

What do community nurses need to know about GDPR?

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New community practice teaching standards published

Stories of strength, kindness and skill

Reducing falls through inclusive building design

How music can lighten up life for dementia patients

Self-neglect and pressure ulcers

Overactive bladder syndrome: what community nurses should know

Long Covid: definition, diagnosis and management

Interstitial cystitis: facilitating earlier diagnosis and management

Medications to treat early rheumatoid arthritis: tackling non-adherence

Dementia: reducing and managing risk

Making a success of a place-based team

Loneliness: what it teaches and what we can do

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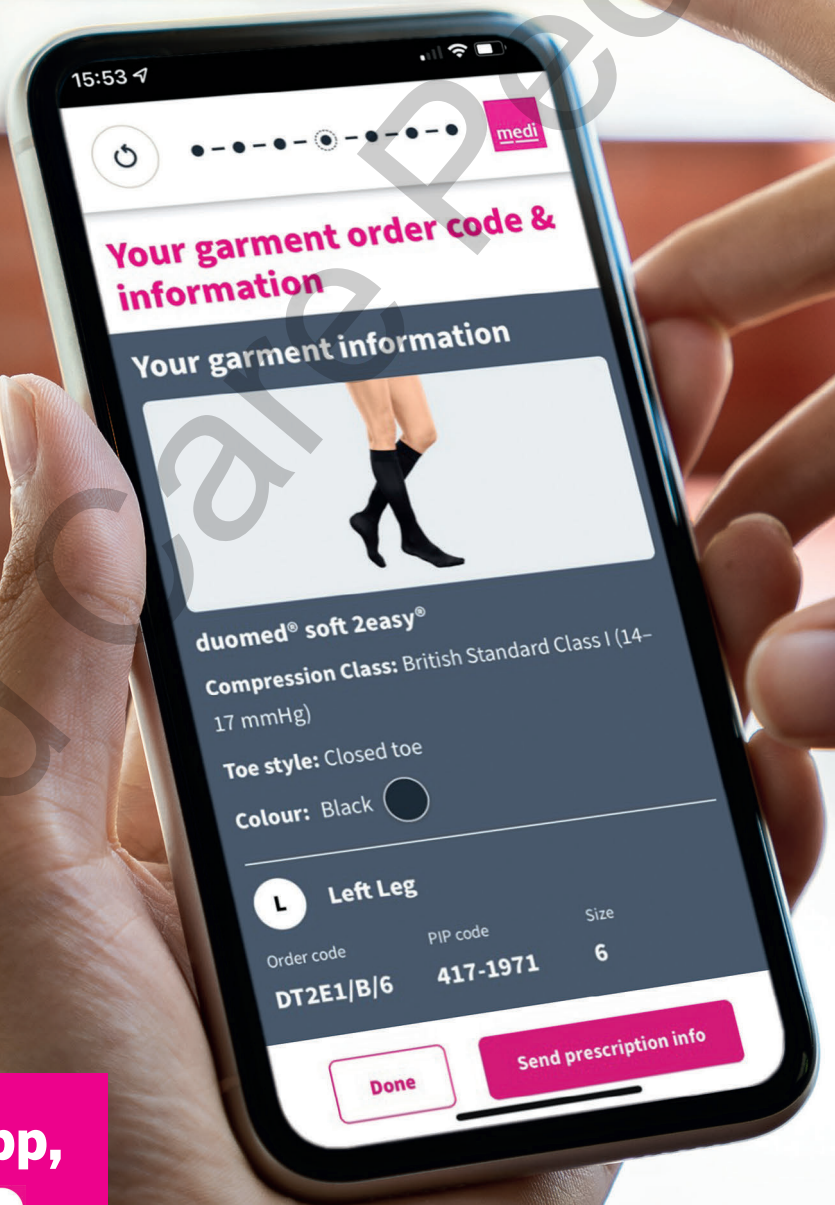
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*Journal of Community Nursing*  
incorporating *Journal of*  
*District Nursing*  
February/March 2023

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ISSN 0263 4465

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*Journal of Community Nursing* is indexed with  
CINAHL and British Nursing Index (BNI)

Published bi-monthly and available  
free online for community and district  
practitioners based at primary and secondary  
care locations throughout the United  
Kingdom. Also distributed with subscription.

Institutional and overseas subscription rates:

United Kingdom: £155.00

Overseas: £285.00

UK subscription rate:

Six issues per year: £80

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*of Community Nursing* may be reproduced,  
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# Getting to grips with GDPR



As we are all aware, the protection and regulation of everyone's personal data is a legal requirement and a framework within which we must work every day. To support you to embrace the challenges surrounding this, do read this issue's 'community matters' feature (pp. 8–11). It is all about GDPR and manages to simplify the subject and make it easily relatable. It highlights areas we should consider and offers guidance on how to follow the basic principles by giving many examples that relate

directly to working within the community setting.

Improving patient outcomes, wellbeing and quality of life while also managing more complex conditions and social care requirements are part and parcel of community nursing. But, this can seem challenging — even overwhelming — especially alongside staff shortages and rising pressures on services. But, I hope that the broad range of clinical articles here might go some way to helping with managing diverse caseloads, such as the diagnosis and management of early stage rheumatoid arthritis (pp. 48–53), interstitial cystitis (pp. 43–47) and overactive bladder syndrome (pp. 31–36), as well as caring for patients with pressure ulcers who self-neglect (pp. 23–30), to name but a few. The first part in our three-part series on Long Covid (pp. 37–41) also provides an understanding of commonly reported symptoms so that you can better support patients whose day-to-day lives are impacted by post-Covid-19 syndrome. I encourage you to read Nicki Haywood's comment piece too (pp. 65–66), which raises what is still considered a taboo subject, the issue of loneliness and social isolation, with valuable insights on how to acknowledge it as both a common experience and health concern and how workplaces and colleagues can offer support for those feeling vulnerable.

As always, do check out when the JCN study days are coming to your area. New sessions this year include the fundamentals of healing wounds; proactive wound healing with a biofilm strategy; getting hands on with self-care solutions; skin tears: recognising, assessing and managing them; demystifying the use of NPWT in the community; as well as a practical guide to vascular assessment (ABPI/TBPI). So, why not come along and enjoy a day of free education and networking with colleagues and friends ([www.jcn.co.uk/events](http://www.jcn.co.uk/events)).

Annette Bades, editor-in-chief, JCN





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**Amanda Young**, *director of nursing programmes (innovation and policy), Queen's Nursing Institute (QNI)*



I am a district nurse, nurse teacher in practice, associate lecturer and Queen's Nurse who believes that excellent community nursing is vital and that community nurses should be more visible. Care should be available to everyone who wishes to remain at home. I have an interest in dementia, end-of-life care and teaching in practice to support newly qualified nurses. I am very pleased to be a part of the JCN editorial board, an accessible journal for all community nurses to inform their practice and strive for excellent care.  
*Gail Goddard*

I am a district nurse and an academic with a passion for end-of-life care, older people and nurse education. I believe that care at home gives people the best opportunity to remain in control of their own health and wellbeing. It is a privilege to be a guest in a person's house and to help them achieve their goals. It is also a privilege to train nurses of the future to adopt this personalised care approach to really make a difference. I am excited to join the editorial board of the JCN where I can see the hard work that community nurses undertake.  
*Amanda Young*



I am a freelance tissue viability nurse (TVN) and health visitor. My true passions are in pressure area care and moisture-associated skin damage. I sit as a registrant panel member on the NMC Fitness to Practice Hearings, and work with the Institute of Health Visiting (IHV), where I have recently supported the development of a training package on domestic violence and abuse (DVA). I am delighted to be part of the JCN editorial board, where current best practice can be discussed.  
*Melanie Lumbers*

I've been working in district and community nursing for 20 years. My particular passion is for continuity of care in community nursing, which encourages healthy behaviour, builds trusting relationships, can reduce healing times, and makes people feel more positive about their healthcare experience. We have a responsibility to prepare for the future by continuing to develop leadership and clinical skills. The JCN is a great resource for support, education and to share best practice.  
*Hattie Taylor*



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**References:** 1. Comparison of the skin hydration of Doublebase Once emollient with Epaderm Ointment in a 24-hour, single application study, in subjects with dry skin. Extract report summarising skin hydration results for wiped off sites. Data on file. Dermal Laboratories Ltd, Hitchin, UK. Epaderm® Ointment is a registered trademark of Mölnlycke Health Care. 2. Antonijević MD & Karajić J. Ointments or a gel emollient? Randomised and blinded comparison of the hydration effect on *ex-vivo* human skin. Data presented at the 17th European Academy of Dermatology and Venereology (EADV) Symposium, May 2022, Ljubljana, Slovenia.

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In each issue of the *Journal of Community Nursing*, we investigate a topic affecting our readers. Here, we ask...

# What do community nurses need to know about GDPR?

**A**s a community nurse, how much information should you know about a patient? You might say it's important to know the condition they have and their medical history. It might be reasonable to enquire if they are on any medication, or even ask for some details about their lifestyle, such as their smoking habits or alcohol consumption, or how many sugars they take in their tea.

In the day-to-day work of a busy practice, you may also need to share some of this information. Some of this sharing may be routine. You may need to pass a patient's notes to a different practice, or provide some information to a physiotherapist. In more dramatic cases, you may feel under pressure to provide the police with information if a patient is suspected of committing a crime,

or to report a child's injuries to social services.

All of these considerations can come under the abbreviated heading of GDPR — or General Data Protection Regulation, to use its full title. However, while many jargon-friendly abbreviations are an attempt to make a boring subject sound more interesting (CQUINS anyone?), understanding GDPR



*In May 2018, General Data Protection Regulation (GDPR) came into force. The overarching aim of this was to ensure that organisations, the government and businesses can only use personal information in safe and controlled ways; in line with the strict data protection principles ensuring transparent and fair usage of all personal data.*

*When GDPR was launched, there was plenty of media coverage around this, discussing the impact GDPR would have in your workplace. It is accepted that most trusts now include GDPR training as part of annual mandatory training and induction training.*

*It is important to remember that GDPR is not just about your patients'/clients' information and how it is accessed or shared; but most importantly, it is also relevant to your own personal data. The reason I refer to the importance of your own personal data is that many healthcare professionals become focused on their role and helping others, and they do not focus on their own needs and safety.*

*All nurses, nursing associates and midwives have to adhere to the Nursing and Midwifery (NMC) 'Code of Conduct' (NMC, 2018). Within 'The Code' is strict guidance on the need for confidentiality. Through our practice as registered professionals and adherence to 'The Code', practising in line with GDPR is part of everyday safe and effective practice.*

*We should all be aware of our own personal data and how it is accessed. For example, does your workplace display a photo of you accompanied by your name and role? This is common practice in many areas to help patients/clients to know who you are, to reassure them and allow them to prepare for their visit to see you. What happens though if a patient/client becomes upset with you? What if they become violent? They have been provided with a great deal of information that could increase the likelihood of your being unsafe at home. This is an extreme example, but if your work perhaps includes a high safeguarding caseload, or with very vulnerable people, you may wish to review how your personal data is shared.*

**Melanie Lumbers**  
Freelance tissue viability nurse





*The information technology storm into health care has created a friction between the long held duty of confidentiality and the vast potential for collaborative sharing and storage of data. It is understandable that nurses, as with other healthcare professionals, will feel cautious with regard to GDPR. It's therefore both useful and valuable to align their approach with the Caldicott Principles of Information Governance, with which we are all already familiar, namely: justify the purpose(s) for using confidential information; use confidential information only when it is necessary; use the minimum necessary confidential information; access to confidential information should be strictly on a need-to-know basis; everyone with access to confidential information should be aware of their responsibilities; comply with the law; the duty to share information for individual care is as important as the duty to protect patient confidentiality; inform patients and service users about how their confidential information is used (The Caldicott Principles of Information Governance, December 2020 — available online: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/942217/Eight\\_Caldicott\\_Principles\\_08.12.20.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/942217/Eight_Caldicott_Principles_08.12.20.pdf)).*

*Informed patient consent is an imperative. Everyone is different and we can never assume that just because other people have had no problems with their information being shared (and maybe you personally would also not perceive this as a problem), the person this immediately relates to may well feel otherwise. We need to uphold individuality and respect diversity.*

*Things do go wrong sometimes and when there has been an identified breach of confidentiality, an important part of the reparation process is to inform the person concerned that this has happened and what steps have been taken to deal with the situation ([www.themdu.com/guidance-and-advice/latest-updates-and-advice/how-to-handle-a-data-breach](http://www.themdu.com/guidance-and-advice/latest-updates-and-advice/how-to-handle-a-data-breach)).*

*By ensuring they are familiar with GDPR legislation, understanding how this aligns with the Caldicott Principles and the relevant policy and procedures at their place of work, nurses should feel confident in handling patient data appropriately.*

#### Rhian Last

RN, Primary care preceptorship lead, Leeds Community Healthcare Trust; board member, RCGP Yorkshire Faculty; board member, Self Care Forum

might actually save you from straying into illegality.

### WHAT IS GDPR?

Like any other healthcare services, general practices have to process a huge amount of personal information about patients. This not only includes demographic information such as a patient's name, date of birth and address, but also details about their health and any treatments, such as that contained in their medical history and nursing notes.

Since 2018, community nurses like all healthcare staff have to comply with GDPR. The regulations require you to keep an individual's personal, medical and financial information secure. You have to justify the disclosure of any patient information, inform the patient and gain their consent, which can be a particular challenge when dealing with vulnerable people who may

not be able to give consent for this information to be shared ('The impact of GDPR on the healthcare sector' — [www.skillsplatform.org](http://www.skillsplatform.org)).

There are some common examples of the kind of work that community nurses are regularly involved in that could require you to apply the principles of GDPR. For example, you might need to share information from a patient's medical records with other healthcare staff. This might be when you refer a patient to a hospital specialist, or send details of a prescription to a pharmacy. Similarly, you might need to notify colleagues in A&E or the ambulance service about a patient's medical condition.

It is also important to understand that some aspects of a patient's personal data are considered more sensitive than others, or what the GDPR legislation terms 'special categories', including the following:

- ▶ Racial or ethnic origin
- ▶ Political opinions
- ▶ Religious or philosophical beliefs
- ▶ Trade union membership
- ▶ Genetic, biometric and health data
- ▶ Sexual orientation
- ▶ Criminal convictions.

Community nurses need to treat this type of data with greater care because collecting and using it is more likely to involve discrimination.

It is also important to remember that a patient has the right to object to any information being shared about their care. They also have the right to have any mistakes or errors in their notes corrected ('GDPR privacy notices for GP practices' — [www.bma.org.uk](http://www.bma.org.uk)).

### SCREENING

Another factor in GDPR that community nurses should be aware of is national screening

programmes. The NHS runs national screening programmes so that certain diseases such as bowel, breast and cervical cancer and aortic aneurysms can be detected at an early stage. Under GDPR data, patients have an extended range of rights, such as the 'right to be forgotten', which means that they can apply to have their information deleted ('Data protection, GDPR and screening' — phescreening.blog.gov.uk).

Community nurses should be aware that practices are permitted to share patients' contact information with Public Health England, for example, so that they can be invited onto screening programmes, but are also required by law to provide the patient with information about how they handle this information.

All of this information should be clearly set out in any practice's data protection policy.

### A MATTER OF PRINCIPLE

The Royal College of Nursing has rather helpfully provided a set of principles for nurses to consider when processing patients' information. These principles state that any information must be ('Data protection monitoring at work' — [www.rcn.org.uk](http://www.rcn.org.uk)):

- ▶ Used fairly, lawfully and transparently
- ▶ Used for specified, explicit purposes
- ▶ Used in a way that is adequate, relevant and limited to only what is necessary
- ▶ Accurate and, where necessary, kept up to date for no longer than is necessary
- ▶ Handled in a way that ensures appropriate security, including protection against unlawful or unauthorised processing, access, loss, destruction or damage.

### ARE YOU PROTECTED?

GDPR has caused some anxiety among healthcare staff about what information can and can't be shared, and whether they might get into trouble for accidentally sharing a patient's details.



*The phrase General Data Protection Regulation, often abbreviated to GDPR, may well create a sense of anxiety in clinical practitioners who might be understandably anxious and potentially fearful that their actions or omissions, and the consequent outcomes, will cause issues for themselves or the individuals that they are nursing and their carers, families and the community around them.*

*However, there are a variety of strategies, mechanisms and legislation in place to inform, educate and protect the clinical practitioner and also to safeguard and protect the rights of the individual who they are involved with or caring for.*

*The support strategies in place may well include trust, organisational and employer policies, processes and procedures regardless of the employer that the individual works for. Such documentation will be present in a variety of formats, digital and hard copy, and will be highlighted to the individual when they are newly appointed in the organisation and promoted, and no doubt on an ongoing basis when there are changes to GDPR and through routine staff training and updates. This may well take the format of 'what if?' scenarios or case studies. Having a multidisciplinary GDPR group discussion may be a useful learning tool.*

*The Nursing and Midwifery Council 'Code' supports the premise that there is an inherent respect of the right to privacy and confidentiality. However, there are clear instances when sharing data is the way forward to protect the individual we are caring for and/or to protect other individuals.*

*As community nurses and indeed all health practitioners, when reviewing our intentions to share data, we will need to consider the best interests of the individual or others involved and act in an appropriate, sensible and informed manner. Seeking a lead-professional's viewpoint, knowledge and experience may well be reassuring and informative. It is vital as community practitioners that we review organisational, legislative and NMC guidelines and strongly endeavour to inform the individual, if at all possible, that you are sharing their data with a best interest approach after having considered the impact of action or inaction.*

**Teresa Burdett**

Principal academic, Bournemouth University

The simple answer is, you probably won't. Any healthcare service such as a GP practice should by now have procedures in place for protecting patients' information, which deal with the high-level information-governance procedures. All practices should also have easily available posters and

leaflets for patients, outlining their data rights.

On a day-to-day level, there are some simple measures that you can take to make sure you are protecting your patients' data. Writing in the journal, *Nursing Management*, Daniel Allen states that these include



simple actions such as 'not sharing passwords, not leaving identifiable patient information on computer screens and logging out after using a computer' ('Data protection in the NHS: what new regulation means for you' — journals.rcni.com).

It is also crucial that you appreciate a patient's right to access their records, which might mean for example, using less medical jargon to ensure that patients can better understand the information. Any patient information must be written in plain language and should be concise and easily understood. Simple access to clear information is important to ensure that patients can make informed decisions about their care ('Applying the Data Protection Act 2018 and General Data Protection Regulation principles in healthcare settings' — journals.rcni.com).

You should also become used to considering a patient's information as something that belongs to them, and not the practice or you or your colleagues. This means that at each point of information-sharing, such as a referral email, you need to consider whether the information is necessary, and whether appropriate consent has been sought from the patient.

## DUTY OF CONFIDENTIALITY

If you are nervous about mistakenly sharing a patient's details, it is important to remember that while GDPR has increased the focus on the processing of patient information, nurses already have a professional duty to ensure confidentiality, which is enshrined in the Nursing and Midwifery Council Code.

The Code principle 'Respect people's right to privacy and confidentiality' states that: 'As a nurse, midwife or nursing associate, you owe a duty of confidentiality to all those who are receiving care. This includes making sure that they are informed about their care and that information about them is shared appropriately' ('The Code Professional standards of practice and behaviour for nurses, midwives and nursing associates' — www.nmc.org.uk).

If you are nervous about GDPR, think of it as an extension of the duty of confidentiality that you already owe to patients in your everyday work as a nurse.

## TOO SCARED TO SHARE

It is also important that community nurses are not intimidated by fear of GDPR into not sharing relevant information when they should, for example, if they fear that a patient is in danger or may endanger others. Similarly, you may feel that you should share information with the police, or warn a colleague about a patient's potentially dangerous behaviour, but are wary of falling foul of GDPR rules.

Remember, GDPR is not intended to prevent you from sharing information where appropriate, but to ensure that any sharing is undertaken in a secure way. Take the example of sharing information about a patient with the police. There are actually some cases when you must share information:

- ▶ Prevention of terrorism — you must inform the police if you have information (including personal or confidential patient information) that may prevent an act of terrorism
- ▶ Traffic accidents — you must tell the police when asked of any information that might identify a driver who is alleged to have committed an offence
- ▶ Female genital mutilation (FGM) — you must report when any girl under the age of 18 has been subject to genital mutilation.

As with other elements of GDPR, it is important to take a common-sense approach to disclosing information. The rules are not there to intimidate, rather to guide. Generally, a disclosure can be made to the police in the public interest to prevent or detect a serious crime or to prevent serious harm to another person ('Sharing information with the police' — transform.england.nhs.uk).

## A COMMON-SENSE APPROACH

The government has supplied some common-sense principles

to help ensure that you do not fall foul of GDPR legislation ('Sharing information — advice for practitioners providing safeguarding services to children, young people, parents and carers' — assets.publishing.service.gov.uk):

- ▶ Be open and honest with the patient and their family about why, what, how and with whom any information may be shared, and seek their agreement, unless it is unsafe or inappropriate to do so
- ▶ Seek advice from colleagues or your practice's GDPR lead if you are in any doubt about sharing the information concerned (without disclosing the identity of the individual where possible)
- ▶ Share information with the patient's consent, and where possible, respect the wishes of those who do not wish to have their information shared. Remember that where you do not have consent, the patient may not expect their information to be shared
- ▶ Consider safety and well-being — base any information-sharing decisions on the safety and well-being of the individual
- ▶ Ensure that any information you share about a patient is necessary for the purpose for which you are sharing it; that it is shared only with those individuals who need it; that it is accurate and up to date; that it is shared in a timely fashion, and that it is shared securely
- ▶ Keep a record of your decision to share a patient's information and the reasons for it. If you decide to share, then record what you have shared, with whom, and for what purpose.

For community nurses or any other healthcare staff, GDPR rules should not be a source of anxiety. Taking a common-sense approach to sharing information, and placing the patient at the centre of any decision about whether to share their details should ensure that you avoid falling foul of the law. If in doubt, just remember that it's good to share, but when it comes to patient's data, make sure you ask first. **JCN**

## Giving confidence to treat hard-to-heal wounds

Ali Hedley, Medical and Professional Affairs Manager, UK, Mölnlycke

### IF YOU FEEL CONFIDENT, YOUR PATIENTS FEEL CONFIDENT

In order to instil confidence in your patients, you yourself need to feel confident in the care you're providing — including the products you use.

This is why we're publishing the results of a recent randomised controlled trial (RCT) comparing the efficacy of Exufiber® with the market leading gelling fibre dressing, in exuding venous and mixed aetiology leg ulcers.

Exufiber® is a gelling fibre dressing with Hydrolock® Technology for use on highly exuding wounds. It also helps to support autolytic debridement by forming a soft, conformable gel on the wound bed. Hydrolock Technology means that Exufiber® stays intact when wet, without the need for

further reinforcement, making it easy to remove in one piece during dressing changes.

### RESULTS

The results show:

- Wounds treated with Exufiber® showed a trend of a greater percentage of reduction in wound size than those of the market leading gelling fibre dressing
- Clinicians reported a significantly greater percentage of 'very good' ratings for Exufiber® with regard to dressing features and technical performance, when compared to the market leading gelling fibre dressing.

