue of poor eating habits which are not in line with appropriate dietary recommendations that affect diabetic self-management are complex, including psychosocial stress and negative emotions.
 - Diabetic distress has been described as a negative emotional condition.
 - The goal should be for community nurses to be empowered to support diabetes self-management.
 - Effectiveness of health education activities are affected by an individual's acceptance of their disease.
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