### EXCESSIVE EXUDATE IS ONE OF THE BIGGEST CHALLENGES WITH HARD-TO-HEAL WOUNDS

Chronic wounds, such as leg ulcers, often produce an excessive volume of exudate. If not managed appropriately, this can lead to maceration of the surrounding skin and in some cases accelerate wound infection, which lengthens healing time.

For community nurses, managing exudate in an appropriate, sensitive manner is an essential part of managing the symptoms of your patient's wound and can also help to provide them with the best possible healing environment.



### WHAT THE RESULTS MEAN FOR YOUR PATIENTS

The study compared the results of one group of patients treated with Exufiber® dressings and the other with the market leading gelling fibre dressing. Specifically, the study compared wound area reduction over time. It also asked the treating clinicians to evaluate both products' features and technical performance. Clinicians reported that Exufiber® demonstrated a:

- 52% increase in terms of the ability to absorb exudate
- 53% increase in ability to retain exudate
- 29% increase in ability to retain blood and slough.

These results apply for wounds requiring both short-term (6 weeks) and long-term (24 weeks) care.

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\* For Exufiber® Ag+, when exposed to a flow rate of 0.6ml/h at 40 mmHg pressure for up to seven days (Mölnlycke Health Care. Exufiber Ag+; Physical properties over time. Mölnlycke Health Care. Data on file. [2019].).

\*\* When comparing lab test results for retention under pressure with Aquacel®, Aquacel® Extra™, Durafiber® and UrgoClean® dressings. \*\*\* As part of a holistic biofilm management approach as per international guidelines (i.e. cleansing, debridement and reassessment) [Bjarnsholt T, Eberlein T, Malone M, Schultz G. Management of wound biofilm Made Easy. London: Wounds International 2017]

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*Matthew Bradby, head of communications, Queen's Nursing Institute (QNI)*

The Queen's Nursing Institute (QNI) has published new Standards of Education and Practice for community practice teaching. This is the seventh in a series of standards developed and published by the QNI since 2015.

The new standards comprise a set of benchmarks and guidance for the role of community practice teacher, the attributes required for community practice teaching, and the support and educational framework needed for learners undertaking a specialist practitioner qualification (SPQ) or specialist community public health nursing (SCPHN). The new standards will ensure that there is a robust basis for contemporary education and practice for registered nurses undertaking a SPQ or SCPHN programme.

The role of community practice teacher is usually reserved for a community-based practitioner who has themselves undertaken an NMC-approved post-registration SPQ or SCPHN programme, plus an additional qualification that prepares them to supervise and assess in practice (for example, a postgraduate certificate in education).

The QNI believes that the new standards make a significant contribution to community nursing education. They make explicit the knowledge framework required to support, supervise and assess registered nurses undertaking

# New community practice teaching standards published

a specialist community post-registration programme, preparing them to work and make complex decisions autonomously. The standards also align with the four pillars (domains) of advanced practice of the Health Education England advanced clinical practice toolkit. The domain titles used in the QNI standards are:

- ▶ Domain 1 — clinical care
- ▶ Domain 2 — leadership and management
- ▶ Domain 3 — education and assessing learning
- ▶ Domain 4 — evidence, research and development.

## BACKGROUND TO THE NEW STANDARDS

When the NMC Community Nursing Practice Teacher Standards were withdrawn in 2018, the practice teacher qualification ceased to be offered by many higher education institutions, impacting adversely on community education and practice at the advanced level. In response to concerns expressed by healthcare provider organisations and educators, the QNI's council therefore resolved in 2021 to develop new standards to provide a new articulation of the professional role of community practice teaching.

The process of developing the standards drew on widespread engagement, support and collaboration from partners across nursing practice and education. Experts by experience, higher education programme leads, practitioners and commissioners from all four countries of the UK contributed to the project through a standards advisory group. There was a consensus from all stakeholders about the need for new standards to support an advanced level of practice teaching.

All QNI projects are given a firm evidence base to ensure that they meet real needs of nurses and students. The QNI began the standards project with a survey of community nurses supervising and assessing registered nurses undertaking SPQ/SCPHN programmes and the views of learners undertaking SPQ/SCPHN programmes. A further survey was undertaken with education leads offering SPQ and SCPHN programmes and/or community practice teaching education programmes or equivalent. Following the survey analysis, focus groups with learners, practitioners and educators were undertaken, enabling around 400 participants to contribute to the consultation. Following this process, the standards reference group was formed.

The QNI is currently working on new standards for specialist practitioner qualifications in the UK, and consultation periods will be announced for these new draft standards later in 2023. To read more about our future SPQ standards work, visit: <https://qni.org.uk/news-and-events/news/qni-field-specific-standards-for-community-nursing-progress-update/>. JCN

## More information

To view previous standards published by the QNI, go to: <https://qni.org.uk/nursing-in-the-community/standards/>

To download the new Practice Teaching Standards, go to: <https://qni.org.uk/nursing-in-the-community/standards/community-nursing-practice-teacher-standards/>



# Lymphoedema Awareness Week

6-10<sup>th</sup> March 2023

## Is it challenging to:

- Differentiate between Lymphoedema, Lipoedema and Obesity and manage it effectively?
- Differentiate between Cellulitis and Red Leg Syndrome?
- Select the right compression garment?
- Ensure your patient can manage their compression and their Lymphoedema well?

## Our Lymphoedema Awareness Week webinars are designed to help:



**Dr Kristiana Gordon**

Monday 6<sup>th</sup> March 13:00-14:00

Lymphoedema-Lipoedema-Obesity:  
How can you tell the difference?



**Justine Whitaker**

Thursday 9<sup>th</sup> March 12:00-13:00

Prescribing compression garments  
for lymphoedema – getting it right  
first time



**Professor Vaughan Keeley**

Tuesday 7<sup>th</sup> March 12:00-13:00

Recognising cellulitis in people with  
lymphoedema, and what to do about  
it



**Natalie Phillips**

Thursday 9<sup>th</sup> March 19:30-20:30

Prescribing a garment is only the  
start - how to help patients manage  
their compression effectively



**Rebecca Elwell**

Wednesday 8<sup>th</sup> March 12:00-13:00

Recognising Red Leg Syndrome and  
what to do about it



**Professor Neil Piller**

Friday 10<sup>th</sup> March 12:00-13:00

Supporting patient self-management  
and empowering patients to  
positively impact their Lymphoedema

## Lymphoedema is a growing public health problem. To help raise awareness:

- Look out for the BLS Lymph Facts on social media and share with colleagues
- Register and share the link to great webinars during Lymphoedema Awareness Week
- Check out our campaign web page and share useful resources
- Register (free) as a Friend of BLS and get regular updates and our quarterly publication

#LymphoedemaAwareness  
[linktr.ee/thebls](https://linktr.ee/thebls)



SCAN ME





Deepa Korea, director, Royal College of Nursing (RCN) Foundation

## Stories of strength, kindness and skill

the 75th anniversary of the NHS and will include illustrations from the renowned illustrator Michael Foreman. It will feature a wide variety of nurses and midwives from different backgrounds, working in different settings (not just the NHS), and in different roles.

**'... it is time to start talking about nursing and midwifery roles to children at an earlier age, demonstrating that these are wonderfully fulfilling and diverse jobs.'**

But, why is it so important for children to know more about the role of a nurse and also a midwife? At a time when the UK nursing and midwifery professions are facing some of the greatest workforce challenges in their history, it may seem odd to be spending time and energy on a project like this.

However, I would argue that it has never been more important to raise the profile of nurses and midwives to a generation of children and young people, and to spark an interest in these roles

as a potential future career. With an estimate of around 50,000 vacancies in the NHS in England alone (NHS Digital, 2022), it is time to start talking about nursing and midwifery roles to children at an earlier age, demonstrating that these are wonderfully fulfilling and diverse jobs. And also highlighting that it is not all about working in a hospital and wearing a uniform.

Using the RCN Foundation's extensive networks, as well as social and digital media channels, a call was put out in 2022 asking nurses and midwives to send their stories and anecdotes. We wanted to hear from people who currently worked in, or had worked in, the many different nursing and midwifery roles, telling their personal accounts of why they had chosen their careers, what motivated them and some of the experiences that they had had.

Scholastic had asked us to find positive stories and anecdotes, aimed at both celebrating nurses and midwives and their roles, as well as encouraging children to consider nursing or midwifery as their future profession.

At a time when nursing and midwifery staff were coming through one of the worst ever healthcare crises, when they were reporting feeling burnt out and 'on their knees', and when time was a commodity in short supply, it was thought that we would struggle to get a response to the call for stories. How wrong this was.

A total of 127 incredible submissions were received, of which 45 were selected. A panel from Scholastic had the difficult task of choosing which stories

Growing up, my understanding of what a nurse does was limited. In school I learnt about Florence Nightingale, the 'Lady with the Lamp', and at home I dressed up in a nurse's uniform for a fancy dress party.

I simply did not know about the breadth, depth and diversity of the nursing profession.

So, when the RCN Foundation was approached by Scholastic, the world's largest publisher and distributor of children's books, to partner with them on a publication, we were thrilled. They wanted to work with us to develop an illustrated book aimed at eight to 11 year olds, which celebrated nursing and midwifery through real-life stories and anecdotes. This project fitted with one of the Foundation's core objectives, which is to raise the profile of nursing and midwifery, and to highlight the contribution that these professions make to improving the health and wellbeing of the public.

The book will be published in February 2023 to celebrate





ultimately ended up in the book and which did not.

The stories were varied and uplifting. They ranged from someone who described how, as a young boy in Nepal, he never thought he would become a nurse, to a nurse who had made lifelong friendships which had lasted 70 years.

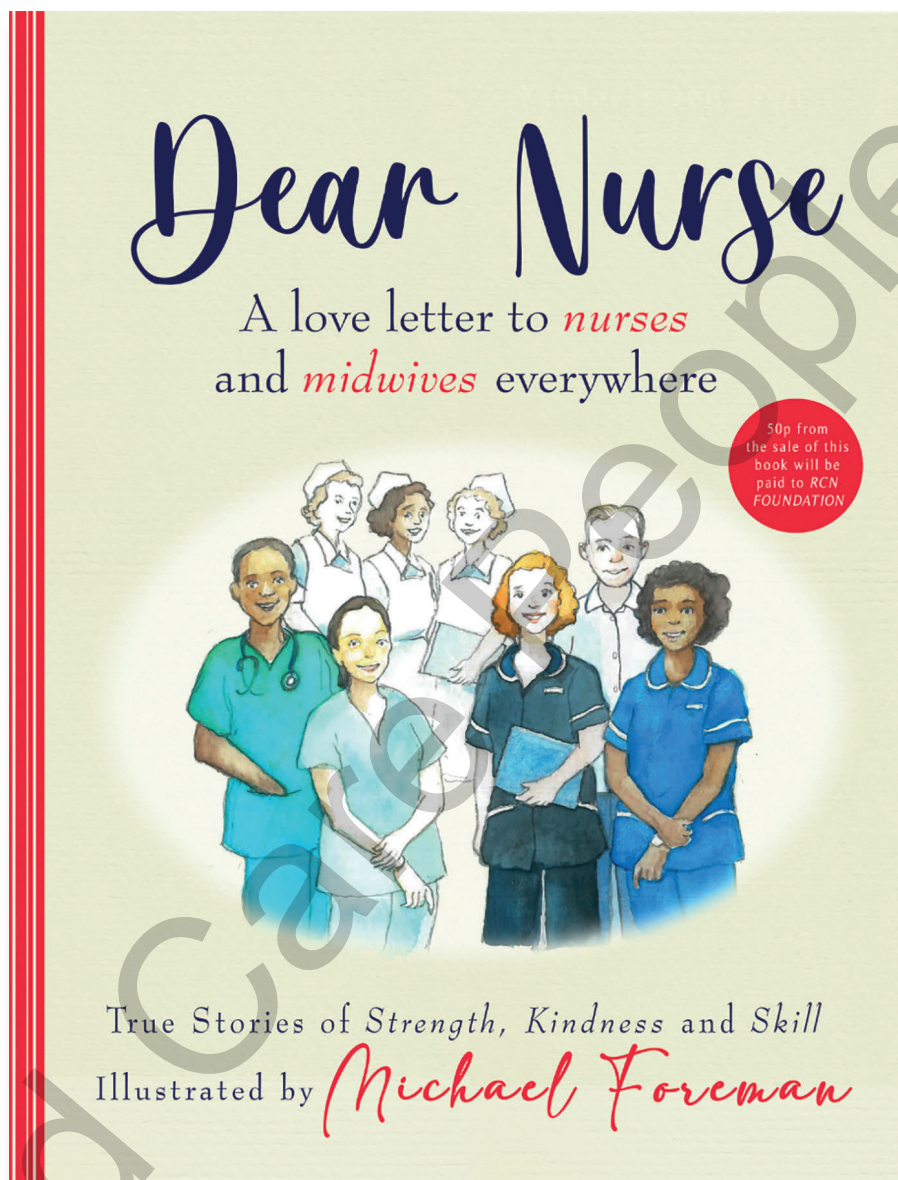
One anecdote that struck me in particular was a seemingly simple tale from a mental health nurse, who recounted how she sat and spoke with a patient on a bench on a sunny day for an hour. In her story, the nurse described her conversation with the patient.

When they ventured back into the hospital and agreed to meet again, her fellow nurse expressed surprise. This was the first time in two weeks that he had heard the patient speak since she had suffered a traumatic experience. The patient had only been communicating her needs through written notes. The talking was seen as a positive sign, the breakthrough that the whole team had been waiting for.

What connects all of the stories in the book is the unwavering commitment to, and passion for, the work that the healthcare professionals do, and the positive difference that they want to make to patients' lives. It shines through each and every story, making for an inspiring read.

And, in among the stories of kindness and compassion that feature in the book, is a strong message about the clinical expertise, skills and knowledge that are required to carry out nursing and midwifery roles.

We were delighted that Christie Watson, the RCN Foundation's patron, a former nurse and best-selling author, agreed to write the introduction, and also radio and television presenter, Jo While, to write the foreword. Jo movingly describes how the expert care of nurses saved the life of her sister, Frances, who has a learning disability and complex needs, when she became very unwell with Covid.



Some of the nurses and midwives who feature in the book also told us how rewarding and gratifying they found the experience of writing these stories, reminding them of why they chose their profession in the first place.

It is hoped that the stories and anecdotes featured in the book will demonstrate the breadth and depth of nursing and midwifery roles on offer. Equally, that they inspire a generation of children and young people to consider a career in nursing and midwifery with all of the challenges and opportunities it presents.

As the largest safety critical profession in the healthcare workforce, it is essential that there is a pipeline of future highly skilled staff. It is ultimately hoped,

therefore, that this book will in some small way encourage and contribute to that pipeline. **JCN**

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## More information...

'Dear Nurse' is available to buy online and at bookstores for £14.99.

[www.rcnfoundation.org.uk](http://www.rcnfoundation.org.uk)



*Fiona Walsh, co-founder and principal architect, DDS (specialist consultancy designing spaces for cognitive and sensory accessibility and inclusion)*

# Reducing falls through inclusive building design

be done to stop older people falling — not with more medication or monitoring gadgets, but with targeted building design.

## DIMINISHED COGNITIVE AND SENSORY CAPACITY

Falls are not simple or monocausal. They can be the result of a whole host of differing and inter-related factors, such as polypharmacy, sedation, sight impairment, environmental hazards, physical frailty and balance issues.

But, one of the key risk factors is something that effects older people, namely reduced cognitive and sensory capacity. It is estimated that 70–80% of people living in long-term care have varying degrees of dementia, either diagnosed or undiagnosed (Matthews et al, 2013; Seitz et al, 2010). Some level of sensory impairment is also extremely common among older people, with 94% of older Americans having some kind of impairment (Correia et al, 2016).

Research shows that these impairments and conditions, such as dementia, lead to an increase in falls (Allali et al, 2017). In general terms, someone with dementia is about eight times more likely to fall than a peer without dementia (Allan et al, 2009). Understanding why is not that difficult: walking becomes automatic for most of us, but actually involves executive function and brainpower. If your brain which is compromised with dementia is now also occupied interpreting the environment, it starts to get cognitively overloaded.

This does not mean that it becomes impossible, but it can mean a distraction, or elements within the environment or a new environment could overwhelm an older person, affecting both their gait and balance. It is these environments that the author focuses on in her work, designing to reduce falls in all

settings, but especially health and care environments. This takes a deep understanding of what might create cognitive load in a building — to know what needs to be eliminated or added to create a safer environment.

## WHY THE ENVIRONMENT MATTERS

One of the last parts of the brain that Alzheimer's disease affects is procedural memory (Bahar-Fuchs et al, 2013). Patients who might have a lot of trouble doing new things can often still carry out their normal habits well, such as making a cup of tea or walking around their own home.

New environments, such as hospitals or care homes, can change this entirely. This is probably why hospitals seem to cause so much cognitive decline in older patients, no matter what they were actually admitted for (James et al, 2019; Sprung et al, 2020).

But, what makes things worse is the way so many of these environments are designed — as complex loud spaces that can easily overwhelm a patient with reduced capacity.

Even totally healthy brains find environments with far too many stimuli distracting and often distressing. But for someone with a reduced working memory, the many auditory and visual stimuli from a new environment can simply overwhelm their ability to process their surroundings, leading to distraction that could affect their balance and change their gait resulting in an unnecessary fall.

This is not to suggest that every hospital corridor be designed to be devoid of character or detail. But, there are ways that the built environment can be far more user friendly.

**N**obody within the health and care system needs to be told how dangerous a fall can be.

Hip fractures caused by falls are the number one source of accident-related deaths in older people (Department of Health [DH], 2009). Thirty percent of older people who have a hip fracture from a fall die within a year — 20% within just four months (DH, 2009). These fractures result in a rapid loss of independence and routine that can be devastating for an individual.

Falls are not rare. About a third of those aged over 65 will have a fall this year, and half of those over 80 (NHS, 2022). While not all of these will result in a hip fracture, about 5% in those over 65 will (Public Health England [PHE], 2017). Those that do not result in a death can also be debilitating — 80% of women aged 75 or over in one survey said they would rather be dead than deal with the lack of independence that a fall could cause (Salkeld et al, 2000).

Despite these dangers, falls continue to frustrate the health and social care systems, with some believing they are inevitable — which is not the case. You do not see headlines about major medical breakthroughs to combat falls, or major campaigns to raise research funds. But while some falls are inevitable, there is far more that could



One aspect of health and care settings which could be changed is the abundance of glare on flooring materials.

Glare is often associated with good things — a room full of light from big windows, or a floor cleaned to a perfect shine. However, a shiny floor can present itself as something slippery like liquid or ice to be avoided. The glare itself can be overwhelming, but the effort needed to interpret what is physically present can lead to a change in balance and gait that may result in a fall.

The author has witnessed patients on wards reacting to pools of glare and exhibiting both anxiety and fear when not being able to read the environment with ease. DDS (a specialist consultancy designing spaces for cognitive and sensory accessibility and inclusion) assess and audit facilities to understand how patients and residents react to their environments, and glare is one factor that often poses a problem. A floor that is the pride of the hospital's cleaning staff — as it signifies cleanliness — can be creating issues for staff and residents/patients. Removing the polish or using a matte finish is an easy and beneficial fix.

Indeed, floors and their design and finish are a complex issue. Patterns, threshold bars, mats, etc all need to be interpreted and decoded to read an environment. Thus, the aim should be to design finishes that are clear, unambiguous and cannot be misinterpreted in order to reduce falls in areas used and occupied by people living with cognitive and sensory impairments.

But, it is not just floors or glare that effect fall rates. A holistic view of an environment should be taken. All our senses are used to interact and decode surroundings, therefore all the senses must be supported and protected. Auditory stimuli can also overwhelm working memory — so more needs to be done to make these spaces quieter and acoustically clear. Vision and depth perception can be enhanced through the correct use of colour. There is a sweet spot with design — where you offer

enough information to make the environment clear and discernible, but not too busy so that it distracts and overwhelms.

In the author's opinion, upgrading the environment with inclusive design interventions works. Analysis of some King's Fund research on the use of these tools suggests a reduction in falls of around 18% (King's Fund, 2013). Other research by the DH (2015) suggests inclusive design interventions do not just reduce falls, they also:

- ▶ Reduce stress and anxiety for patients
- ▶ Increase quality of life
- ▶ Increase independence.

Institutions also see the benefits, of more discharges, reduced readmission, and increased staff retention (DH, 2015).

Every fall cannot be eliminated as there are far too many factors involved, but given that design changes are relatively simple and affordable with expert analysis and understanding of the issues, there is no good reason why design solutions should not be included into any major falls strategy or at the initial design of a new building or refurbishment. To not do so, would be a lost opportunity... **JCN**

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Grace Meadows, campaign director,  
*Music for Dementia*

Over the past decade, the author believes that society has begun to awaken to the transformative power music can have both for those living with dementia, and those who care for them. There have been a number of viral news stories which have really captured the nation's hearts and brought us all to tears — think of Paul Harvey with his beautiful Four Notes improvisation and Marta C Gonzalez, a former prima ballerina living with Alzheimer's who became animated listening to Swan Lake.

Yet, it is also disheartening that this growing awareness has not turned into action and music is not being used routinely as part of care. One of the greatest barriers for family carers/unpaid carers in using music is knowing where to start and having a sense of confidence in how to use music as part of their care. There is a perception that they must be musically trained or proficient in playing an instrument.

The beauty of using music to enhance and enrich the health and wellbeing of people living with dementia is that it is easy to use and can be low cost or even free to make happen — just think about singing with a loved one. At a time when the health and social care system is understaffed and underfunded, music should be embraced and made part of daily care. Part of the author's role as campaign director for Music for Dementia is to raise awareness about

# How music can lighten up life for dementia patients

the power of music for people living with dementia, and empower carers to know that they have the skills and mobilise them to start using music more as part of the vital care they provide, both as paid and unpaid carers.

Like many advancements in society, technology can lend a helping hand in empowering and mobilising people. For example, Casio pioneered a new keyboard with light-up keys and asked Music for Dementia to be involved, who invited a care provider, Methodist Homes (MHA), to become a partner in the pilot 'Light Up My Life' scheme.

Casio provided the light-up keyboards to care home managers, staff and music therapists across the MHA network of care homes (50 keyboards were distributed to 50 settings) to use in music therapy sessions and as part of everyday musical activities. The lighting technology of the keyboards was fundamental; it meant participants could simply follow the lights on the keyboard, which would guide them to the correct notes without any prior musical knowledge or piano playing experience. A range of well-known pieces of music were also pre-loaded into the keyboards.

For carers, the technology meant that they too did not require any previous musical knowledge or piano playing experience. Their role was to help facilitate the use of the keyboard and support residents in following the lights and being with them as they explored the instruments.

A key goal of the pilot project was to gain a better understanding and insight into how the musical instruments, as part of a musical care plan, can better help those living with dementia at various stages of the condition. The direct impact of using the keyboards to make

music on the residents' wellbeing was clearly evident. Over 70% of music therapists working across the MHA care homes saw a reduction in anxiety and depression among residents, while care home staff reported a notable increase in their sense of fulfilment and achievement, as well as significant improvement with symptoms such as agitation.

The project also revealed that residents displayed improved signs of memory recall after playing the keyboard and producing a recognisable song — a statement that was supported by 79% of music therapists and 64% of care home staff. In addition, 95% of music therapists and 71% of care home staff were in agreement that playing the keyboard increased or enhanced opportunities for social interaction for the residents with staff and relatives. Amazingly, 95% of the residents who participated said that they were elated or felt happy after completing a song on the keyboard — a statement backed up by 86% of music therapists.

These results speak for themselves. They show that innovative, creative initiatives such as 'Light Up My Life' help to remove both perceived and practical barriers to making music a part of care. This collaboration has demonstrated how carers can be empowered with technology that makes making music a part of care simple, easy and fun.

Music has a transformative impact on those living with dementia, providing a short-cut to meaningful personalised care and should be an integral part of dementia care so everyone can experience its benefits.

## More information...

To download the full report, visit: [www.casio.co.uk/emi/lightupmylife](http://www.casio.co.uk/emi/lightupmylife)



# Self-neglect and pressure ulcers

Kulvant Sandhu, Joanne Beresford

As healthcare professionals, our purpose is to deliver treatments and interventions to patients to aid recovery and prevent deterioration in health. But what does that look like when patients do not wish to follow advice, do not want treatment or interventions, even if that means significant consequences such as loss of limbs, sepsis or death — where do we legally stand in these situations and how do we work with patients to achieve the best possible outcomes for them? Over years of clinical experience, the authors have found that working with those who self-neglect can be complex. This is due to a range of factors, such as risks to the individual and sometimes others. Other issues involved include healthcare professionals' views and moral conflict between respecting patient autonomy and their duty of care, challenges in trying to engage patients who may not want services involved, attempting to assess and being clear on the patient's mental capacity, working within task-orientated systems which may not always be conducive to building rapport, and working with the patient's socio-economic factors which impact upon their health (Research in Practice, 2020).

## KEYWORDS:

- Pressure ulcers ■ Self-neglect ■ Mental capacity
- Safeguarding ■ Best interests

A pressure ulcer (PU) is localised injury to the skin and/or underlying tissue usually over a bony prominence, such as the heel or sacrum, as a result of pressure, or pressure in combination with shear (National Pressure Injury Advisory Panel/ European Pressure Ulcer Advisory Panel/Pan Pacific Pressure Injury Alliance [NPIAP/EPUAP/PPPIA], 2019). They range in severity from categories 1–4, and unstageable and suspected deep tissue injury (DTI) are also now included in the NPUAP/EPUAP/PPPIA categorisation (Table 1). Once a PU has been identified, there needs to be clinical agreement with the PU classification (NPIAP/EPUAP/PPPIA, 2019) to enable prescribing of treatment and care planning.

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There is potential for all patients to be at risk of pressure ulceration. However, patients who are critically ill, have a neurological condition, impaired mobility and nutrition, or poor posture and deformity are at a greater risk (National Institute for Health and Care Excellence [NICE], 2014). Patients with a spinal cord injury (SCI) have a PU prevalence of 20–30% in the first one to five years after their injury (Department of Health [DH], 2022).

The Burden of Wounds study reported that PUs accounted for 9% of all wounds managed by the National Health Service (NHS) during 2012/13 (Guest et al, 2015), with a £531.1 million estimated cost to the NHS in managing these wounds and the associated comorbidities (Guest et al, 2017).

There is no single factor which can explain pressure ulcer risk, rather a complex interplay of factors (Coleman et al, 2013). Reduced mobility and sensory perception are two prominent risk factors. However,

## Box 1.

### PRESSURE ULCERATION RISK FACTORS (PURPOSE T)

- ▶ Reduced mobility
- ▶ Damaged skin
- ▶ Previous PU history/patient has current pressure damage
- ▶ Medical devices
- ▶ Perfusion
- ▶ Reduced/lack of sensory perception
- ▶ Moisture
- ▶ Diabetes
- ▶ Poor nutritional/hydration status

(Coleman et al, 2018)

patients may present with additional risk factors, depending on risk assessment (Box 1).

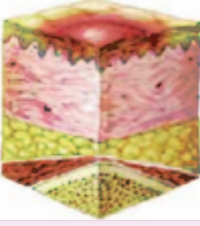
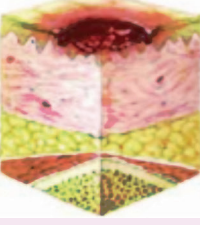
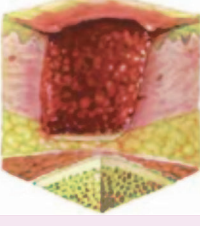
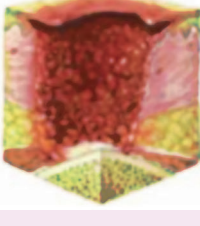
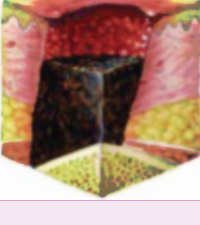
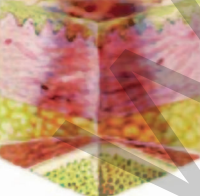
These risk factors can be intrinsic, such as mobility, sensory impairment, nutrition, or extrinsic, such as pressure, shear, moisture, patient beliefs.

Pressure ulcer risk assessment is required in all patients within six hours of acute admission or on the first visit within a community setting, using a recognised pressure ulcer risk assessment tool (such as Braden, Waterlow, PURPOSE T [Pressure Ulcer Risk Primary or Secondary Evaluation Tool]) (NICE, 2014). Clinical judgement should also be employed and local policy followed when assessing a patient's risk of developing a pressure ulcer. It is also vital that patients are regularly

## Practice point

Pressure ulcers can impact on quality of life, having a physical, social and psychological effect on patients (Jones, 2013), as well as their families and carers.

**Table 1: Pressure ulcer categories**

<b>Category 1</b>	
	<p>Non-blanchable erythema, intact skin with non-blanchable redness of a localised area usually over a bony prominence. Darkly pigmented skin may not have visible blanching; its colour may differ from the surrounding area.</p> <p>The area may be painful, firm, soft, warmer or cooler as compared to adjacent tissue.</p>
<b>Category 2</b>	
	<p>Partial-thickness loss of dermis presenting as a shallow open ulcer with a red pink wound bed, without slough. May also present as an intact or open/ruptured serum-filled blister. Presents as a shiny or dry shallow ulcer without slough or bruising (bruising indicates suspected deep tissue injury).</p> <p>This category should not be used to describe skin tears, tape burns, perineal dermatitis, maceration or excoriation.</p>
<b>Category 3</b>	
	<p>Full-thickness tissue loss. Subcutaneous fat may be visible but bone, tendon or muscle are not exposed. Slough may be present but does not obscure the depth of tissue loss. May include undermining and tunneling. The depth of a category 3 pressure ulcer varies by anatomical location. The bridge of the nose, ear, occiput and malleolus do not have subcutaneous tissue and category 3 ulcers can be shallow. In contrast, areas of significant adiposity can develop extremely deep category 3 pressure ulcers. Bone/tendon is not visible or directly palpable.</p>
<b>Category 4</b>	
	<p>Full-thickness tissue loss with exposed bone, tendon or muscle. Slough or eschar may be present on some parts of the wound bed. Often include undermining and tunneling. The depth of a category 4 pressure ulcer varies by anatomical location. The bridge of the nose, ear, occiput and malleolus do not have subcutaneous tissue and these ulcers can be shallow. Category 4 ulcers can extend into muscle and/or supporting structures (e.g. fascia, tendon or joint capsule) making osteomyelitis possible. Exposed bone/tendon is visible or directly palpable.</p>
<b>Unstageable: depth unknown</b>	
	<p>Full-thickness tissue loss in which the base of the ulcer is covered by slough (yellow, tan, grey, green or brown) and/or eschar (tan, brown or black) in the wound bed. Until enough slough and/or eschar is removed to expose the base of the wound, the true depth, and therefore category, cannot be determined. Stable (dry, adherent, intact without erythema or fluctuance) eschar on the heels serves as 'the body's natural (biological) cover' and should not be removed.</p>
<b>Suspected deep tissue injury (DTI): depth unknown</b>	
	<p>Purple or maroon localised area of discoloured intact skin or blood-filled blister due to damage of underlying soft tissue from pressure and/or shear. The area may be preceded by tissue that is painful, firm, mushy, boggy, warmer or cooler as compared to adjacent tissue. DTI may be difficult to detect in individuals with dark skin tones. Evolution may include a thin blister over a dark wound bed. The wound may further evolve and become covered by thin eschar. Evolution may be rapid exposing additional layers of tissue even with optimal treatment.</p>

Images in Table 1 reproduced courtesy of National Pressure Ulcer Advisory, European Pressure Ulcer Advisory Panel and Pan Pacific Pressure Injury Alliance (2014) *Prevention and Treatment of Pressure Ulcers: Quick Reference Guide*. Emily Haesler (Ed). Cambridge Media: Obsbourn Park, Australia

reassessed, e.g. when washing or dressing and during dressing changes, as pressure ulcers can develop rapidly.

Once patient risk factors are identified (such as those in *Box 1*),

also including socio-demographic and behavioural factors, a plan can be incorporated into their care to help prevent the development of avoidable pressure ulcers. This should be completed in partnership with the individual. Indeed, identifying

and preventing pressure ulcers is considered an indication of the quality of care given (Vowden and Vowden, 2015).

Reassessment of patients' PU risk factors and plan of care, including wound assessment, should be completed in accordance with local PU policy and in agreement with the patient. This should include the patient's ability to undertake activities of daily living (ADLs), as a person who neglects their personal hygiene and has reduced mobility will be increasing their risk of PU. Pressure ulcers can occur as a result of neglect or self-neglect through acts of omissions, including ignoring medical, emotional or physical care needs. Where this is evident, it is likely to result in preventable skin damage (Department of Health and Social Care, 2018).

## CASE STUDY

This male patient with a SCI presented to his GP surgery feeling unwell with a category 4 pressure ulcer (*Table 1*) to the sacrum and bilateral ischial tuberosities. A high volume of exudate was being produced and there was malodour. Before the development of the pressure ulcer, he had been receiving no other community care services. The GP arranged hospital admission, where the plastics team diagnosed Fournier's gangrene, which resulted in a long admission and failed skin graft. The plastics team also prescribed an extended course of oral antibiotics. A referral was made to the community nursing team (CNT) for his discharge home, as he required application of negative pressure wound therapy (NPWT), and to ensure that pressure relief equipment was in place.

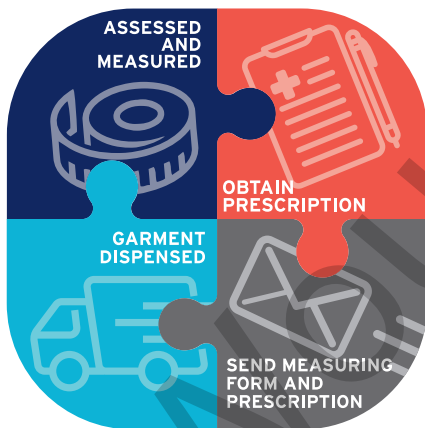
## Practice point

A systematic review found that being male increased pressure ulcer risk for patients with a SCI (Gelis et al, 2009). Additional risk factors to consider include lack of self-care or hygiene and the environment, i.e. cases of hoarding.





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The CNT visited the patient at home and performed a holistic assessment, including wound assessment (this involved photography) and PURPOSE T risk assessment, which highlighted his risk factors (mobility, current pressure damage, sensory perception, moisture and poor nutritional status). A pressure ulcer care plan was implemented to address the risk factors, including referral to a dietician and advice on a positioning schedule.

Within his first week at home, the tissue viability nurse (TVN) visited and performed a comprehensive assessment. NPWT was subsequently discontinued as it required daily dressing changes. This was mainly due to the patient wishing to transfer independently using a banana board (transfer board) and the dressings becoming dislodged. As a result of the patient's risk of infection and the high volume of exudate being produced, the TVN prescribed antimicrobial and superabsorbent dressings. During the assessment with the TVN, he presented with local and systemic signs of wound infection (high exudate, odour from the wound on dressing removal, and delayed healing — systemic infection is a stage of infection when microorganisms spread throughout the body [International Wound Infection Institute, 2022]). Due to his SCI, he was not able to express pain from the PU. Current antibiotics were being taken as prescribed, and wounds swabs were taken and the GP informed.

Both the TVN and GP advised hospital admission, but he declined. This was mostly due to his recent long admission and being away from his wife, who

suffered with her own mental health issues. As a compromise, the TVN liaised with the plastics team and the patient agreed to weekly outpatient appointments for ongoing monitoring, with daily CNT visits continuing for wound care, assessment and clinical observations.

**'Safeguarding adults boards (SABs) have a statutory duty to help and protect adults with care and support needs who are experiencing, or at risk of abuse and neglect. Practitioners within health care also have a statutory duty to work with and support those patients who self-neglect.'**

Unfortunately, within four weeks of being at home, the patient declined these CNT visits. He and his wife were very private, they had not had community services visiting in the past and did not like this happening, as the patient felt that it was having a negative impact on his wife's mental health. The severity of the PU, risk factors and his health had been explained to him daily by the CNT and during the TVN assessments, and he was assessed as having mental capacity to make his own decisions. He was able to communicate his needs, he retained information from previous visits regarding his treatment and pressure prevention care plan, he understood the severity of his condition and was able to weigh up that, if left untreated, his current condition was life-threatening.

A further compromise was therefore reached whereby the patient would attend the GP surgery three times per week, replacing dressings himself between appointments, with the weekly outpatient appointment to plastics continuing. Two members of the CNT attended the GP surgery appointments, with weekly TVN assessment. Clinical observations (including bloods if required) and wound assessment were

documented. This indicated that he had ongoing infection and was at risk of sepsis. Hospital admission was again advised, but he continued to decline. Home visits were thus offered, as he was still attending the surgery during the winter and his dressings were extremely saturated with exudate. However, his preference was to continue attending the appointments at the surgery three times a week.

Due to identified complexities with this individual, such as severe pressure damage, self-neglect, resulting in ongoing risk of wound infection and osteomyelitis, a multidisciplinary approach was adopted, incorporating the CNT, TVN, trust safeguarding, GP and plastics team.

### Safeguarding perspective

Since the implementation of the Care Act in 2014, self-neglect has been defined as a form of abuse and neglect which comes under the remit of safeguarding adults practice. Safeguarding adults boards (SABs) have a statutory duty to help and protect adults with care and support needs who are experiencing, or at risk of abuse and neglect. Practitioners within health care also have a statutory duty to work with and support those patients who self-neglect (Social Care Institute for Excellence [SCIE], 2018).

SABs have a duty to undertake safeguarding adults reviews (SARs) when an adult with care and support needs has died or suffered serious harm, with the cause suspected or known to be neglect or abuse (including self-neglect). Self-neglect has become the most prevalent type of abuse featured within SARs nationally (Local Government Association, 2022; Box 2).

Self-neglect can include people both with or without mental capacity, who demonstrate:

- ▶ Lack of self-care (neglect of personal hygiene, nutrition, hydration and health, thereby endangering their safety and wellbeing)
- ▶ Lack of care of one's environment (squalor and hoarding)

### Practice point

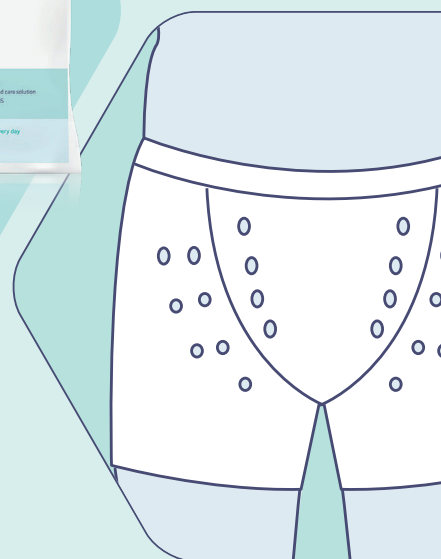
Self-neglect has been identified by Leeds safeguarding adult board as:

'... a wide range of behaviour neglecting to care for one's personal hygiene, health or surrounding and includes behaviour such as hoarding.'



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- ▶ Refusal of services that would mitigate the risk of harm (Government Publications, 2022).

### Legal frameworks: consent and Mental Capacity Act (MCA)

There are a few legal frameworks available to consider when responding to self-neglect, such as the Care Act 2014, Mental Capacity Act (MCA) 2005 (Box 3), and Human Rights Act 1998. From the perspective of working within a community setting, the starting point for healthcare professionals is to be clear about which legal frameworks are underpinning the care and treatment being delivered to the patient, such as:

- ▶ Law on consent
- ▶ Mental Capacity Act 2005 (England and Wales)/The Adults with Incapacity Act 2000 (Scotland).

The law on consent for delivering care and treatment is that adults and those aged 16 years and over have the legal right to make decisions about their own care and treatment if they have mental capacity (which must be assumed they do unless evidence is found otherwise). This also means that they have the legal right to decline interventions and treatments (NHS, 2019).

However, if healthcare professionals have concerns about a patient's ability to make decisions, their mental capacity needs to be assessed for the self-neglect decision they are making. If the patient lacks mental capacity (Box 3), professionals should work in the patient's best interests (Box 4). This involves professionals making decisions about how to provide interventions that are the least restrictive, i.e. keeping them safe while restricting their rights and freedoms as little as possible, and taking into account the patient's views and wishes (Mental Capacity Act, 2005).

Professionals also need to be mindful that if the patient is refusing treatment they may not fully understand the risks or consequences involved. Thus, it should be explored if treatment can

### Box 2.

#### LEARNING FROM SARs/SELF-NEGLECT RESEARCH

Self-neglect can arise due to a range of factors rather than simply being someone's own choice. These factors include mental and physical health, as well as social and environmental factors. It could be a longstanding pattern, a recent change, be linked to loss, past trauma, as well as low self-esteem.

Evidence of good practice recommends (Research in Practice, 2020):

- ▶ Taking time to build rapport and a relationship of trust through persistence, patience and continuity of involvement
- ▶ Seeking to 'find' the whole person and to understand the meaning of their self-neglect in the context of their life history
- ▶ Working at the individual's pace, spotting moments of motivation that could facilitate change, even when the steps towards that are small
- ▶ Ensuring an understanding of the patient's mental capacity, knowing which legal framework to work under (consent or Mental Capacity Act [MCA]). Remember, mental capacity is decision-specific
- ▶ Being honest, open and transparent about risks and options. The authors show photos of wounds to patients, especially if located in a place that the patient cannot see easily
- ▶ Understanding legal options for intervention (MCA, Mental Health Act [MHA], as well as advance care planning [ACP], recommended summary plan for emergency care and treatment [ReSPECT] forms, do not attempt cardiopulmonary resuscitation [DNACPR], advance decisions to refuse treatment [ADRT], and lasting power of attorney [LPA])
- ▶ Being creative with flexible interventions, including family members and community resources where appropriate
- ▶ Engaging in effective multi-agency working to ensure interdisciplinary and specialist perspectives are included, as well as coordination of work towards shared goals.

be delivered in a way that the patient may accept.

### Managing this case with the patient having mental capacity

As the patient presented here was deemed to have mental capacity, the authors approached his case through:

- ▶ Respecting the patient's autonomy: treatment or visits could not be forced and his decisions needed to be respected as he had mental capacity. He did not want home visits due to the distress it caused his wife, so they were arranged at the GP surgery. As he did not want to be seen daily, a compromise of three times a week was reached
- ▶ Building relationships: consistent staff were used, who took the time to develop a rapport with him and understand his circumstances. It was thereby

learnt that he was a carer for his wife whose mental health was impacting his engagement with services

- ▶ Multi-agency working: multi-agency meetings involving the GP, district nurses, TVN, safeguarding colleagues and adult social care were held to discuss the risks and how the multidisciplinary team (MDT) could work together to best support the patient (to avoid overlapping appointments, having joint visits where possible, sharing information to save him repeating his story, etc)
- ▶ Advance care planning (ACP): as the patient was not accepting a great deal of advice or treatment, inevitably his health would decline. Thus, ACP was important to see what he would want that to look like, e.g. end-of-life care. Parts of MCA can be used, such

## Box 3.

## MENTAL CAPACITY ACT

Be clear on your patient's capacity. If uncertain, then assess this. Mental capacity can be assessed by any healthcare professional (this does not need to be a specialist psychiatrist or social worker), but the person who assesses capacity should be the 'decision maker', i.e. the healthcare professional who is delivering/overseeing the patient's care and treatment.

## How to assess mental capacity

Stage 1: does the patient have an impairment and/or disturbance of the mind and brain? (which could be causing them to lack capacity)

Stage 2: can the patient do all of the below (in relation to the self-neglect decision). If the patient is unable to do any one of these, it means they lack capacity for the decision:

- ▶ Understand information relevant to their self-neglect, the risks
- ▶ Retain information long enough to make the decision
- ▶ Use and weigh up information about the self-neglect risks, pros and cons of having treatment or not
- ▶ Communicate — can they communicate their decision (by any means, verbal or non-verbal)

(Department for Constitutional Affairs, 2007)

as advance decisions to refuse treatment (ADRT) and lasting power of attorney (LPA) to give him a sense of more control when his health declined

- ▶ Good documentation: this was kept of all discussions, attempts to engage with him and, most importantly, capacity assessments for his self-neglect decisions, as there was the possibility of his health deteriorating and risk of death.

## Managing the case if the patient lacked capacity

If the patient discussed here had been found to lack capacity, the case would have needed to be approached differently, namely:

- ▶ Professionals would make best interests decisions for him —when a patient lacks capacity, consent will not come from anyone else (such as family or carers) unless they have specific legal powers to make decisions, such as being named on a LPA or a court appointed deputy for health and welfare decisions (Gov, 2022)

**'Mr Justice Munby, a judge in the Court of Protection, said in his famous 2007 judgement: "what's the point of making someone safe, if in doing so you just make them miserable?".'**

- ▶ Take his views/wishes into account. Treatment may still have been provided at his GP surgery or visits three times a week rather than daily, so it was less distressing for his wife. Where possible, treatment would have been provided in his preferred environment (home or GP surgery). If this was not possible, hospital admission may have been considered, but again within a best interests framework (Box 4)
- ▶ Least restrictive options: it may not have been appropriate to take him to hospital or move him to a care home away from his home and wife, which is clearly where he wanted to remain. In the authors' clinical opinion, just because the patient lacks capacity, it does not give healthcare professionals the right to do what they want.

Mr Justice Munby, a judge in the Court of Protection, said in his famous 2007 judgement: 'what's the point of making someone safe, if in doing so you just make them miserable?' This captures the balancing act between managing risks and the patient's wishes when considering what is best interests for them.

## OTHER LOCAL SERVICES

In cases where patients are refusing treatment or at risk of self-neglect, other services can be involved to offer support/advice, such as:

- ▶ Rapid review meetings: within the authors' trust, pressure ulcers category 3 and above are discussed in these meetings and involve representation from the trust's safeguarding team. Other health organisations may have similar forums/risk management meetings where these cases can be discussed with wider colleagues for guidance and support
- ▶ Exceptional risk forum: Established by the Leeds safeguarding adults board (LSAB), the LSAB exceptional risk forum is a place where agencies can refer cases (including self-neglect) for a multi-agency panel perspective, which offers advice and recommendations on how a patient's risk can be reduced.

Other SABs may have something similar but named differently, such as vulnerable adults meetings. Check with your local SAB or consider setting one up with multi-agency colleagues.

## OTHER MECHANISMS TO SUPPORT SELF-NEGLECT CASES

In the authors' clinical experience, healthcare professionals should also be aware of other local services/leads to link with when they encounter cases of self-neglect, such as:

- ▶ Safeguarding adults/Mental Capacity Act leads where support is required and access to safeguarding supervision
- ▶ Local safeguarding adults/self-neglect policies and guidelines, as local SABs will be doing work around self-neglect
- ▶ Adult social care, housing, fire services and police, which can provide valuable input, especially in cases involving other aspects of self-neglect, such as hoarding.

## CONCLUSION

Self-neglect can be a common feature in complex wound management patients. It is important for healthcare professionals to know about and



## Box 4.

## BEST INTERESTS CHECKLIST

If you are unsure what a best interests decision may be for a patient, apply the checklist (below) to help ensure your decision follows the best interests principles:

- ▶ Encourage participation
- ▶ Identify all relevant circumstances (consider the least restrictive)
- ▶ Find out the person's point of view (any past wishes and feelings, ACP, beliefs and values)
- ▶ Avoid discrimination
- ▶ Will the person regain capacity? (after medical treatment, can the decision wait?)
- ▶ Consult others, such as family (or refer for an Independent Mental Capacity Advocate [IMCA] for serious medical treatment/change of residence)
- ▶ If the decision concerns life-sustaining treatment, it must not be motivated to bring about the patient's death
- ▶ Avoid restricting the person's rights.

Take all of the above into account and weigh up these factors in order to work out what is in the patient's best interests.

Department for Constitutional Affairs, 2007

understand self-neglect in the context of safeguarding adults practice, rather than view it as a lifestyle choice. Self-neglect can have significant consequences to the patient's physical health, especially if healthcare professionals do not consider adapting their own approaches to work with patients proactively to achieve the best outcomes. Also, a multi-agency approach involving safeguarding and mental capacity expertise is key to supporting healthcare professionals who are delivering care to people who self-neglect. **JCN**

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# Overactive bladder syndrome: what community nurses should know

Ann Yates

Overactive bladder (OAB) syndrome is a chronic disabling condition that affects both men and women. It is a little known condition and is diagnosed on symptom presentation, which is mainly urgency but with associated frequency, nocturia and urge incontinence. It is important to assess the individual using the correct process and then initiate first-line conservative therapies, which are usually behaviour modifying. If these are ineffective, second-line pharmacology preparations can be introduced. This article explores these aspects.

## KEYWORDS:

- Overactive bladder ■ Urgency ■ Frequency ■ Assessment
- OAB treatment

Overactive bladder (OAB) syndrome is a chronic condition that affects both men and women, which can have a significant impact on an individual's physical, psychological, social and financial quality of life (QoL) (Scarneci et al, 2021). It has been identified that the syndrome is more common in those aged over 40, but it can also affect children and young people (Scarneci et al, 2021). Studies show that OAB affects 12% of both men and women, with the incidence increasing with advancing age, as 70–80% of people by the age of 80 show more severe symptoms (International Continence Society [ICS], 2013).

Overactive bladder syndrome is defined as 'urinary urgency, usually accompanied by frequency and nocturia, with or without urinary urge incontinence, in the absence

## 'The pathophysiology of OAB is poorly understood and there are several underlying mechanisms that can incite symptoms.'

of urinary tract infection or other obvious pathology' (Araklitis et al, 2020). Many individuals will present with a combination of symptoms with varying severity (*Table 1*). The main element that characterises OAB is urgency. However, this can be accompanied with frequency, nocturia and urge incontinence, which are considered the most exasperating of symptoms (Robinson and Cardozo, 2019). It has been estimated that urgency incontinence or OAB wet is more common in women, while urgency and frequency (OAB dry) is more common in men (Scarneci et al, 2021). As identified, the condition is extremely common.

Symptoms associated with OAB syndrome have far reaching effects on individuals' QoL, including:

- ▶ Frequent sleep disorders and sleep disruption due to waking

at night numerous times to void. There is a correlation that due to sleep disorders, individuals with OAB have a much higher risk of fractures or fall-related injuries (Lightner et al, 2019; Burkhard et al, 2020)

- ▶ Association between OAB and anxiety and depression (Lai et al, 2016)
- ▶ Due to fear of not reaching the toilet in time or needing to go frequently, there is a reduction of physical activity, social interactions and work opportunities. This in turn leads to isolation and avoidance of situations whereby urinary accidents can occur (Scarneci et al, 2021)
- ▶ Loss of self-esteem, which can have a negative impact on sexuality and relationships and result in a reduction in sexual activity (Scrivens, 2022)
- ▶ An economic burden, with loss of work capacity, washing facilities, management/treatment options (Scarneci et al, 2021).

The pathophysiology of OAB is poorly understood and there are several underlying mechanisms that can incite symptoms. Peyronnet et al (2019) challenge the assumed rational that OAB is solely caused by detrusor muscle overactivity, as individuals presenting with OAB do not always show detrusor overactivity on further investigations, i.e. urodynamics. This highlights that other possible underlying mechanisms might be contributing factors.

## RISK FACTORS FOR OAB

There are numerous risk factors which could contribute to an individual presenting with symptoms of OAB (*Table 2*).



To identify the underlying cause and start an individual treatment pathway, it is imperative to undertake a comprehensive initial assessment, which includes understanding the patient's experience and how OAB is affecting their QoL.

## ASSESSMENT

As diagnosis of OAB is based on symptoms, taking a detailed comprehensive history is extremely important. It has long been identified that the assessment of continence problems should be undertaken by an experienced professional (McClurg et al, 2013), in line with recommended minimum standards (United Kingdom Continence Society [UKCS], 2015).

Basic continence assessment should consist of the following components (Yates, 2019):

- ▶ Type of continence problem, i.e. main complaints of urgency/frequency/nocturia etc identify the differential diagnosis
- ▶ Information about the onset, duration, current presentation and severity of the symptoms and whether related to a specific event/condition. This information can be gathered via numerous validated symptom profiles, such as the International Consultation on Incontinence Questionnaire Overactive bladder (ICIQ-OAB; <https://iciq.net/iciq-oab>). However, these are not well known or used in general community nursing (Scarneciu, 2021)
- ▶ Impact of symptoms on current QoL (again not currently commonly incorporated in basic QoL assessments) should be advocated to see patient-reported outcomes of improvement after treatment initiated (National Institute for Health and Care Excellence [NICE], 2019)
- ▶ How individuals are currently managing symptoms
- ▶ Identification of any presenting red flags, e.g. associated pain or haematuria (blood in urine) that may require onward referral to a specialist (Scrivens, 2022)
- ▶ Complete medical, surgical, obstetric (parity, weight of baby, type of delivery), neurological and

**Table 1:** Presenting symptoms and definitions of overactive bladder syndrome

Presenting symptom	Definition
Urgency	▶ A sudden, compelling desire to pass urine that is difficult to defer
Frequency	▶ The need to void frequently, usually more than eight times in 24 hours
Nocturia	▶ Waking up at night needing to void usually more than one to two times
OAB dry	▶ Having the above symptoms, but no urinary urge incontinence
OAB wet	▶ Having the above symptoms but also urge urinary incontinence — an involuntary leakage of urine associated with urgency

**Table 2:** Contributory risk factors for OAB (adapted from Scarneciu et al, 2019; Hutchinson et al, 2020)

Non-modifiable	Modifiable
Increase in age in both sexes	Weight/body mass index (BMI) >30kg in both sexes
Sex (female), mainly associated with menopause and reduction in oestrogen	Smoking
Autonomic nervous dysfunction	Caffeine intake
Functional gastrointestinal disorders — most common is irritable bowel syndrome (IBS) (present in 33% of cases of OAB)	Alcohol
Benign prostatic hyperplasia	Diet, including spices/artificial sweeteners
Pelvic organ prolapse (POP)	Poor fluid intake or one which consists of carbonated beverages/sour drinks
Mental health disorders, i.e. anxiety/depression (studies show that the presence of these disorders can increase the risk of OAB)	Medication
Ethnicity — studies with higher prevalence in African-American and Hispanic patients	Sleep apnoea

mental health history. Also history of stress incontinence may lead to OAB (Willis-Gray et al 2016)

- ▶ Details of any allergies, smoking status, mobility, dexterity, and cognitive, body mass index (BMI) or social issues
- ▶ Details of all medication, including over-the-counter medication, herbal remedies and recreational drug use (Table 3). Professionals should also be aware of increased comorbidities and polypharmacy in certain individuals which can contribute to OAB.

Assessment findings should be supported by basic investigations, which include (Yates, 2019; Colley, 2020):

- ▶ A completed 24-hour three-day bladder diary, which should include individuals' fluid intake and type of fluid, voided volumes, frequency of voiding, frequency of urinary leakage and amount of leakage. This diary can help to identify any associated triggers for intervention, e.g. excessive

drinking or too little fluid intake and any bladder irritants, e.g. caffeine, alcohol

- ▶ Dipstick urinalysis — this is used in an initial continence assessment as a screening rather than diagnostic test. It helps to rule out numerous abnormalities, e.g. renal problems, haematuria (blood in the urine), or other constituents in the blood, such as glucose (indicating potential diabetes) and protein. It is also a good indicator of an individual's hydration state. However, a diagnosis of urinary tract infection (UTI) should be based on the patient's symptoms, not on dipstick urine testing (Public Health England [PHE], 2019a; 2019b)
- ▶ Post-void residual (PVR) urine bladder scans — if presenting with symptoms of poor flow, feelings of incomplete emptying and recurrent UTIs, or have an underlying neuropathy. There are two methods of assessing PRV urine volume: sterile urethral in/out catheterisation (a direct measurement of urine



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**Table 3:** Medications that may affect continence (adapted from the Royal College of Nursing [RCN], 2016; British National Formulary [BNF], 2022)

Medication	Action
Diuretics (water tablets), such as thiazides and furosemide	Increase urine production and urinary urgency and frequency
Angiotensin-converting enzyme (ACE) inhibitors, such as ramipril and captopril	Usually used to treat high blood pressure. They can worsen incontinence
Antidepressants such as citalopram/ amitriptyline hydrochloride	Used to treat mood disorders and can result in urinary retention. Can contribute to symptoms of OAB and overflow incontinence
Analgesia, such as morphine/codeine	Can interfere with bladder contraction and cause or exacerbate constipation
Alphablockers, such as alfuzosin hydrochloride, doxazosin	Can reduce bladder outlet resistance, which can lead to urinary incontinence
Antimuscarinics/anticholinergics, such as oxybutynin hydrochloride, solifenacin succinate, tolterodine tartrate	Affect the contraction of the bladder muscle. Can treat or cause bladder problems. Also associated with diarrhoea, constipation, gastrointestinal disorders
Sedatives, such as diazepam and lorazepam	Can slow reflexes, affecting the ability to recognise the signal that the bladder is full
Hormone replacement therapy (HRT)	The lower urinary tract is sensitive to the effects of oestrogen and during the menopause levels naturally decline. The evidence to support whether or not HRT affects the bladder is conflicting
Alcohol and caffeine	Are diuretics that can increase urine production. Caffeine can cause irritation of the bladder lining
Nicotine	Is thought to irritate the detrusor muscle and trigger OAB incontinence. Smoking can also cause a cough, which can lead to urine leakage
Ketamine	Used medically in anaesthesia and as a pain killer, but has been used as a recreational drug due to its hallucinogenic and euphoric properties. In large and repeated doses, it has been found to cause shrinkage and fibrotic changes to the bladder. It can cause frequency, bleeding and pain on passing urine

volume) and bladder ultrasound scanning (an indirect estimation of urine volume). Both of these investigations require a competent skilled professional trained in these procedures for implementation and interpretation of results. There is no clear consensus regarding the constitution of a normal or abnormal PVR urine volume with regards to retention. Volumes of 100–150ml are usually considered significant, but this will depend on total bladder capacity (Yates, 2021a)

- ▶ Physical examinations (vaginal/rectal/abdominal/neurological), if required, but only performed by a competent professional. However, while most community professionals may not have the required skills or competency to undertake all of these examinations, they may well have the skills to do some of the

most basic ones, such as a visual examination of the perineum area to identify abnormalities such as skin excoriation, atrophic vaginitis, visual prolapses, visual urinary leakage or alterations to female genitalia which may indicate female genital mutilation (FGM) (Yates, 2021a).

## TREATMENT

Treatment options come in two forms — initial first-line treatments or non-pharmacological conservative therapies, which are based on behavioural lifestyle changes and carry little risk, and second-line pharmacological treatments.

### First-line, conservative therapies

Lifestyle interventions that can be offered as treatment options for individuals with OAB syndrome include (Herbert, 2019; Burkhard et al, 2020):

- ▶ Fluid advice — amount and type and avoidance of bladder irritants
- ▶ Weight loss
- ▶ Smoking cessation
- ▶ Timed voiding
- ▶ Urge suppression techniques
- ▶ Pelvic floor rehabilitation
- ▶ Bladder retraining.

These will now be discussed in more detail.

It is important to discuss fluid intake with individuals. The general consensus is that an average healthy adult needs a daily fluid intake of approximately 1.5–2 litres in 24 hours to replace natural loss. Maintaining appropriate fluid intake is vital to individuals with OAB, as low fluid intake may contribute to dehydration which leads to bladder urgency and frequency, although increased fluid can, of course, increase voiding problems (Yates, 2021b). The best form of fluid to advise is water, although some diluted squash or decaffeinated drinks can be alternatives. It is usual to advise individuals to decrease caffeine intake, as experts agree that it may have a stimulant effect on the bladder and exacerbate urgency, frequency and nocturnal voiding (Burkhard et al, 2020). Caffeine is mainly found in coffee, tea, drinking chocolate, cola and other carbonated drinks. Restricting fluids about two hours before bedtime may reduce nocturia.

Weight loss has been shown to reduce the symptoms of OAB and incontinence and discussion with individuals and correct signposting to appropriate services for help could be beneficial (Scrivens, 2022). Smoking is another behaviour that can contribute to OAB, as nicotine has been shown to irritate the bladder (Madhu et al, 2015).

Timed voiding and urge suppression (when the individual is encouraged to use techniques, e.g. holding on, standing or sitting still to delay voiding), with bladder retraining, which consists of a scheduled voiding regimen with gradual adjusted voiding intervals (Herbert, 2019), aim to:

- ▶ Improve bladder urgency,

- frequency, time between voids
- ▶ Increase bladder capacity
- ▶ Reduce incontinence episodes (Herbert, 2019).

Bladder retraining is recommended for at least six weeks (Herbert, 2019; NICE, 2019). Within clinical practice, all these techniques identified above, i.e. urge suppression, timed voiding, bladder retraining are usually employed to assist treating OAB combined with pelvic floor training to help individuals contract their muscles for longer periods and potentially safely reach a toilet. A combination of all usually produces optimal results and better patient outcomes (Scarneciú et al, 2021).

### Second-line treatments — medication

Pharmacological therapies should only be initiated following a trial of non-pharmacological management and can often be used as an add-on to these therapies. *Table 4* outlines drugs used to manage OAB.

### REFERRAL ONWARDS

If individual patients do not respond to conservative first-line plus instigation of second-line drug therapy, referral to secondary services may be appropriate. Patients can then be assessed for further treatments that may include botulinum toxin, percutaneous posterior tibial nerve stimulation, or sacral nerve stimulation. However, these treatments may not be available everywhere.

### CONCLUSION

Overactive bladder syndrome is a highly prevalent disabling condition which affects individual QoL. It is diagnosed by its presenting symptoms made in the absence of other pathologies. Healthcare professionals can make a difference to an individual's QoL with conservative first-line therapies. If these interventions do not produce the expected change in symptoms, they can be supported by introducing second-line pharmacology. It is important to review the symptom presentation

**Table 4:** Summary of medication used in OAB problems (adapted from Burkhard et al, 2020)

Medication class	Medication name	How they work	Most common side-effects
Anticholinergics/antimuscarinics	Oxybutynin, tolteradine, darifenacin, solifenacin, trospium choloride, fesoterodine	Cause relaxation of the detrusor muscle in the bladder by blocking the M2 and M3 receptors. Also inhibit afferent nerve activity  To be used with caution in frail patients. There has been growing concern about the use of antimuscarinics due to the association with declining cognitive function, especially in the elderly and over 65s. An antimuscarinic burden scale (ABS) has been developed to assess individuals risk with regards to this type of medication (Tooze-Hobson and Robinson, 2019)	Dry mouth, constipation, blurred vision, dry eyes, gastric disturbances  Contraindicated in patients with narrow angle glaucoma
Beta-3 adrenoceptor agonist	Mirabegron	Causes bladder relaxation during filling and inhibits detrusor overactivity  Recommended when antimuscarinics are contraindicated, ineffective or have unacceptable side-effects (NICE, 2019)	Hypertension, nasopharyngitis, and urinary tract infections
Hormone replacement	Oestrogen cream	Intravaginal oestrogens can be used in post-menopausal women with urinary incontinence and vaginal atrophy	

and, if still bothersome, referral onwards may be appropriate. **JCN**

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## Case report

Mrs Y was aged 54, with a BMI of 28, and a smoker (10 cigarettes per day). At her first assessment, she was given a QoL questionnaire and bladder diary to complete. She was referred to the bladder/bowel service with symptoms of bladder urgency. Her completed bladder diary showed frequency of voiding 17 times in 24 hours (including x3 nocte). Her maximum bladder capacity was 320mls, with a minimum of 40mls. Symptoms of urge urinary incontinence occurred four times daily — very wet — and Mrs Y purchased pad products for protection. She rated her QoL score as 0 (on a scale of 0–5, where 0 = poor quality of life), indicating that her incontinence was having a great impact on her life. She had given up her job due to symptoms and was having no social life as she was too scared to go out in case of leakage.

Her past medical history included having two children (one weighed over 8lb at birth and she needed to have stitches due to tear), and she was now post menopausal. She was on no medication. Her fluid intake was poor, less than 1 litre due to worry about leakage. Her bowels opened on alternate days, type 3 on the Bristol stool chart. A urinalysis detected no abnormality and a post void bladder scan showed it was essentially empty.

### Initial plan

Mrs Y was advised to drink less coffee or change to decaffeinated, and generally increase her fluid intake, with mainly water if possible. She was also given advice with regards to diet and referred to a dietician. Smoking cessation information was also given.

She was then reviewed after eight weeks. Her symptoms had improved but she was still leaking twice daily — frequency reduced to 11 times in 24 hours, but urgency still remained an issue.

At this second visit (eight-week review, a pelvic floor examination took place and initial bladder retraining and pelvic floor rehabilitation was commenced. Mrs Y was currently losing weight.

At her third visit (12 weeks later), Mrs Y's symptoms had much improved, with her reporting that frequency was now nine times in 24 hours (including x1 nocte), and that she was able to get to the toilet as she had better control. There had only been one episode of leakage in the past month and she was not having to purchase pad protection any more. She had also been able to increase social activities, as was no longer worried about leakage. Mrs Y was happy with the outcome and now rated her QoL as 5 on the questionnaire. She was discharged with contact details of the bladder and bowel service.

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# Long Covid: definition, diagnosis and management

Thuvia Flannery\*, Hannah Brady Sawant\*, Tracy Lee, Gerda Bayliss, Rachel Tarrant, Jenna Shardha, Denise Ross

This article, the first in a three-part series on Long Covid, provides a definition of post-Covid-19 syndrome and Long Covid. It highlights the considerations for diagnosis and an overview of the management of commonly reported symptoms through the experience of one of the 90 NHS England commissioned post Covid (Long Covid) assessment clinics, in addition to lived experiences of persons with Long Covid (PwLC). The next two articles in this series will look at the use of digital technology in Long Covid self-management and virtual group assessments.

## KEYWORDS:

- Long Covid ■ Common symptoms ■ Diagnosis
- Patient pathways ■ Service development

The Covid-19 pandemic led to rapid changes in how health care could be accessed and delivered in the UK. This was aimed at protecting acute NHS services and limiting face-to-face contacts, which were likely to increase the spread of the novel virus (NHS England, 2020). The early emergence of post Covid-19 syndrome (PCS), synonymous with and more frequently referred to as Long Covid (LC), presented an unanticipated and unique set of health needs at a time of considerable disruption to existing NHS services (Health Foundation, 2022).

Compounding factors included:

- ▶ Limited understanding of the aetiology of the condition
- ▶ Its apparent multisystem involvement

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**‘Long Covid is globally described by persons with LC (PwLC) as a complex, multifaceted condition with physical, mental and social implications.’**

- ▶ Absence of a diagnostic test
- ▶ Lack of knowledge on safe and effective management approaches that could address commonly reported symptoms (Halpin et al, 2021; Health Foundation, 2022).

As Covid-19 infection rates increased exponentially in the UK, the incidence of LC has followed a similar trajectory. The Office for National Statistics (ONS) data from November 2022 estimates that approximately 2.2 million people in the UK are self-reporting LC symptoms, the equivalent of 3.4% of the population (ONS, 2022).

## WHAT IS POST-COVID-19 SYNDROME/LONG COVID?

The National Institute for Health and

Care Excellence (NICE, 2022) defines post-Covid-19 syndrome as:

*Signs and symptoms that develop during or after an infection consistent with Covid-19, continue for more than 12 weeks and are not explained by an alternative diagnosis. It usually presents with clusters of symptoms, often overlapping, which can fluctuate and change over time and can affect any system in the body.*

(NICE, 2022: 5).

Long Covid‘is commonly used to describe signs and symptoms that continue or develop after acute Covid-19. It includes both ongoing symptomatic Covid-19 (from four to 12 weeks) and post-Covid-19 syndrome (12 weeks or more)’ (NICE, 2022). For this reason, the umbrella term Long Covid (LC) will be used throughout the following text.

## COMMON SYMPTOMS OF LONG COVID AND DIAGNOSIS

Long Covid is globally described by persons with LC (PwLC) as a complex, multifaceted condition with physical, mental and social implications (Carson, 2021). Long Covid symptoms may include fatigue, breathing issues (shortness of breath), ‘brain fog’ (cognitive impairment), depression and anxiety, palpitations, dizziness, dietary issues, and joint pain (NICE, 2022) (Table 1). For these reasons, LC is considered a multisystem condition with symptoms that may improve and then be exacerbated over time conducive with a non-linear path to recovery (Centers for Disease Control and Prevention [CDC], 2022; Greenlagh et al, 2022).



There is some variability in resolution or self-management of symptoms (Greenlagh et al, 2022). A LC diagnosis can therefore be difficult to obtain and without this a referral to a LC clinic to access treatment may take many weeks or months and, in some circumstances from the initial wave of patients, years. This is due in part to the complexity and fluctuating nature of reported symptoms, i.e. fatigue might improve so an individual could get back to some normal activities but then would have a sudden relapse (Greenlagh et al, 2022), difficulty accessing health services as a direct effect of the pandemic on healthcare systems, and finally, lack of knowledge and awareness of the condition. Possible explanations for the symptoms outlined in *Table 1* can include organ damage by the Covid-19 virus, dysregulated inflammatory state, ongoing viral activity, and immune system responses (CDC, 2022), or several of these interacting simultaneously (Greenlagh et al, 2022).

Diagnosis is currently based on persisting symptoms that cannot be explained by any other cause (NICE, 2022). Persons suspected of having LC may require screening for common cardiac, respiratory, neurological, musculoskeletal, and digestive conditions before a diagnosis of LC can be formally made. However previously, tests and scans may have been conducted in a disjointed manner which might contribute to the uncertainty of

**Table 1: Commonly reported symptoms of Long Covid**

System	Common symptoms
Cardiac	Chest tightness, palpitations, chest pain
Respiratory	Breathlessness
Neurological	Cognitive impairment ('brain fog'), insomnia, headache, dysautonomia (including postural tachycardia syndrome [PoTS] with erratic heart rate with labile blood pressure [BP])
Digestive	Abdominal pain, nausea, loss of appetite, heartburn
Musculoskeletal	Diffuse joint and muscle pain, costochondritis
Psychological	Anxiety, depression, intrusive memories and/or thoughts
General	Post exertional malaise, fatigue, fever, difficulty communicating

not knowing what is happening that PwLC report as being a major issue with the condition (Fancourt et al, 2022). It is therefore still possible that some people with LC symptoms, from early 2020 Covid-19 infections, remain undiagnosed and so unable to access existing LC health interventions.

The list of symptoms described in *Table 1* are those most commonly experienced within clinical practice, however this is not exhaustive as each person's experience of LC can vary greatly. In addition to these symptoms, PwLC can experience profound lifestyle changes. These can include reduction in full-time employment and financial instability. The Institute of Fiscal Studies (IFS) estimates that UK workers with LC represent £1.5 billion per month in lost earnings (Financial Times, 2022). A recent University of Portsmouth study highlighted a startling reduction in workforce availability due to LC (Reuschke and Houston, 2022). This inevitably negatively impacts on social interaction,

personal relationships, and for some, a sense of loss of their former self (Fancourt et al, 2022).

In terms of demographics, the Leeds Long Covid Rehabilitation Service (LLCRS) sees PwLC with an age range from 16–91 years, and a mix of both males and females. However, it has been identified that the caseload within the LLCRS are predominantly female (68%), have an average age of 48 (Parkin et al, 2021; Flannery, Brady-Sawant et al, 2022), and have not been admitted to hospital for Covid-19 infection (74%) (Parkin et al, 2021). The risk of LC can be increased in (Crook et al, 2021):

- ▶ Those with pre-existing asthma
- ▶ Women who are aged between 50 and 60 years
- ▶ Those who had poor mental or physical health before the pandemic
- ▶ Those with obesity (Thompson et al, 2022).

Few other clinical risks have been identified (Cook et al, 2021) and more investigation as to the reasons behind these risk factors is required (Thompson et al, 2022).

### LLCRS SET UP AND PATIENT PATHWAYS

The LLCRS was officially launched in September 2020 following a rapid process of collaborative development (*Figure 1*) and has a current caseload of 1,166 PwLC as of December 2022, having discharged 1,200 of its 2,366 total cohort.

A review of available evidence and acute NHS trusts' follow-up of discharged patients to check on their Covid-19 recovery, identified

April 2020  
Evidence review

May - June 2020  
Service Evaluation



Ongoing  
Quarterly formal evaluation  
Constant learning, sharing, innovation

Adaptation & images from: Rachel Tarrant & Jenny Davison Clinical leads/ Pathway co-ordinators & Specialist Physiotherapists: Lessons Learnt from The Leeds Long COVID Community Rehabilitation (2022)



**Figure 1.**  
*Leeds Long Covid Rehabilitation Service innovation: rapid, dynamic and intersectoral.*

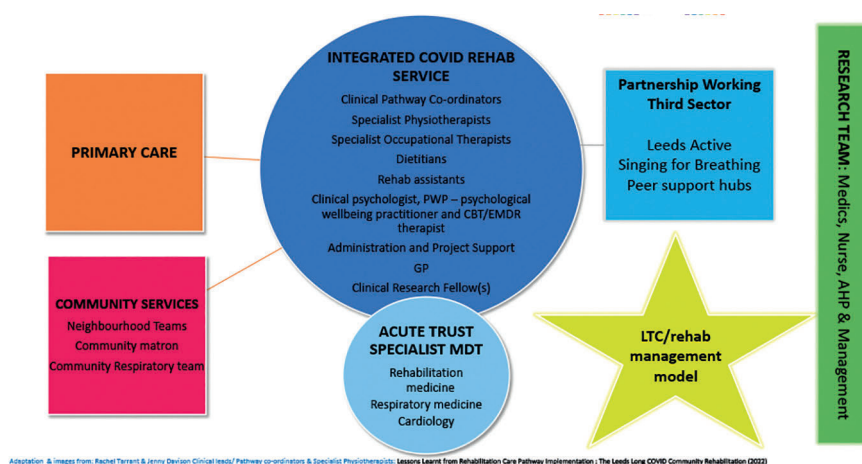


Figure 2.

*Leeds Long Covid Rehabilitation Service Model.*

the unmet needs of PwLC in the community (Halpin et al, 2021). Many PwLC presented with a cluster of the debilitating symptoms described in *Table 1* and means of addressing these were sought by adopting a co-design approach to intersectoral service development involving a local acute NHS trust, NHS community services and third-sector organisations — thus embracing an integrated care system (ICS) model (NHS England, 2022).

This involved a close relationship with local commissioners and public health services at a challenging time in the Covid-19 pandemic. NHS England's commissioning of post Covid-19 syndrome clinics followed, and there are now 90 nationally, with established guidelines which are regularly updated (NHS England, 2022).

Leeds Long Covid Rehabilitation Service accepts referrals from general practitioners (GPs) or community-based teams, such as district nursing, therapy or specialist services via the single point of referral. This means that PwLC rely on being identified by these health professionals. It is recognised that PwLC are often not diagnosed within a beneficial timeframe, or in some cases, not at all (Greenhalgh et al, 2022). Referrals are accepted for PwLC who are 16 years old and over. The service receives between 80 and 140 referrals per month (Flannery et al, 2022), with a waiting time for initial assessment of over 18 weeks during December 2022. Delays in treatment are recognised as common, and that

a supportive role in primary care services is essential to assist with the management of this (Greenhalgh et al, 2022). Patients with LC are sent an 'opt in' letter and once they have confirmed they wish to receive care from the service they are asked to complete a set of outcome measures, i.e. Covid-19 Yorkshire Rehabilitation Scale (C19YRS), Modified Fatigue Impact Scale (MFIS), Medical Research Council Dyspnoea Scale (MRC) and EuroQol 5 Dimension scale (EQ5D). These outcome measures are itemised in the C19YRS app, although those unable to complete via the app or website can complete a paper version.

It is recommended that these are completed monthly following the initial completion to facilitate tracking of symptoms. Once the initial outcome measures are completed, PwLC are currently offered a 'first assessment' telephone appointment. This is followed by the virtual rehabilitation programme (VRP), which provides education on LC and self-management approaches in a group setting on Microsoft Teams digital platform (Flannery et al, 2022). This is complemented, where needed, with face-to-face and virtual clinician input.

The LLCRS clinical team includes physiotherapists, occupational therapists, dietitians, psychological therapies, GPs and rehabilitation assistants, working alongside a dedicated LC research team and hospital-based services. Therapies use a health coaching approach in

partnership with each individual to self-manage the main LC symptoms being experienced, namely:

- ▶ Physiotherapists provide techniques to assist with breathlessness
- ▶ Occupational therapists offer pacing techniques to help with fatigue
- ▶ Dietitians support nutritional aspects
- ▶ Psychology practitioners address emotional issues associated with LC, such as anxiety, depression, intrusive memories and/or thoughts (post-traumatic stress disorder [PTSD]).

This multidisciplinary team (MDT) approach is required by NHS England (NHS England, 2021) and is recognised as essential for the management of LC symptoms globally (Carson, 2021).

Often PwLC are asked to keep diaries of symptoms and activities to assist with identifying triggers of exacerbations of symptoms and insight into lived experience (CDC, 2022). Other interventions focus on breathing exercises or gradual increases of activity (CDC, 2022), which overall should support self-management (Greenhalgh et al, 2022).

Team members are also able to refer between one another based on the specific needs of the PwLC as they change. In the case of patients with complex needs, there is the ability to discuss their care at a weekly MDT meeting. This consists of LLCRS team members and respiratory, rehabilitation and cardiology consultants. They are able to discuss PwLC at an individual level and raise any concerns. This alleviates the need for the lengthy process of new referrals to individual specialities and avoids unnecessary duplication of tests and subsequent delays. This ICS model has encouraged close liaisons between GPs, community services and the local acute NHS services to best meet the needs of PwLC in a timely manner. There are also links to third-sector organisations, which provide peer support and assistance with access to technology and financial management support.



## ONGOING SERVICE DEVELOPMENT

It is recognised within the LLCRS that there is a developing evidence base of knowledge surrounding LC, and therefore ongoing service evaluation and development is essential. The need for building this knowledge base is recognised by the National Institute of Health Research (NIHR), which states that £50 million of funding from the government is currently in circulation to provide guidance for healthcare professionals and PwLC (NIHR, 2022).

Within the Leeds services, this is supported by a dedicated research team consisting of two clinical research fellows (one district nurse and one physiotherapist), clinical academic supervisors, operational leads of the LLCRS clinical team, and ongoing benchmarking, reviews of guidance and communication with other LC services. Much of the research team's work is focused on amplifying the needs and voices of PwLC so that the service can meet these. To assist this, a patient, carer and public involvement (PCPI) group has been developed, with members contributing towards identifying current service and research needs. Alongside this, research is being carried out collaboratively with the team and academics, for example, the LOCOMOTION study (Sivan et al, 2022).

Some of the additional challenges faced by the LLCRS include encouraging those less well represented communities (including Black and minority ethnic groups, those with learning disabilities and Gypsy and Traveller communities) to access services, and addressing digital literacy and availability of technology. There are ongoing service development projects to understand and deal with these challenges.

### Digital innovations

The LLCRS use of digital technology to deliver self-management allows earlier intervention to greater numbers of PwLC while accelerating the uptake of e-health as per the *NHS Long Term Plan* (NHS England, 2019). Within the LLCRS, the

Before my illness I was extremely fit and active, with no medical issues, and had three vaccinations in 2021. My illness started with flu-like symptoms in December 2021, confirmed by a Covid PCR test. After a month, I tried a phased return to my physically active job, but my symptoms worsened, and I have been on sick leave ever since. My main post-Covid infection symptoms are fatigue, post-exertional malaise, tachycardia and myalgia. I have had to reduce my physical activity to only 10–15 minutes of light housework and gentle exercise each day, and my illness is stable, but not improving with rest.

Tracy's story,  
59 years

I was referred to the Long Covid service in May, and had a telephone appointment in October. I received assurance that I was self-managing my illness well, i.e. following the advice in the Long Covid rehabilitation booklet, but that I should reduce my mental activity as this impacts fatigue. I have my physical assessment and rehabilitation therapy appointments booked in January, with returning to work being my primary goal, but I am expecting to have to change my job to a sedentary role to achieve this. I have participated in Long Covid research studies involving fatigue and vocational rehabilitation.

I caught Covid in the first wave, and then what we now know as Long Covid. It was a frightening and traumatic experience. I struggled to breathe, I suddenly couldn't walk, among a whole host of other scary symptoms. During this time the support I had was minimal. I found it very confusing and scary that I couldn't get help when I was obviously so ill. The best doctors and nurses I spoke to during this time were the ones that empathised, listened, admitted that they didn't know. These small words of support were beacons in among a sea of denial. The amount of work that went into trying to get myself any support and help was incredibly frustrating.

Gerda's story,  
43 years

My restorative yoga practice has been a lifeline, as it has given me a focus and way to help myself. With my own experience and other teachers' support, I have been able to ease my symptoms, support and rehabilitate myself. It helped me at the start when I was struggling to breathe as I could get myself into positions to ease my breath and also my panic (they prone patients in the intensive care units [ICUs] when breathing is bad as it helps to bring the breath more into the back lungs). I believe that my yoga has eased my symptoms, headaches, palpitations, panic, anxiety, dizziness, nausea to name just a few. It's also helped me deal with the relentlessness of having a chronic illness.

As I am coming out of the other side after two years, the physical symptoms are less but the emotional impact of Long Covid is still ongoing. My yoga practice gives me a focus and support still.

10-week virtual rehabilitation programme (VRP) provides education and peer support, while the C19YRS app supports self-management through validated outcome measures, telephone clinician input and assessment. The former two are the focus of the second LC article in this series of three.

In addition, virtual courses for relaxation, stress and anxiety in LC and low mood are facilitated by the team. A new digital health addition planned for 2023 will be virtual group assessments (VGA), where PwLC are assessed in groups of six to eight followed by attendance on the VRP. The aim of this new intervention is to reduce waiting times, allowing for earlier interventions and peer support. The implementation and evaluation of this will be included in the third and final article of this three-part series about LC.

## LONG COVID LIVED EXPERIENCE

The LLCRS continues to engage with PwLC to shape and influence service developments from direct individual feedback, taking part in formal evaluations and through the Leeds LC PCPI group. Two PCPI partners are co-authors of this article and describe their lived experience in the patient stories here.

## CONCLUSION

Long Covid is a complex, multi-system condition with fluctuating symptoms, that have a great impact on the individual and for which no other cause can be found. Primary and community services are most likely to encounter PwLC requiring a diagnosis of LC, an exclusion of other pathologies, and referral to LC clinical services. The evidence base that underpins interventions for LC is still being developed and at this time no specific cause has been identified. Community-based health coaching utilising an MDT with direct links to acute care services allows for an ICS management approach for this community. People with LC should be supported to be active participants in their health care and benefit from peer support and signposting to third-sector organisations. **JCN**

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# Interstitial cystitis: facilitating earlier diagnosis and treatment

Margaret Perry

Interstitial cystitis (IC) is a disease which, despite years of research, remains poorly understood. Once thought to be rare, prevalence rates have increased in recent years, which has been attributed to improved understanding of the disease and more selective diagnostic criteria. Despite this, the condition remains difficult to diagnose, and as a result many of those affected suffer for years before the cause of their symptoms is confirmed. This article hopes to give nurses and non-medical prescribers more knowledge of this complex disease so that they can facilitate earlier diagnosis and treatment, reducing the risk of misdiagnosis, which will ultimately improve outcomes and reduce the impact on the health and wellbeing of all those with this condition.

## KEYWORDS:

■ Interstitial cystitis ■ Women ■ Diagnosis ■ Treatment

Interstitial cystitis (IC), (also called bladder pain syndrome [BPS]) is an unpleasant condition with several symptoms which can be debilitating and have an impact on quality of life and the mental wellbeing of those affected (Chen et al, 2022). Despite research, the disorder remains poorly understood but over time, treatment and management strategies have evolved to help control the effects and symptoms the disease causes. This article hopes to give nurses and non-medical prescribers information on recognition, diagnosis and treatment with the aim of increasing their confidence when they encounter patients with either a suspected or confirmed diagnosis.

## PREVALENCE RATES

Once considered a rare condition, in recent years prevalence rates have increased significantly, largely

because of greater clinician awareness (Moutzouris and Falagas, 2009), and more inclusive diagnostic criteria (Davis et al, 2015). Interstitial cystitis can affect both males and females but estimates indicate that nine out of 10 cases occur in women, with 75% of these in those over the age of 30 (Urology Foundation, 2022).

## SIGNS AND SYMPTOMS

The condition can present with a variety of signs and symptoms, many of which are shared by other conditions, the commonest of these being, overactive bladder, vulvodynia, recurrent urinary tract infections (UTIs) and endometriosis (Bogart et al, 2007). This makes diagnosis difficult and, as a result, it may not be confirmed for years after initial onset. Initially, there is a gradual appearance of symptoms which may be mild and intermittent early on in the disease process, becoming more constant and increasing in severity over time (Moutzouris and Falagas, 2009). Symptoms are variable from person to person. Some of those affected may suffer with a feeling of pressure or sometimes tenderness in the pelvic area with associated discomfort.

Symptoms usually worsen over the first five years and then settle, but there may be periods where symptoms flare up again (Urology Foundation, 2022).

## Additional urinary symptoms

These include (Mishra, 2015; National Institute of Diabetes and Digestive and Kidney Diseases [NIDDK], 2017):

- ▶ Frequency and urgency
- ▶ Pain.

## Frequency and urgency

Frequency is the need to pass urine many more times than would be expected in relation to the amount of fluid ingested, which may be accompanied by urinary urgency, a need to pass urine when the bladder is not full and the feeling that urination cannot be deferred. In health, most people need to pass urine between four and seven times each day, but in those with IC the need to urinate, day or night, may occur as many as 60 times a day in severe cases (Urology Foundation, 2022).

## Pain

For the majority of patients with IC, the need to pass urine is at least eight times per day (Mishra, 2015).

## Red Flags

- Majority of cases occur in women over the age of 30
- Patients experience multiple signs and symptoms, many of which are shared by other conditions making diagnosis difficult
- Symptoms may be mild at onset, becoming more severe over time
- Even when symptoms settle, there may be intermittent flare ups.

Margaret Perry, advanced nurse practitioner

**Table 1: Unusual symptoms of interstitial cystitis (Mishra, 2015)**

Unusual obstructive symptoms	Additional information
Feeling of bladder fullness	A feeling of obstruction when passing urine with an inability to empty the bladder completely
Poor stream, dribbling and a need to strain to pass urine	Approximately 50% suffer with these symptoms
Continuous urge to pass urine and frequent visits to the toilet	Patient may be misdiagnosed as having a urethral stricture
Unusual non-urinary symptoms	Additional information
Vulvar and glandular pruritis, burning and dyspareunia	Occur in up to 25% of patients
Post-intercourse symptoms	Can affect both males and females and it is thought some of this may be due to inability to relax pelvic muscles or increased muscle tone

The degree of pain worsens until the patient urinates, and usually improves for a while once this has taken place. Patients with severe disease need to pass urine very frequently, often every five to 10 minutes (Mishra, 2015), which is clearly distressing and will severely impact on the ability to live a normal life. Some people may have pain without urgency or frequency, but pain is rarely constant and may go away for weeks or sometimes months before recurring (NIDDK, 2017). This pain may originate from a spasm in muscles of the pelvic floor, which are attached to the pelvic bones supporting the bladder, bowel, uterus or prostate, and the pain from pelvic floor muscle spasm can get worse during sexual intercourse (NIDDK, 2017).

There are also some unusual symptoms of the condition, which are broadly classified as obstructive or non-obstructive urinary symptoms (Table 1).

**PATHOPHYSIOLOGY**

The underlying processes associated with the disease are complex and remain poorly understood. A simple explanation will therefore be given here. A number of possible causes have been investigated and one theory is that the protective bladder lining in healthy individuals is damaged allowing toxic substances to penetrate the epithelium and activate sensory nerve endings (Moutzouris et al, 2008).

The following have also been suggested as possibly being involved

in disease onset (Interstitial Cystitis Association, 2015; Rovner, 2020):

- ▶ Pelvic floor dysfunction: problems with the muscles in the lower pelvic area which in IC causes a poor urinary stream and the need to bear down to pass urine, and possible painful intercourse
- ▶ Disruption of the proteoglycan/ glycosaminoglycan (GAG) layer: malfunctioning of this layer can lead to transmigration of urinary solutes across the mucosal surface, affecting nerves and muscles, potentially leading to pain.

In addition to the above, 5–10% of patients with IC are found to have Hunner’s ulcers, also called Hunner’s lesions, which are distinctive areas of inflammation of the bladder wall and are characteristic of classic IC (Interstitial Cystitis Association, 2015). Often, patients with this form of IC have more severe symptoms than patients with non-ulcerative IC (Interstitial Cystitis Association, 2015). The non-ulcerative type of interstitial cystitis is characterised by similar clinical symptoms, but Hunner’s ulcers are not evident when the bladder is examined. However, in the non-ulcerative type, glomerulations (submucosal haemorrhages) will be seen in the bladder wall when the patient undergoes investigation (Rovner, 2020).

**RISK FACTORS**

The exact cause of IC remains unclear. However, research has identified several possible triggers which may lead to the onset of symptoms (Table 2).

**DIAGNOSIS**

There is no universally accepted clinical criteria for the diagnosis of IC and the disease is therefore a diagnosis of exclusion (GP Notebook, 2022). A thorough history is essential and should include information relating to onset of symptoms, duration, associated nocturia, urgency and frequency and pain. In addition, information about past history of urine infections, pelvic surgery, central nervous system, or autoimmune diseases should be obtained (Moutzouris and Falagas, 2009). Physical examination often does not normally reveal any abnormalities specific to IC. Table 3 gives a guide to suspecting IC when taking the history, and Table 4 suggests some conditions which can be considered as a possible cause for the patient’s symptoms.

**Further investigations**

Following initial assessment and history-taking, with the exception of urinalysis, all other investigations are done in the secondary care setting, following referral to a urologist. These include:

- ▶ Urinalysis: a urine dipstick if abnormal will identify the need for further testing and if findings suggest urinary tract infection (UTI) a sample should be sent to the laboratory for culture and sensitivity
- ▶ Cystoscopy: done under general anaesthetic, this will confirm the presence or absence of Hunner’s ulcers and glomerulations and will also confirm or exclude bladder cancer as a cause for the patient’s symptoms. Cystoscopy is useful for excluding bladder

**Table 2: Suggested risk factors for interstitial cystitis (Interstitial Cystitis Association, 2022)**

▶ Blood trauma, such as from pelvic surgery
▶ Bacterial infections (cystitis)
▶ Over distension of the bladder (anecdotal cases have suggested onset after long periods without access to lavatory facilities)
▶ Autoimmune disorders
▶ Inflammation or hypersensitivity of the pelvic nerves

cancer, swelling or redness and is sometimes combined with hydrodistension (filling the bladder with water) to evaluate bladder capacity. Maximal bladder capacity in healthy adults is approximately about 1,150mL, small bladder capacity occurs in severe IC but may be close to normal in patients with mild to moderate symptoms (French and Bambore, 2011)

- ▶ Ultrasound scan, magnetic resonance imaging (MRI)/ computed tomography (CT) scanning: there is a lack of proven imaging tools to assist in differentiation of IC/BPS from other urinary disorders and there is therefore no specific imaging test for the diagnosis of IC (Tyagi et al, 2018). Unless indicated to help exclude alternative diagnoses, radiographic studies have only a limited role in the evaluation of IC, but imaging, including MRI, CT scanning, and pelvic ultrasonography, may be performed if needed to help confirm or exclude a differential diagnosis, such as a suspected pelvic mass that is causing compression of the bladder or for an adjacent inflammatory process (e.g. diverticulitis) (Rovner, 2020).

## TREATMENT AND MANAGEMENT

There is no cure for interstitial cystitis and there is no one specific treatment which will be effective for everyone (NIDDK, 2017). Treatment therefore

### Red Flags

- There is no universally accepted criteria for diagnosis
- No specific tests are currently available to confirm the diagnosis
- Multiple investigations may be undertaken and may be useful in eliminating a differential diagnosis
- Cystoscopy will confirm the presence or absence of Hunner's ulcers and glomerulations and will also confirm or exclude bladder cancer as a cause for the patient's symptoms.

aims to tackle and alleviate pain and inflammation (Harvard Medical School, 2023), and may need a combination of non-pharmacological and pharmacological options to achieve an effect. Patients may also need to try more than one treatment, either singly or in combination, before finding something which suits them (NHS, 2022).

### First-line treatment

In common with the management of a number of diseases, conservative management is often used as the first option. This includes education, behavioural modification, and stress management, and training relating to normal bladder function as well as amendment to behaviours leading to increased bladder pain, all of which are considered integral to symptom control (Colaco and Evans, 2015).

The following may be offered initially (Tirlapur et al, 2016; Urology Foundation, 2022):

- ▶ Dietary changes: avoidance of caffeine, alcohol, acidic foods and drinks may help. Patients may find it useful to keep a food diary to help them determine which foods, if any, may be worsening their symptoms
- ▶ Stress management and adopting techniques to reduce stress levels may be useful and regular exercise is also recommended. Learning basic relaxation techniques, such as meditation and massage, may be helpful in relieving stress (International Cystitis Association, 2015)
- ▶ Bladder retraining aims to 'retrain' the bladder so that the constant need to urinate is controlled. Patients use exercises and relaxation techniques and follow a schedule to urinate only at specific times. The time between urinating is gradually lengthened as bladder muscles strengthen
- ▶ Transcutaneous electrical nerve stimulation (TENS) uses skin pads to send electric impulses to the body with the aim of strengthening pelvic muscles, increasing blood flow to the bladder and aiding the release of hormones to block pain.

If the above options do not achieve

**Table 3: Tips to help diagnose IC/BPS (Mishra, 2015)**

▶ Lower abdominal discomfort with urinary frequency and/or urgency
▶ Discomfort worsens as the bladder fills and decreases on emptying
▶ Once the patient has the desire to void, it cannot be delayed
▶ There is no other pathology present to explain the symptoms
▶ There is a desire to pass urine again immediately after micturition
▶ The patient experiences anal pain with their urinary symptoms but there is no abnormal anal pathology

sufficient relief, oral medication is the next step and includes (Willacy, 2021; Mayo Clinic, 2022):

- ▶ Standard pain killers: over-the-counter (OTC) medications such as ibuprofen and paracetamol may be helpful for some patients, or in more severe cases, gabapentin or pregabalin may be needed to relieve pain. Amitriptyline may be prescribed to relax the bladder and reduce pain. One study reported 63% of participants experienced improvement after four months' use, compared to 4% in the placebo group. However, benefits were outweighed by adverse effects, with 79% experiencing nausea, drowsiness, weight gain and sedation (Colaco and Evans, 2015). Stronger pain relief, such as gabapentin or pregabalin, may be needed by some patients
- ▶ Antihistamines: loratadine or alternative antihistamines may reduce urinary urgency and frequency and provide relief from other symptoms (Mayo Clinic, 2022)
- ▶ Alternative drug options: tolterodine, solifenacin or mirabegron may be prescribed to effectively relax bladder muscles. Pentosan polysulfate sodium is recommended by the National Institute for Health and Care Excellence (NICE, 2019) as an option for patients experiencing moderate to severe pain with frequency of micturition and urgency, and is given in a hospital



**Red Flags**

- There is no cure and no one treatment will be beneficial for all affected
- Non-pharmacological and pharmacological options may be used
- Patients may need to try several treatments, singly or in combination, before they find something which gives relief
- Even when symptoms settle flare ups may occur.

setting. However, it is only given in the following circumstances: (Willacy, 2021):

- Symptoms have failed to respond to an adequate trial of the standard oral treatments above
- The treatment cannot be given in combination with bladder instillations
- Any previous use of bladder instillations was not terminated because of lack of response.

Bladder instillations involve insertion of drugs directly into the bladder and may be offered for those who have failed to respond to any of the other available options. However, as with other treatments, the evidence is not conclusive for their use and they may therefore be ineffective (NHS, 2022).

Examples of drugs used include (NHS, 2022):

- ▶ Hyaluronic acid or chondroitin sulfate which are thought to restore and strengthen the lining of the bladder
- ▶ Lignocaine which acts as an anaesthetic to numb the bladder
- ▶ Antibiotics may be given singly or in combination with a steroid preparation or an anaesthetic with the aim of reducing or treating infection and minimising inflammation.

**SURGERY**

Bladder surgery is generally a last resort (Interstitial Cystitis Association, 2015), and the following may be suggested when all else has failed:



- ▶ Laser surgery or partial removal of the bladder (cystectomy) used to treat Hunner’s ulcers
- ▶ Cystoscopy with hydrodistension: this involves filling the bladder with water during cystoscopy. The procedure has been shown to be relatively safe with low rates of adverse effects and for reasons unknown can relieve pain up to six months (Colaco and Evans, 2015)
- ▶ Sacral nerve stimulation: this involves stimulation of the pelvic and pudendal nerves, initially by an external stimulator later exchanged for a permanent implant if results are successful. Although positive outcomes have been reported in some studies, they have not been reported in others (Rovner, 2020)
- ▶ Cystectomy: the ureters are rerouted to form a stoma on the abdomen where urine is collected into a bag, however the procedure does not guarantee complete resolution and some patients will continue to have symptoms (Urology Foundation, 2022).

**COMPLICATIONS**

Symptoms of IC such as urgency, frequency, and pain may interfere with social activities, work, and other activities of daily life, leading to reduced quality of life (Mayo Foundation for Medical Education and Research, 2022). Both males and females with pelvic pain may have pain during intercourse, affecting relationships with partners and leading to avoidance of intimacy (NIDDK, 2017). Poor sleep due to nocturia may be a problem and those living with IC may develop depression and anxiety as they struggle to cope with their symptoms (Mayo Foundation for Medical Education and Research, 2022).

**PROGNOSIS**

Unfortunately in many cases, IC responds poorly to treatment (DeCaria, 2020) and, to date, no treatment has been found which can successfully prevent or decrease disease progression. Due to there

**Table 4: Conditions to be considered as a differential diagnosis in IC (French and Bhambore, 2011; Rovner, 2020)**

Gynaecological	Urological	Infectious or inflammatory	Neurological
Pelvic mass (fibroids or malignancy)	Bladder cancer	Recurrent UTIs	Multiple sclerosis
Endometriosis	Bladder outlet obstruction	Vaginitis	Parkinson’s disease
Pelvic inflammatory disease	Overactive bladder	Urethral diverticulum	Spinal tumour
Genital atrophy		Vulvodynia	Spinal stenosis

being no cure, patients may need to try several treatments, often in combination, before some relief is felt. Patients should be advised that they may need to persevere as it may be months before they feel things are improving, and even when things settle patients may experience intermittent flare ups (Willacy, 2021). Unfortunately, even with successful treatment, ICS may not be completely cured and there is a risk of recurrence (Willacy, 2021).

## CONCLUSION

IC is clearly a complex, highly challenging condition which currently has no cure. It is associated with variable symptoms, making diagnosis difficult because of its similarity with numerous other conditions. The

## KEY POINTS

- Interstitial cystitis (IC) is a disease which, despite years of research, remains poorly understood.
- Prevalence rates have increased in recent years, which has been attributed to improved understanding of the disease and more selective diagnostic criteria.
- The condition remains difficult to diagnose and, as a result, many of those affected suffer for years before the cause of their symptoms is confirmed.
- Treatment therefore aims to tackle and alleviate symptoms of concern to the patient, and may need a combination of non-pharmacological and pharmacological options to achieve an effect.
- Symptoms of IC, such as urgency, frequency, and pain, may lead to avoidance of social interaction, which in turn impacts on mental health and reduces quality of life.
- Unfortunately, even with successful treatment, ICS may not be completely cured and there is a risk of recurrence.

delay in diagnosis makes the disease highly distressing for those affected to cope with and hence the condition impacts on daily living activities and quality of life. This article hopes to give nurses and non-medical prescribers a greater awareness of signs and symptoms, with the aim of increasing their confidence in recognising its unpleasant effects, so that they can get those affected earlier investigations and treatment, which will ultimately impact on their ability to cope with this condition and improve quality of life. **JCN**

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# Medications to treat early rheumatoid arthritis: tackling non-adherence

Tracy French

Rheumatoid arthritis (RA) is a condition which causes inflammation in synovial joints. Patients experience pain, stiffness and swelling commonly in their hands and feet, but it can also be a systemic disease which affects the heart, lungs and eyes in some patients. It is more common in women than men, and the peak age for diagnosis is around 70 years; however, it can affect all ages. Early diagnosis and treatment should be prompt to reduce the chance of permanent damage to the joints, as this will cause functional impairment and affect quality of life, and work/leisure activities (Heidari, 2011). A treat-to-target strategy aims to achieve remission or low disease activity by up-titrating medication from the point of diagnosis, thus minimising the impact of the disease (National Institute for Health and Care Excellence [NICE], 2018). This strategy only works if patients take the prescribed medication. The nurse's role is vital in supporting patients' understanding of the medications and advising on how to manage side-effects.

## KEYWORDS:

- Rheumatoid arthritis ■ DMARDs ■ Non-adherence
- Health beliefs ■ Shared decision-making

Rheumatoid arthritis (RA) can have periods where inflammation is more active, known as 'flares', and periods where the condition is more settled (Arthritis Foundation, 2022). However, for some patients, their disease is so aggressive that they are in a permanent flare. Medications used need to be taken constantly to be effective and are generally continued long term (National Health Service, 2022).

There are various types of medication used to manage RA (Table 1). Non-steroidal anti-inflammatory drugs (NSAIDs) and COX-2 inhibitors reduce inflammation and give symptomatic relief. They should be used while waiting for disease modifying drugs to become effective

**'... for some patients, their disease is so aggressive that they are in a permanent flare. Medications used need to be taken constantly to be effective and are generally continued long term.'**

and during flares, rather than for long-term daily use due to the risk of adverse effects which are well documented (Borer and Simon, 2005; Crofford, 2013).

Steroids in varying forms are used to manage flares; this can be a short course of oral prednisolone, an intramuscular injection, intra articular injection or, in severe cases, intravenous (IV) methylprednisolone infusions. Steroids are quick acting and effective in reducing inflammation, but due to well recognised adverse effects from larger

doses or prolonged use, they should only be used as a bridging therapy while waiting for other treatments to become effective (National Rheumatoid Arthritis Society, 2023a).

Disease modifying anti-rheumatic drugs (DMARDs) are the mainstay of initial RA management (Kalyuzhny, 2021). These drugs slow down the disease process and reduce the risk of joint damage. They are first-line therapies used alone or in combination depending on the severity of the disease (Kalyuzhny, 2021).

Severity is judged on clinical examination and by using a validated assessment tool called disease activity score (DAS) (van der Heijde et al, 1993). The DMARD dose is up-titrated quickly (if tolerated) to reduce the DAS as low as possible and as quickly as possible (treat-to-target). DMARDs take a long time to be fully effective (eight to 12 weeks), so when first diagnosed patients will often also be taking some form of steroid and an NSAID to manage symptoms (Del Grossi Moura et al, 2018; John Hopkins Arthritis Centre, 2023).

For some patients, their RA is managed effectively with DMARDs. However, other patients with a more severe form of the disease, or those who have had adverse effects from DMARDs, require stronger therapies which target specific parts of the immune system (Table 1). These biologic DMARDs and targeted synthetic DMARDs are approved for use by the National Institute for Health and Care Excellence (NICE, 2018). Part of the eligibility criteria for these therapies is to have tried at least two conventional DMARDs, one of which must be methotrexate unless contraindicated or not tolerated (NICE, 2016).

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**Table 1: Medications used to treat rheumatoid arthritis**

Type of medication	Name of medication	Format (s/c = subcutaneous; IV = intravenous)
NSAIDs	Ibuprofen	Oral
	Naproxen	Oral
	Etodolac	Oral
	Meloxicam	Oral
COX-2 inhibitors	Etoricoxib	Oral
	Celecoxib	Oral
Steroid	Prednisolone	Oral
	Methylprednisolone or Triamcinolone acetonide	Intramuscular Intra articular
	Methylprednisolone	Intravenous
Conventional DMARDs	Methotrexate	Oral or S/C
	Leflunomide	Oral
	Sulfasalazine	Oral
	Hydroxychloroquine	Oral
Biologic DMARDs	TNF inhibitors:	
	Adalimumab	S/C
	Certolizumab	S/C
	Etanercept	S/C
	Golimumab	S/C
	Infliximab	S/C or IV
	CD20 inhibitor:	
	Rituximab	IV
	T-cell inhibitor:	
	Abatacept	IV or S/C
	IL-6 inhibitors:	
	Tocilizumab	IV or S/C
	Sarilumab	S/C
Targeted synthetic DMARDs	JAK inhibitors:	
	Baricitinib	Oral
	Tofacitinib	Oral
	Filgotinib	Oral
	Upadacitinib	Oral

DMARD = disease modifying anti-rheumatic drug; NSAID = non-steroidal anti-inflammatory drug

DMARDs are, therefore, the cornerstone of treating early RA, but in the author's experience, DMARDs are the therapies where most issues with adherence occur. This is at the most pivotal point in a patient's disease management and irrevocably determines how the disease will impact their quality of life.

### WHAT ARE THE REASONS FOR NON-ADHERENCE?

There are varying reasons for non-adherence to DMARDs, the following patient scenarios reflect the most common, namely:

- ▶ Lack of awareness of side-effects and efficacy of DMARDs
- ▶ Health beliefs and perception of DMARD therapies as toxic

- ▶ Impact of DMARDs on social and work life.

### Lack of awareness of side-effects and efficacy of DMARDs

Clive is 54, newly diagnosed with mild RA, and has been taking sulfasalazine for three weeks. He has been troubled by wind and bloating which he finds embarrassing. His joints are worse than when he saw the rheumatologist and fatigue is affecting his work as a taxi driver. He thinks the tiredness came on since he has been taking sulfasalazine, so has decided to stop it.

Sulfasalazine is up-titrated over the initial four weeks to a maintenance dose. Sulfasalazine can cause wind and bloating, but this will often settle by returning to a lower dose (which

was tolerated) and up-titrating slower (Table 2). The sulfasalazine will take eight to 12 weeks to be fully effective. If Clive does not understand this, he may feel resentful that he is having side-effects from the medication, but no benefits. It is also important that he understands that the medication will not make his joint pain worse — this is more likely to be because his arthritis is progressing as the medication is not yet controlling it fully. Sulfasalazine can occasionally cause fatigue (Pope, 2020), but it is more likely caused by his condition, so it is again important that he realises that fatigue is part of his condition.

### How nursing support can help

This scenario reflects the importance of educating patients on how:

- ▶ Long the medication will take to be effective
- ▶ To manage common and minor side-effects
- ▶ To differentiate between effects likely related to the medication and to those related to the disease itself.

This education should occur in secondary care but can of course be reinforced in primary care, as information is often not retained, particularly when first diagnosed.

### Health beliefs and perception of DMARD therapies as toxic

Kavita is 65 years old and was diagnosed with moderately active RA 12 months ago. She attends the clinic in a significant flare — she has swollen joints, is in considerable pain, has lost weight and is anaemic due to ongoing inflammation. She does not speak English, so an interpreter is used and family members are also present.

When first diagnosed she was not given oral glucocorticoids, as she has diabetes which is not well controlled. It was recommended by her healthcare practitioner that she starts methotrexate tablets and was given an intramuscular methylprednisolone injection. Looking back through her notes, it is hard to establish if she takes the methotrexate consistently (if at all). At every visit she requests another steroid injection, as she finds them very effective as they give her

relief quickly. This is given based on the expectation that she will continue to take methotrexate. She has not had any monitoring blood tests, except the ones taken at the visits to the rheumatology clinic, so it may also be that her GP is not happy to keep prescribing methotrexate without regular monitoring.

An additional visit with the nurse specialist in secondary care is arranged to allow time to discuss Kavita's concerns about taking methotrexate. This reveals that she perceives the medication as 'poison' because of the need for blood tests and the possibility of hair loss as a side-effect. However, she did take it for the first few weeks but had nausea for 24 hours after each dose, which meant she did not eat or drink anything and spent the day in bed.

Kavita's reliance on the steroid as a fast way to manage her arthritis is, in the author's clinical experience, commonly seen in practice. While she feels fast relief from her symptoms and does not experience any immediate side-effects, reliance on steroids has health implications, particularly in relation to control of her diabetes.

#### How nursing support can help

Some simple solutions to encourage regular dosing of methotrexate

### Practice points

- ▶ Ask your RA patients if they take their DMARD medications regularly, clarify they understand they should not just be taken when flaring but all the time. If they do not take them as prescribed, try to explore why not
- ▶ Remember positive reassurance from nurses (in primary and secondary care) about the long-term safety of DMARDs can improve adherence. If you know a patient whose RA has responded really well to methotrexate without tolerability issues, share this with other patients who may have anxiety about taking it. If both patients consent, perhaps put them in touch with each other.

**Table 2:** 'Quick fixes' to try if patient experiencing mild/moderate side-effects (table developed by author of this article)

DMARD	Side-effect	Quick fix	Dose schedule
Sulfasalazine	Bloating, flatulence, loose stools, intermittent headache	Reduce back to previous tolerated dose and increase up slower to maintenance dose of 1gram twice a day	Increased over first four weeks: 500mg once a day one week 500mg twice a day one week 1gram AM 500mg PM one week 1gram AM 1gram PM continue (can be increased to 1.5gram twice a day if indicated)
Methotrexate	Nausea, diarrhoea, mouth ulcers	Take in evening ▶ Folic acid 5mg six days a week (not to be taken on day of methotrexate) ▶ Switch to injectable form	Start at 7.5mg once a week, increase up to maximum weekly dose of 25mg
Leflunomide	Diarrhoea	If on 20mg daily, reduce to 10mg daily, or reduce to every other day to see if helps, then gradually increase up to daily prescribed dose again	10mg or 20mg once a day

would be to suggest that she takes the methotrexate tablets at night, as this will reduce daytime nausea. Another 'quick fix' can be ensuring she is taking folic acid 5mg every day of the week, except the day that she takes the methotrexate, as this can reduce side-effects such as nausea. Finally, if these are not effective, a switch to methotrexate injections should mean the nausea no longer occurs (*Table 2*).

#### Impact of DMARDs on social and work life

Alex is 28 and was diagnosed with RA six months ago. He works in the TV industry, which involves significant travel and socialising.

He is reviewed in clinic but despite being on 20mg methotrexate weekly, his arthritis continues to flare, and he has needed two intra articular injections into his wrists. During the consultation it becomes evident that he has not been taking methotrexate every week as prescribed. He has been missing doses at events where he likes to drink alcohol. He has also had issues taking time out of work to have regular blood tests, resulting in missed doses.

It is important for Alex to understand that he needs to take methotrexate regularly for it to be effective, even if his arthritis is not flaring. It is recommended with both

methotrexate and leflunomide that alcohol intake is no more than 14 units a week (National Rheumatoid Society, 2023b; Versus Arthritis, 2023).

#### How nursing support can help

It is vital that Alex is given the opportunity to have a frank discussion about his lifestyle choices and for the nurse to discern whether he is willing to compromise on these. It would also be advisable to clarify whether there can be flexibility in scheduling his blood monitoring appointments to minimise the impact that this has on his work. Without regular tests, it would not be safe for him to continue taking methotrexate.

While these three scenarios are different, they all exhibit similar themes. They show how crucial the nurse's role is if a patient experiences minor side-effects and these are addressed quickly (*Table 2*). In the author's clinical opinion, this means patients are more likely to persevere with the medication.

However, if unpleasant effects are ignored, patients are more likely to stop treatment. The scenarios also reflect the role health beliefs play in patients' perceptions of medications, how they experience and deal with side-effects, and the importance of shared decision-making in managing patients on DMARDs.

## IMPACT OF HEALTH BELIEFS AND SIDE-EFFECTS ON ADHERENCE

In all three scenarios, patients weigh up the need to take the DMARD versus their concerns regarding potential adverse effects. There is also the alternative option of steroid (in various forms), which is often (mistakenly) perceived as a much quicker solution with less adverse effects in the author's opinion.

A cross-sectional survey of over 600 RA patients examined the beliefs they had about their medications, what factors related to these beliefs and how the beliefs affected adherence (Neame and Hammond, 2005). Seventy-five percent of patients had positive beliefs about the necessity of their medication, but 50% had strong concerns about potential adverse effects in the long term (Neame and Hammond, 2005). The greater number of DMARDs patients were taking, the greater their concerns about medications, even after adjusting for variables such as pain, fatigue and disability. Unfortunately, the patients with the most active disease are those who will need to take two or three DMARDs, and if they are non-adherent, they will have the most to lose in terms of damage to their joints and long-term disability. The least adherent patients in the study were the ones with the greater medication concerns, but the beliefs about the necessity for the medications was the same in all patients (Neame and Hammond, 2005). This would suggest that reassuring patients about the long-term safety of medications is



more important than about how effective they will be.

A further longitudinal study of 100 RA patients examined the relationship between medication beliefs and side-effects, at baseline and six months later (Nestoriuc et al, 2010). The majority of the reported side-effects in this study were non-serious and the reported non-specific symptoms were not clearly related to the pharmacologic action of the drug in question (Nestoriuc et al, 2010). Yet, these symptoms are still frightening for patients, and often result in non-adherence. The authors of this study refer to the 'nocebo phenomenon'; where patients report side-effects to placebo (Nestoriuc et al, 2010). They found that patients' beliefs about medications influenced their experience of side-effects, even after adjusting for variables such as disease activity, types of medications and levels of prior experience of side-effects. In effect, patients with greater concerns about their medications experience more side-effects, and patients starting new medications are more likely to have side-effects if they have negative perceptions about medicines at baseline (Nestoriuc et al, 2010).

The National Rheumatoid Arthritis Society (NRAS) patient experience survey found that the primary impact upon treatment adherence was unpleasant gastrointestinal side-effects, with 53% stopping treatment due to these effects (NRAS, 2021). Further findings also suggest that poor adherence to methotrexate is linked to the patient's lack of understanding

and involvement in their treatment choice. Over 70% of patients stopped taking their oral methotrexate, increasing the risk of worsening symptoms and remission relapse (NRAS, 2021).

The survey also highlighted that 75% of patients subsequently switched from oral to injectable methotrexate, with 42% experiencing a significant reduction in their side-effects and nearly 50% reporting a positive impact on their quality of life. This additionally underlines the importance of shared decision-making, and providing patients with all available treatment options.

It is important to note that when referring to side-effects, these are presumed to be minor and manageable. If there are any significant or more serious side-effects, the patient should be referred urgently to secondary care, usually via a nurse specialist advice line or by calling the on-call team (*Red flags* box).

### SHARED DECISION-MAKING

The Royal Pharmaceutical Society (RPS) recognises that understanding the patient experience is key to adherence (RPS, 2013). To obtain the best possible outcome for patients, the RPS suggests that it is vital to have an ongoing and open dialogue with them about their choices and experience of using medicines (RPS, 2013).

In each of the scenarios outlined, having the opportunity to explore the beliefs and preferences of Clive, Kavita and Alex, along with a safe space for them to be open about

### Practice points

- ▶ Make a point of knowing the best way for patients to access their rheumatology team and encourage them to do this as soon as they experience side-effects
- ▶ What are the options for patients working full time to attend for blood tests at your practice; is there a way they could attend without having to take time off work?



**Red Flags Alert rheumatology team if:**

- Methotrexate is not being taken appropriately, it should only ever be taken ONCE A WEEK, NEVER daily
- Persistent nausea and vomiting or severe mouth ulcers
- Sudden onset of dry cough, fever and shortness of breath if on methotrexate or leflunomide (could be hypersensitivity pneumonitis)
- Skin rash (if looks allergic) — this will often result in discontinuation of the DMARD
- Blood abnormalities:
  - Low white cell count (neutropenia)
  - Low haemoglobin
  - Raised liver function tests (particularly aspartate transaminase/alanine transaminase [ALT/AST])
  - Sudden deterioration in renal function (this would not necessarily be caused by a DMARD, but could mean that the treatment would need to be paused or dose reduced due to risk of toxicity).

Note: This list is not exhaustive, there will be locally agreed guidance for each drug detailing what adverse effects can occur and how to report them.

how the medication impacts their daily lives can result in true shared decision-making, which would hopefully result in better adherence.

The opportunity for this should not be limited to secondary care — practitioners in primary care are in a unique position to have these open conversations with patients, as they are often seeing them on a more frequent basis, for example when patients undergo blood monitoring.

If patients are having problems tolerating their medications, it is important that they know there are ways to manage this or therapy alternatives. There is also the opportunity at an annual review to monitor repeat prescription requests to assess if medication is being taken regularly.

Nurse advice lines are the most common way rheumatology patients access their team. A large number of these calls will be about adverse effects from DMARDs. This is often the platform where shared decision-making takes place. For example, a female patient calls who is in their 20s and having significant nausea and loose bowels for 48 hours after taking methotrexate orally. They have tried taking it on a Friday evening so they are unwell over the weekend but can still perform at work Monday to Friday. This means that they are unable to socialise with friends at the weekend and are too tired to do

so on weeknights. They are feeling socially isolated and miserable. Their arthritis is under control, but they do not feel like they are experiencing a good quality of life outside of work. The nurse establishes that they are already taking folic acid 5mg six days a week. The next step is to suggest they try injectable methotrexate, as this should mean they will not have any gastrointestinal side-effects. Although there is often hesitancy about injecting a medication, with reassurance and a nurse visit to teach patients how to self-inject can be a way to overcome this obstacle.

### ASK APPROACH TO IMPROVE THE CONSULTATION EXPERIENCE

Shared decision-making can be challenging to implement when working in a time-pressured environment. Interactions which patients have with nurses (in primary and secondary care) can be fundamental to helping them feel involved in their treatment plan and empowered to express their concerns.

NRAS have promoted the ASK approach to patients to help them get the most out of their consultations and hopefully maximise treatment adherence (<https://nras.org.uk/resource/how-to-approach-your-rheumatology-consultation/>). This would involve the following.

**Address** their main concerns at the start of the consultation:

- ▶ Only 45% of patients felt able to voice their concerns about their consultation
- ▶ 40% of patients felt as though their opinions and concerns had little to no influence on their treatment decision.

**Share** details of their symptoms, prioritising those that have most impact on their quality of life:

- ▶ 71% of patients' RA symptoms impacted their mobility
- ▶ 66% reported a negative impact on their mental health.

**Know** everything about their prescribed treatment, what format they can take it in and any options:

- ▶ Only 35% of patients felt as though they received enough information about their proposed treatment
- ▶ Nearly 60% were not told what their next treatment option would be should the initial therapy fail.

### CONCLUSION

The best outcome for patients with RA can be assured if the treat-to-target strategy is followed. This strategy is only effective if there is adherence to DMARDs. Some of the reasons for non-adherence are beyond the control of the nurse, but others are within their grasp to positively impact on the patient's early experience of the disease and medications (such as identifying and managing minor side-effects quickly or educating patients about their medication). Supporting patients to be involved in making decisions about the right treatment for them, can give them the best chance to 'live well' with RA. **JCN**

### Practice points

- ▶ If patients are on subcutaneous injections of methotrexate, is it being prescribed by brand in your practice? If patients are trained to self-inject in secondary care but prescribed a different brand and therefore a different device by their GP, this can cause confusion and affect patient confidence in self-injecting, especially if they have dexterity issues.

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## KEY POINTS

- Early diagnosis, prompt treatment (at the appropriate dose) and maintenance of treatment supports adequate disease control, reduction in symptoms and reduces the risk of long-term joint damage and deformity.
- There are varying types of treatment for RA — it is important to understand how and when these should be taken.
- There are varying reasons for non-adherence, commonly it is related to side-effects and tolerability, but also patients' health beliefs and understanding of the medication.
- There are some 'quick fixes' for minor side-effects that can be used to support adherence, but, if ineffective, alerting the secondary care team promptly is key.
- Shared decision-making is crucial to ensure patients have the best medication for them and that it is in the right format.

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## USEFUL WEBSITES

National Rheumatoid Arthritis Society: [www.nras.org.uk](http://www.nras.org.uk)  
Versus Arthritis: [www.versusarthritis.org](http://www.versusarthritis.org)

## Revalidation Alert

Having read this article, reflect on:

- Your knowledge of rheumatoid arthritis
- The different medication options available
- The patient/carer education you give.

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

# Dementia: reducing and managing risk

Karen Harrison Denning

The number of people with dementia is expected to increase with a consequential effect on the wellbeing of families and increasing pressure on an already over-burdened health and social care system. Risk factors for dementia, both modifiable and non-modifiable, if appropriately understood and identified are amenable to management and amelioration. Community and primary care nurses are in an ideal position to support the reduction and management of risk pre and post dementia diagnosis. Using a case study, this paper highlights some of the issues in identifying, assessing and managing risk in a person with an existing diagnosis of dementia and their family/carer. The potential for dementia-related risks to escalate can have a much wider impact on a family unit if not appropriately identified, managed and mitigated against.

## KEYWORDS:

■ Dementia ■ Risk ■ Non-modifiable risk ■ Modifiable risk ■ Family

There are estimated to be 944,000 people living with a dementia in the UK (Wittenberg et al, 2019), with a financial cost of care estimated to be almost £37 billion to the country's economy. However, the costs are not spread evenly across health (14%) and social care (45%), with a significant personal contribution of 40% from families affected by dementia (Wittenberg et al, 2019). There is increasing evidence identifying risk factors that lead to the development of dementia, both modifiable and non-modifiable. Programmes of health promotion could have a significant impact on reducing some of the cost burden (Livingston et al, 2020).

**'Nurses in a community and primary care setting are presented with many opportunities to educate patients about healthy lifestyles and monitor their individual risk factors.'**

## RISK FACTORS FOR DEVELOPING DEMENTIA

Increasing age is the most significant risk factor to developing dementia in later life. However, although rarer, a person can develop dementia at any age (Kuruppu and Matthews, 2013). It is estimated that almost 71,000 people in the UK have young onset dementia where symptoms occur under the age of 65 years (Carter et al, 2022). There are several other risks factors, aside from age, associated with the development of dementia, some modifiable and others non-modifiable (Livingston et al, 2020). Risk factors for dementia, whether

modifiable or not, can be seen over an individual's life course (Figure 1; (Livingston et al, 2020)). However, a third of all cases of dementia are associated with modifiable risk factors, where a better awareness of these and steps taken to modify them can reduce the possibility of a person going on to develop dementia later in life (Livingston et al, 2020; National Institute for Health and Care Excellence [NICE], 2021).

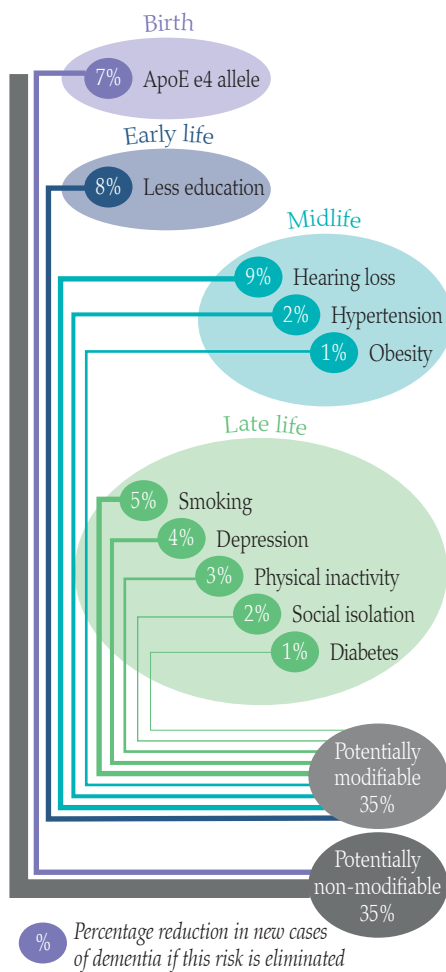
Nurses in a community and primary care setting are presented with many opportunities to educate patients about healthy lifestyles and monitor their individual risk factors. This can enable patients to reduce or delay their risk burden for dementia in the coming years. This may involve activities such as support and management of long-term conditions, promoting healthy lifestyles through to providing timely interventions, treatments, and support to manage dementia-related symptoms as they appear — all of which can provide considerable benefits and health gains to the health and social care systems and individuals themselves (Livingston et al, 2020).

### Non-modifiable risk factors

Risk factors are characteristics of lifestyle, environment, and genetic background that increase the likelihood of getting a disease. Risk factors, on their own, are not causes of a disease. Rather, they represent an increased chance, but not a certainty, that dementia will develop. However, there are certain risk factors that we are unable to modify through health promotion interventions (Table 1), namely:

- ▶ Age: this is the strongest risk factor of dementia. A person's risk





**Figure 1.** Risk factors for dementia over a life course (adapted from Livingston et al, 2020).

of developing Alzheimer’s disease or vascular dementia doubles every five years over the age of 65, due to biological decline and increasing comorbidity (Prince et al, 2014)

- ▶ **Ethnicity:** Black, Asian, and minority ethnic communities have differing cultural, biological and social dementia risk factors, related to a higher prevalence of diabetes, hypertension, cardiovascular disease, genetic variations (Pham et al, 2018) and socioeconomic factors, such as levels of cultural understanding of dementia (Shiekh et al, 2021)
- ▶ **Learning disabilities:** prevalence of dementia in people with a learning disability is two to three times greater than in the general population, particularly for people with Down’s syndrome (Llewellyn, 2011)
- ▶ **Gender:** 65% of those diagnosed with dementia are women, largely due to a greater life expectancy

than in men (Prince et al, 2014), some links associated with the menopause and hormonal changes (Scheyer et al, 2018)

- ▶ **Genetics:** there is an increased risk to developing dementia associated for those who have a family history of three or more generations of Alzheimer’s dementia (Loy et al, 2014)
- ▶ **Mild cognitive impairment (MCI):** one-third of all people who have MCI go on to develop a dementia within three years (Barrett and Burns, 2014), thus it is important to monitor people with MCI to enable early access to treatment and support or treat another primary cause
- ▶ **Parkinson’s disease:** dementia occurs more commonly in Parkinson’s disease than in the age-matched general population (McKeith and Burn, 2000).

**Modifiable risk factors**

There are several potentially modifiable risk factors that can serve as a target for risk reduction, health promotion and preventative interventions, to delay or even prevent the onset of dementia (Eggink et al, 2019). Tackling many of these modifiable risk factors involves health promotion early on in life and in a primary health care and/or educational setting (Livingston et al, 2020). Of all of the modifiable risk factors for dementia, poor education is considered the most significant influencing factor, but when combined with other risks, such as hypertension, smoking and diabetes, can escalate an individual’s risk (Table 1). Other modifiable risk factors include:

- ▶ **Education:** higher level of education in childhood is associated with a 7% reduction in the risk of developing dementia in later life (Livingston et al, 2020; NICE, 2021)
- ▶ **Hypertension:** persistent midlife hypertension is associated with an increased risk of dementia in later life. To help reduce this risk, achieving a systolic blood pressure of 130mmHg or less is a key aim from around the age of 40 years (Livingston et al, 2020; NICE, 2021)
- ▶ **Midlife hearing impairment:** untreated midlife hearing

loss can increase the risk of dementia in later life as a result of cognitive overload (exceeding cognitive capacity leading to an inability to process further information, causing feelings to be overwhelmed and confusion) and reduced cognitive stimulation as hearing loss progresses (Ray et al, 2018; Livingstone et al, 2020)

- ▶ **Smoking:** smokers are at a 50–80% increased risk of dementia due to the toxic effects of the smoke on the lungs and vascular system. However, smoking cessation at any age can help to reduce the risk of dementia in later life by 5% (NICE, 2021)
- ▶ **Depression:** depression in later life is associated with a twofold increase in Alzheimer’s disease, although there is a school of thought that depression may be prodromal to dementia (Bennett and Thomas, 2014)
- ▶ **Physical activity:** this has the largest influence on modifiable risk reduction of dementia. Even exercise of low physical intensity can reduce the risk of dementia by 40% and even reverse causation of dementia (Norton, 2014)
- ▶ **Diabetes:** having diabetes increases the risk of vascular, Alzheimer’s or mixed dementia by 50% in later life, with increasing risk with the duration of diagnosis, poor control and severity (NICE, 2021)
- ▶ **Obesity/diet:** a persistently high body mass index (BMI) ( $\geq 30$ ) can increase the risk of dementia in later life (Albanese et al, 2017). Diets high in plants, nuts, and olive oil intake, such as contained in a Mediterranean diet (Bussell, 2022), which is also low in saturated lipids and red meat, can reduce the risk of dementia (Livingston et al, 2020)
- ▶ **Social isolation:** this has a detrimental effect on brain function, leading to depression and dementia in later life. Older people who have few opportunities to socialise due to, for example, frailty, multiple conditions, etc, can feel lonely, leading to increased risk of dementia (Holwerda et al, 2012)
- ▶ **High alcohol consumption:** high alcohol consumption is associated

with many health risks when abused long term, including cognitive impairment and dementia. Guidance recommends ≤14 units per week. Chronic drinking of more than 21 units per week can lead to a 17% increased risk of dementia (Sabia et al, 2018)

- ▶ Traumatic brain injury (TBI): TBI is a key contributory risk factor in dementia, for example, those who have sporting careers where frequent head injuries increase this risk, such as in rugby and football (Livingston et al, 2020)
- ▶ Air pollution: exposure to environmental air pollutants increases the risk of cognitive impairment and dementia (Livingston et al, 2020).

### MANAGEMENT OF RISK FACTORS OF DEMENTIA

Supporting patients to understand the risk associated with inappropriate or poor health behaviours and lifestyles is a key activity for community and primary care nurses. Interventions and monitoring to support smoking cessation, control of systolic blood pressure, depression, treatment for cardiovascular complications and control of diabetes are performed as part of the primary care Quality Outcomes Framework (QOF) (NHS, 2022a). As has been seen, if poorly managed, all of these can lead to a greater risk of developing dementia. However, there are other modifiable risk factors for dementia that may be less obvious and require vigilance, such as hearing loss, social isolation, and increased alcohol intake. Promoting brain health (and emotional health) in addition to general physical health requires a multiprofessional collaborative approach, as understanding and knowledge of both dementia and risk factors may vary (Kulmala et al, 2021).

### REDUCING RISK BURDEN IN PEOPLE WITH AN EXISTING DIAGNOSIS OF DEMENTIA

Promoting a healthy lifestyle in people who already have a diagnosis of dementia is also important. Attention to the modifiable risk factors in a person who already has a diagnosis

of dementia has the ability to improve both their health status and quality of life. In the author’s clinical opinion, nurses in any care setting, but especially primary care, are well placed to support a range of interventions, such as supporting health education, as well as prevention and risk reduction of an exacerbation of the symptoms of dementia within their practice population.

### CASE EXAMPLE

Angela, aged 76 years, went to see her GP four years ago with concerns about her memory and was found to have iron deficient anaemia. Although corrected, her memory concerns remained and following referral to the local memory assessment for further tests she was found to have early vascular dementia, which was not amenable to a prescription of anti-dementia medications (due to the lack of efficacy of their use in this type of dementia) and was discharged back to her GP for continued health monitoring with standard annual health checks.

However, nine months later, Angela failed to attend her annual health check at the surgery or routine blood tests for her anaemia, nor had they received any requests for repeat medications from her for over three months. A few weeks later, Angela’s daughter, Rose, rang the surgery stating that she was worried about her mum’s worsening memory and said she was finding it difficult to encourage her to look after herself and even to go out to her usual clubs and groups. The nurse asked if Rose felt able to bring her mother in to the surgery for an assessment and to take her bloods. The nurse was also conscious that she needed to assess Rose’s needs in her role as her mother’s main carer.

Angela seemed apathetic and her speech was slow and aphasic and Rose said she had noticed some deterioration in her over the last couple of months, saying that her mother now seemed to have little energy and was taking far less care of herself or the home, unusual characteristics for her mother. The

**Table 1:** Risk factors for dementia (Livingston et al, 2020)

Non-modifiable	Modifiable
▶ Age	▶ Education
▶ Ethnicity	▶ Hypertension
▶ Learning disability	▶ Midlife hearing impairment
▶ Gender	▶ Smoking
▶ Genetics	▶ Depression
▶ Mild cognitive impairment (MCI)	▶ Physical activity/obesity
▶ Parkinson’s disease (PD)	▶ Diabetes
	▶ Diet
	▶ Social isolation
	▶ High alcohol consumption
	▶ Traumatic brain injury
	▶ Air pollution

nurse took a full blood screen sample from Angela, in part to check her haemoglobin levels, as Angela had clear signs of anaemia again in addition to her worsening cognition. The nurse arranged for Angela to have a dosette box to help in her medication management, and with some initial guidance, Rose was able to manage this prompting her mother’s compliance. The nurse also enquired about Rose’s needs as a carer and offered advice and support, and with her agreement, referred her to the local Admiral Nursing Service.

A few months later, their care was reviewed. Angela appeared more alert and was starting to resume her usual social activities and Rose said she felt better able to cope and that her mother was now taking her medications regularly and seemed to be functioning better, although not back to her levels. As the situation became more settled, initial risks reduced and with other support services in place, such as implementation of the dosette box to enable compliance with medications and a small care package to prompt personal care and diet, the nurse was able to step back.

### Discussion

It is important for nurses working in community and primary care settings to consider the opportunities that may arise within their everyday practice to promote brain health and dementia prevention. This

case study presents an example of a situation where, even with an existing diagnosis of dementia, much can be done to promote better brain health. Support provided in such a way improved Angela's cognition, even in the context of her diagnosis of dementia. Angela's failure to maintain her connection with the surgery in management of her dementia and anaemia led to these becoming poorly controlled, leading to a poor diet, loss of function and social isolation; all of which were modifiable risk factors. Reassessing the risks posed to exacerbating Angela's existing diagnosis of dementia, ultimately resulted in better management of her care enabling her to regain much of her previous function. Similarly, identifying Rose's needs as Angela's main carer enabled her access to support in her own right and to continue to care for her mother.

NHS health checks (NHS 2022b) alongside other routine checks, support long-term health conditions to be monitored and optimum management achieved in a primary care setting. However, patients 75 years and over, have an identified accountable GP who will follow up their care on an annual basis (NHS, 2022b). Equally, many untoward opportunities may arise during interactions with other healthcare professionals, such as nurses, through routine appointments for a blood pressure check or interaction with a social prescriber or wellbeing coach, where health checks can be made for any modifiable risks of dementia (Livingston et al, 2020). The objective of preventative interventions is to support individuals to manage and reduce risks to focus on wellbeing, ensuring that guidance is personalised, supports gradual change and is sustainable at a level suitable for each individual patient (Goss-Hill and Aldridge, 2020; NHS, 2022b).

For those patients who do not attend their GP appointments and health checks, as in the case of Angela, the reasons for this require investigation as there may be other, undiagnosed modifiable risk factors that are in danger of falling off the

radar', which may only become apparent in a crisis (Yates et al, 2020). Often the situation may have become exacerbated to the point where any remedial interventions become more of a challenge. In Angela's situation, there was significant risk of an assumption that her dementia had progressed to the point of requiring institutional care. Also, Rose was becoming increasingly distressed in her attempts to support her mother

**'The objective of preventative interventions is to support individuals to manage and reduce risks to focus on wellbeing, ensuring that guidance is personalised, supports gradual change and is sustainable... .'**

to remain at home; many family carers can ignore their own needs as they invest all their energy into the person with dementia (Connors et al, 2020). The nurse's support of Rose included providing information to enable a greater understanding of the impact of maintaining her mother's physical health and the effect this would have on her dementia and, importantly, why it was essential she care for herself to enable her to continue to care.

The nurse's role in both reducing risk of dementia in a general population and also in minimising risk in a person with an existing diagnosis of dementia is pivotal. Outcomes to such a role have the potential to:

- ▶ Reduce the risk of a breakdown in care at home
- ▶ Offset premature transition to institutional care
- ▶ Avoid inappropriate hospital admissions
- ▶ Avoid the development of more burdensome treatment plans (Goss-Hill and Aldridge, 2020).

In turn, this leads to the effective use of resources in a wider, multidisciplinary team, and also providing the opportunity to reduce the number of GP contacts.

Patients who are beginning to show signs of risky health and lifestyle behaviours in their early and middle life years, such that may lead to a high-risk factor burden for dementia, can be monitored and supported to make lifestyle changes by primary care staff through the development of a trusting, therapeutic relationship. This can reduce, delay, or even prevent the risks of developing dementia in later life (Lisko et al, 2021).

Even when effective treatments for dementia do become available, risk reduction will likely remain central to a national strategy in reducing the number of individuals affected by dementia (Baumgart et al, 2015) and a reduction in the costs associated (Wittenberg et al, 2019).

## CONCLUSION

It is never too early or too late to reduce the risks in dementia, whether this be in preventative approaches adopted earlier in the life course or after a diagnosis of dementia has been established. There are many factors which can increase the risk of dementia, both modifiable and non-modifiable. Risk factors should be considered on an individual, patient by patient basis so as to tailor effective monitoring and interventions to reduce them.

There are challenges, particularly where the risk factor burden is high and in patients that fail to engage in routine health checks. However, continuing to enhance professional insight and knowledge on the risks of dementia and monitoring of patients to support timely interventions from health and social care professionals within primary and integrated care, requires a proactive approach to enable early intervention. The benefits of such an approach may reduce the need for increased out-of-hours care and reduce the frequency of GP visits. **JCN**

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## KEY POINTS

- The number of people with dementia is expected to increase with a consequential effect on the wellbeing of families and increasing pressure on an already over-burdened health and social care system.
- Risk factors for dementia, both modifiable and non-modifiable, if appropriately understood and identified are amenable to management and amelioration.
- The potential for dementia-related risks to escalate can have a much wider impact on a family unit if not appropriately identified, managed and mitigated against.
- Risk factors should be considered on an individual, patient by patient basis so as to tailor effective monitoring and interventions to reduce them.
- Community and primary care nurses are in an ideal position to support the reduction and management of risk pre and post dementia diagnosis.

# Making a success of a place-based team

Jane Parsons, Sian Wade

In 2019, South Warwickshire NHS Foundation Trust implemented a pilot scheme to create place-based teams (PBTs) across the community under its leadership. These were to align themselves to the newly formed, geographically located, primary care networks (NHS England, 2019), and renamed integrated care systems (NHS White Paper, 2021). Their implementation and leadership was, as a result, devolved to these individual localities. In part, the drive behind this initiative was to address many of the social challenges that patients face, such as social isolation, anxiety and mental health problems — situations that often lead patients to consult general practitioners and healthcare professionals, even when there are alternative interventions that would serve their needs more effectively. This article outlines how the setting up and implementation of a PBT, and its success in meeting patient needs, is attributed to a number of key elements and the committed organisational leadership and involvement of all those involved.

## KEYWORDS:

- Place-based teams ■ Leadership ■ Challenges
- Person-centred care ■ Careful planning

Over the years, the approach to integrated multidisciplinary working has tended to dissipate across community nursing and general practice. This is due to changing demands, lack of resources (particularly social services) and a lack of knowledge or understanding of newly emerging services by community nurses and other healthcare professionals (Turnbull, 2021). Concerns about integrated and collaborative working across the health and social care systems, as a whole, was recognised by NHS England in 2019 and is the driver that led to the development of integrated care systems (ICSs). Subsequently, with the publication of

the NHS White Paper (2021), it was proposed that a Health and Care Bill will legislate for their establishment and that they will be mandatory as statutory bodies in 2022.

The principle underpinning the work of ICSs is collaboration and partnership between social care, the NHS and local government. The fundamental work of the ICSs is envisioned to occur at a local level and will be achieved through the development of place-based partnerships (PBPs) working with populations located over smaller geographies.

*Thus, the term 'Place' refers to the local geographic level below the wider ICSs, and it is here that most of the work to join up budgets, plan and deliver services for routine health and social care (particularly community-based services) will happen.*

(King's Fund, 2021: 2)

This seems to be an effective way to ensure that health and social care services are appropriately and effectively delivered.

Place-based partnerships or teams (PBTs), as they are generally known, are anticipated to offer an ideal forum for community nurses, who, from the authors' experience and as discussed at the Queen's Nursing Institute (QNI) conference in 2021, are often at a loss to know who they can turn to when they are concerned about a 'non-clinical' situation being experienced by their patients. To date, in the authors' opinion, there have been few 'joined up' forums in which to bring, discuss or explore strategies or services that might assist patients whose needs are often of a more social, psychological, environmental or financial nature. Such factors have all been demonstrated to lead to poorer health outcomes and health inequalities among some health and social care populations; problems which can be magnified further if impacted by unexpected events, such as a pandemic (Gray, 1982; Smith et al, 1990; NHS White Paper, 2021).

These concerns were discussed in depth at the QNI Conference 2021, 'Building Back Further', which confirmed that these inequalities not only exist, but are continuing to widen. The consequence of this, it can be argued, is that community nurses run the risk of focusing on 'getting through' tasks, rather than holistic 'person-centred' care, or alternatively, of over visiting patients to try to overcome the deficiencies they are encountering in practice. It is important to note that these are not situations which are severe enough to be categorised as a safeguarding issue and, for which, there are already well established mechanisms to refer to.

Inequalities, their associated consequences, and the impact they often have on health and wellbeing are not new and have long been recognised as a significant concern for healthcare professionals, particularly when caring for older people (Fennell et al, 1991; Bury and Holmes, 1992; Tunstall, 1996; Age Concern, 1974; 2018). Despite this recognition, it is clear that these issues continue to remain unresolved and have a significant impact on the demand for healthcare services (NHS White Paper, 2021). In response, the UK Government promised to recruit 1,000 social prescribing link workers and pledged £5 million for a new national academy for social prescribing (NHS England, 2019). The aim being to give 900,000 more patients access to social prescribing by 2021 (White Paper, 2019; Skivington et al, 2018; King's Fund, 2020; Royal College of Nursing [RCN], 2020). Other initiatives, such as the introduction of health and wellbeing centres, the appointment of care navigators, along with the work of many voluntary organisations are all charged with the responsibility to work to aid people in need. The creation of PBTs is designed to bring these agencies together to provide the ideal forum to promote integrated and inter-agency working.

### KEY DRIVERS FOR THE CREATION OF PLACE-BASED TEAMS (PBTs)

The drivers for creating local PBTs are extensive, with the importance of tailoring care to local need and linking in with local assets and organisations being a key component. One of the underlying remits of the PBT is to enable patients to remain at home or, to be located appropriately, before a crisis emerges that may lead to a possible hospital admission, an escalation of an existing problem, or a 'fall back' to GPs or specialist or community nursing services.

With community nursing resources pushed to the limit (QNI, 2017), avoiding unnecessary over-visiting or inappropriate service delivery has become critical and never more so in the context of the Covid-19 pandemic, where resources were further stretched with a need for

community nurses to re-direct their skills and/or re-skill to address local patient needs.

The ultimate goal of a PBT is to find better ways to meet the social, psychological, environmental and financial needs of patients, both to improve their quality of life and enhance their ability to manage their own self-care where able. If successful, this would enable community nurses to adapt and develop a wider range of skills and attributes, and to broaden the range of care and services they offer, which in turn would go a good way to enhance their sense of fulfilment and satisfaction (QNI, 2017).

### GETTING STARTED AND IMPLEMENTING A PBT

In the authors' case, the implementation of a PBT in Stratford-upon-Avon was phased over a year towards the end of 2019, and was one of the last across the trust to be initiated. The following steps were initiated:

- ▶ Step 1: the professional lead for the local district and community nursing team acted as lead and, in preparation, observed another PBT to gain insights into how it worked in practice
- ▶ Step 2: an engagement meeting was set up with a range of potential key players from different agencies and organisations (Table 1)
  - Step 2.1: the meeting outlined the key aims and objectives for the PBT
  - Step 2.2: the PBT membership was agreed, along with future dates of meetings, their frequency, times and venue
  - Step 2.3: it was also agreed that rather than GPs needing to attend, a mechanism for feeding back to GPs would be devised to inform them if any of their patients were referred to the PBT. They would also be approached and asked to assess or intervene if it was felt appropriate.

There were several key players or enablers involved in the authors' PBT, namely:

- ▶ A care navigator from their team

had been appointed earlier in the year, and became an integral part of its activity and success, and was instrumental in coordinating and progressing actions and keeping communication channels open, effective and tight

- ▶ An administrator also took a key role, organising and communicating meeting details, and typing and disseminating minutes to all participants in advance of meetings
- ▶ The enthusiasm, drive, determination and leadership of the professional lead proved to be pivotal, and without that the initiative of the PBT would, in the authors' opinion, almost certainly have failed
- ▶ The broader membership was extensive with a wide range of organisations and agencies being approached to join.

As the initiative progressed, and proved to be an effective way to liaise and communicate, more organisations and agencies have requested to join the PBT, demonstrating the engagement, enthusiasm and recognition of its value (see *Practice point* box). As Aneurin Bevan argued in 1946:

*... no legislation can ever give the public a greater health service unless the people who administer it want to do it and are enthusiastic in so doing.*

(Bevan 1946 cited in the NHS White Paper, 2021).

### Practice point

- ▶ Practice-based teams (PBTs) provide the perfect forum to bring agencies together to work collaboratively with a shared vision and purpose
- ▶ PBTs can help tailor care to individual and local need
- ▶ Effective leadership, enthusiasm and commitment by participants is pivotal to the success of a PBT
- ▶ Developing a PBT requires careful planning
- ▶ The time involved to resolve some issues cannot be underestimated.



A format and processes for the meetings had to be established. For example, participants are asked to introduce themselves, and it is important to make sure that there is a sound procedure in place to ensure patient confidentiality. To enable this, a statement is read out at the start of every meeting. Members also have to sign an agreement form. Subsequently, due to the introduction of Covid-19 pandemic protocols, they were required to agree via the chat forum online. New patients are introduced first and a discussion takes place as to how they might be helped in their particular situation or circumstances. Where possible, the practitioner who has referred the patient is invited to present (as it is much easier to understand and explore an individual's needs when they are known personally by their practitioner). An action plan is then drawn up where specific members of the PBT are charged with taking action. The care navigator often takes on a liaising role and visits the patient and their carers to ensure that they have understood what help and interventions can be offered, and importantly, ensure their consent is gained.

Where appropriate, GPs are informed of the plan and a record of this and ongoing progress recorded on EMIS and the paper referral form. The progress of active referrals is always reviewed, supported by discussion between the agencies and organisations regarding their

involvement and progress. These discussions also include suggestions from any participating PBT member not directly involved in an individual case. Once an intervention is completed, the patient is discharged. The length of time the patient remains active depends on the complexity of their case and the access to relevant resources, such as house clearances and cleaning, assistance with claiming benefits or grants, referral to befriending services or psychological therapies, funding etc, if that is needed, to achieve the desired outcome identified.

### INITIAL CHALLENGES FACED

Implementation is not without its challenges. Some GPs were resistant and felt that they already met the needs of their patients without any further intervention being needed. Another major concern was the issue of commitment and time for members to attend. In the event, this did not materialise as a problem. Attendance at each meeting has been good throughout, and members remain committed. The care navigator is a new role, which required working on a new venture, while fulfilling a role within the district/community nursing team. At the inception of the care navigator role, there were no contractual arrangements or job description, so expectations were unclear. However over time, these have evolved and now there is an allocation of a number of hours each week (in our case 19 hours) to follow

up actions from meetings and to communicate with patients, relevant practitioners and other agencies. As a result, the care navigator soon adapted to the role, taking it on with enthusiasm and commitment.

The PBT chair needed to possess insight and emotional intelligence to recognise when things were not quite right and adjustments needed. It is also essential for them to have a sound knowledge of local geographical and social issues, as these are fundamental to the outcomes that were to be achieved. As the meetings progressed, this requirement became more evident due to the complexity of need of many of the patients referred. There is also a requirement for the chair to have skills in assisting the team to adapt and regroup when key members leave and new members join. Perhaps one of the most significant challenges during the development of the group was the impact that an unexpected event could have on the team, in this case the Covid-19 pandemic, particularly at the point when the group is beginning to 'gel' and 'normalise', as described by Tuckman and Jensen (2010).

### OVERCOMING CHALLENGES

A number of strategies and skills were needed to overcome the challenges. The importance of resilience and persistence were central at all times. Good preparation is also vital and it became routine for the chair, care navigator and administrator to 'touch base' the day before the meeting, either in person or virtually. It became evident that it helped everyone if the impending referrals were reviewed before the meeting, so that any potential need for clarifications could be identified in advance. To achieve this, the deadline for submission of new referrals is mid-day the day before the meeting.

During the meetings the chair needed to acknowledge and demonstrate their awareness of the contribution made by all participants. This is crucial to ensuring no contributions are missed. Another key but simple action when meeting face to face is to provide tea, coffee and biscuits. As these are lunch time meetings, attendees really

The district nurses were very concerned about this lady, Brenda, as she wore the same flimsy clothes at each visit and appeared to have little food or comforts in the house. After discussion, permission was gained to refer her to the PBT. This led to the Citizens Advice Bureau (CAB) outreach worker reviewing her finances. It was discovered that she was on expensive tariffs for her utilities which revealed she had been paying extortionate amounts for water. Closer investigative work by her allocated CAB worker revealed a leaking water pipe and with support she was reimbursed a considerable amount of money from the supplier. Combined with a review of her benefit entitlement, her weekly income was increased from £158 a week to about £340. By working together, different agencies associated with the PBT were able to help ensure that she had food delivered, meals provided, and items of clothing, etc.

#### Patient story one

appreciate this, particularly if they may have missed a break earlier. Having refreshments available is also important in helping to 'break the ice' (while still virtual, this was provided by each individual as required).

With the arrival of Covid-19 in March 2020, the trust made a blanket decision for all meetings to be cancelled so that it could take stock of the situation and deal with the immediate challenges of the pandemic. This, as previously noted, was at a time when the PBT initiative was just taking off. Despite this, the team were not deterred and, although meetings were cancelled and the focus of work changed, the fact that participants had built and established good relationships meant that they were still able to work together to assist patients in a wide diversity of ways. The health and wellbeing manager quickly engaged a group of volunteers from the community who could help in a number of ways. One of these was to deliver food parcels, provided by the food retailer, Morrisons, to some of the most vulnerable and isolated patients, until other sources of food delivery could be established. Morrisons later went on to develop their 'Priority Food Delivery Service' for older and vulnerable people; with nurses implicit in sharing that information with patients. The Fire Service provided invaluable assistance to the PBT, as they took on the delivery of dressings to patients and continued with their fire safety checks throughout. Other agencies involved with the PBT continued their work virtually with contacts made by phone if direct referrals were needed.

By June 2020, the PBT was in a position to re-establish meetings through a virtual route, using Microsoft Teams. As a result of the strength of the early work and team building, all members were keen to be involved. The meetings were arranged to be fortnightly, as it was taking longer with the various limitations and demands on the PBT participants during the pandemic for actions to be fulfilled. This proved to be the best way forward. As the meetings have progressed, other organisations have wanted to join and be involved in achieving the aims of the PBT. This

The district nurses were visiting Veronica to treat her leg ulcers, which were making little progress. The house was cluttered and unkempt. It also had a very unpleasant odour as she had a beloved cat who used a litter tray, but which she was unable to empty properly. The GP was asked to review her general wellbeing.

## Patient story two

Veronica had full capacity, but seemed unable to recognise that there was a problem. However, following a visit from the nurse practitioner and team leader of the patient team, she was carefully helped to understand that she needed help and that her environment was unsuitable for herself and the nurses visiting. She agreed to a fire risk and safety assessment and house deep clean, which were managed while she and the cat were still in the house. A cleaner, with whom the team had established a good relationship, agreed to visit and clean regularly and to empty the two cat litter trays (Veronica agreed to a second one). The vet also reviewed the wellbeing of the cat as she was very elderly and thin. The cat now receives regular treatment. While still not ideal, the environment and situation for Veronica and her cat have greatly improved. She has help with shopping, preparing meals and regular domestic cleaning. Veronica also had an assessment for a local authority grant to construct a ramp to provide her with much needed access to her outdoor garden, which she had not been able to enjoy for many years. These relatively small changes significantly improved Veronica's quality of life, particularly as, at one point, it was considered that her beloved cat and only companion might have to be re-homed. This is no longer the case.

is a positive outcome as it ensures that many different needs can be addressed by the various members and their organisations/agencies. Another positive byproduct of meeting virtually is it becomes possible for members to attend without having to travel and park.

## ACHIEVEMENTS AND LIMITATIONS

While the work related to the PBT is time intensive, it is recognised by all involved that the initiative does achieve significant improvements and changes for a wide range of patients and/or their families (*patient stories one and two*). This can be attributed to the commitment of members to engage and adopt a 'can do attitude'. This has undoubtedly resulted in a positive experience for participants, which has in turn led to achieving sustainability and a sense of feeling valued for all those involved.

Importantly, patients have been helped to develop a stronger sense

of control over their situation and outcomes by realising that it can be changed and improved. This is assisted by their recognition that there are people who genuinely want to help and act as advocates for them when needed.

As already noted, the PBT initiative has not been without its challenges and one that has emerged over time has been resistance. District nurses are used to the challenges of gaining full concordance with treatment, so it has come as no surprise that, despite their best efforts and apparent progress being made, some patients find themselves unable to engage. Although experience dictated that this is to be expected, it is nevertheless disappointing (*patient story three*).

While some of the strategies undertaken by the PBT can be improved, the team are aware that some were compromised by the pandemic, particularly those that involved bringing lonely or isolated

District nurses attended weekly to support

David's partner with his diabetes management, as he was reluctant to take any ownership or responsibility for his own health. David and his partner agreed to be referred to the PBT, as they were both struggling with housework and the general upkeep of their home. A full review of David's benefits entitlement was carried out and he received an increase. With this additional income, David and his partner agreed to the PBT sourcing a reliable cleaner. While this was agreed in principle, David later rejected this support by refusing to pay for the cleaning services. This highlighted to the PBT that it is not always about a patient's available financial resources, but working in partnership and engaging them with healthier life choices that are sustainable and have long lasting benefits. Sadly, this can often not be achieved with finance alone.

### Patient story three

what could be put in place to achieve those outcomes.

From the outset, the PBT has been aware of the need to develop some form of simple, but meaningful feedback, for those it has supported. Initially, the PBT collected a number of audit tools that were known to members. However, on review, none appeared to be appropriate as they were either too subjective or complex. Also, they were not designed to capture the impact that this kind of initiative could have, especially as some outcomes could be described as a 'slow burn'. For example, some cases need time to access appropriate help, resource or funding from other agencies or individuals, but there was no scope to record such data with the available audit tools. Development of the team's own tool was delayed due to the pandemic, but it has now been devised. The PBT have submitted it to the trust to review through its quality assurance and approval scheme.

### PLANS FOR THE FUTURE

On the strength of the success achieved, the authors plan to continue to develop the PBT initiative, as it achieves outcomes that enhance quality of life for patients, carers and families. Using a robust audit tool to gather data will provide an opportunity to analyse the impact of the PBT, which it is hoped will provide the evidence required to justify its continuation. It is the authors' hope that, as a result, holistic care will become 'second nature'

patients or their relatives/carers together in supportive forums, or when trying to provide visits to patients. Members however, worked hard to achieve as many positive patient outcomes as possible virtually, by providing supportive calls to carers. The commitment to continue work 'as usual' by phone, was incredible from some of the agencies/organisations. It may have taken longer, but determination won out. The Citizens Advice Bureau (CAB) outreach worker and social prescriber would liaise by phone and, when needed, arrange to deliver and collect documentation that they had helped a client to fill in over the phone. Where a personal touch was necessary, the care navigator acted as a conduit to support patients or their carers/friends. Improving access to psychological therapy (IAPT) and a wellbeing advisor effectively provided emotional support and developed trusting relationships via the virtual route, even when some recipients struggled without face-to-face contact. As lockdown rules eased, some of the organisations/agencies were able to recommence in-person contact, which eased many of those challenges.

This strength of the cohesion among members certainly helped the PBT to adapt and adjust during the worst of the pandemic. It also led the PBT to review some of its working practices and procedures, a strategy that has continued as there is no doubt that it does facilitate

success and achieving the initiative's full potential.

Initially, a different nurse from the team was allocated, each week, to attend the meeting. With Covid restrictions and absences this dissipated and, as a result, many of the community nurses are not fully conversant with the purpose of the PBT and what it can achieve. This, in turn, means that they are not aware of its potential to help patients in their care. To militate against this, the community nurses are re-introducing the rota; capacity allowing. The community nurses in the PBT are continuing to encourage the member of staff who has made a referral to attend and present their case to outline what help and outcomes they are hoping may be achieved or, if uncertain, working out with them

**Table 1: Membership of Stratford-upon-Avon PBT**

Professional lead for district nursing and rapid response service, South Warwickshire Foundation Trust (SWFT) — (chair)
Care navigator — SWFT
Administrator — SWFT
Occupational therapist — SWFT
NHS social prescriber
IAPT-CBT therapist (improving access to psychological therapies and cognitive behaviour therapy)
Carer's Trust — wellbeing advisor
ORBIT tenancy coaches (local housing association)
Warwickshire Fire and Rescue Service
Citizens Advice Bureau (CAB), South Warwickshire outreach case worker
CAB — food bank
Dementia advisor, Alzheimer's Society
Health and Wellbeing Information Centre
Warwickshire Carer Wellbeing Service
Warwickshire County Council
District/community nurses (take it in turn to attend meetings and gain an understanding of the function of the PBT and/or to present a patient they have referred)



to the staff across the teams and they will be constantly alert to the opportunities and ways in which they can contribute to improving their patients' lives.

In support of that, the authors would like all members of the agencies/organisations within the community to recognise the role of the PBT, what can be achieved through it, and to see it as an integral and essential part of daily work, and, as such, a 'beacon' embedded in the community. They would also like agencies/organisations, not already involved, to feel able to refer patients to the PBT. It is also important, if possible, for the PBT to extend its reach and inclusivity by opening it up to forums, such as the Patient Advice and Liaison Service (PALS), who also act as advocates of patients. From a community nursing perspective, it is essential to demonstrate how the PBT fits in with the Nursing and Midwifery Council (NMC) themes and standards for the specialist community nurses' role. The aims and objectives have shifted over time, but the work that can be achieved through a PBT can be of significant value and 'tie in' with the principles of 'Making Every Contact Count' (MECC) (National Institute for Health and Care Excellence [NICE], 2016; Public Health England [PHE], 2016).

## ADVICE TO OTHERS PLANNING TO SET UP SUCH AN INITIATIVE

Careful and thorough planning is central to the development of a PBT, as this pre-empts some of the challenges that can occur. It is also paramount to ensure that there is a reliable administrator in place to achieve the smooth running of the PBT. Also fundamental is having a committed and enthusiastic care navigator, who is well supported in their role. There is no doubt that the adoption of a determined and 'can do attitude' is vital, as is the need to maintain a strong and sustained drive forward with commitment and enthusiasm.

Accepting the inevitability of staff moving on and other changes that occur over time, such as budgetary constraints and unexpected events,

are a constant in any initiative. It is therefore important to ensure sustainability and a coherent response to uncertainties. It is also crucial to recognise that rewards and outcomes that can be achieved should never be underestimated.

## CONCLUSION

This article has outlined what a PBT is and what can be achieved through it. The authors are passionate about facilitating a 'person-centred' approach and their experience of setting up and maintaining an effective PBT has demonstrated its value and the way in which the lives of some of those in our care can be changed and improved. As with all initiatives, there will be challenges and a need to be flexible and pragmatic. Fundamental to overcoming this is the commitment of all involved. An effective and passionate PBT chair, efficient administration and a committed co-ordinator (here, the care navigator), who are given the time and resources to fulfil their roles, are paramount. When those elements are in place and the 'chemistry is right', holistic care becomes integral and embedded in the culture and work of those involved. For patients, carers, families and staff, that is a 'win win' outcome.

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# Loneliness: what it teaches and what we can do

Here, Nicki Haywood, founder and director, The Honeycomb Foundation community interest company (CIC), shines a spotlight on loneliness and social isolation in the workplace and explains why acknowledging it, both as a common experience and health concern, is a way to start tackling it. Please note that personal information about bereavement is included that some readers might find difficult.

According to Campaign to End Loneliness, 45% of adults in England feel occasionally, sometimes or often lonely in England ([www.campaigntoendloneliness.org/facts-and-statistics/](http://www.campaigntoendloneliness.org/facts-and-statistics/)). This means that 25 million people feel lonely or socially isolated.

Chronic feelings of loneliness are a public health concern. Indeed, it is likened to similar health outcomes as smoking 15 cigarettes a day and obesity (Holt-Lunstad et al, 2010). It is also associated with increased risk of:

- ▶ Cardiovascular disease and stroke (Valtorta et al, 2016)
- ▶ High blood pressure (Hawkey et al, 2010)
- ▶ Depression in the elderly (Courtin and Knapp, 2017)
- ▶ Cognitive decline and dementia (Cacioppo et al, 2014).

A sense of connection to others is a basic human need. When we do not feel connected with others, we are likely to feel socially isolated and lonely.

Feelings of loneliness and social isolation can vary from person to person. We can feel lonely among a group of people and yet we can still feel connected when we are alone. This is perhaps the first lesson — that loneliness is not just about being alone. Loneliness is how we feel about ourselves regardless of whether we are in a crowd or on our own.

*To help those experiencing loneliness, the author is sharing her experiences through her community interest company, with workshops and providing peer to peer support. For further information, contact Nicki at: [nicki@thehoneycombfoundationcic.org](mailto:nicki@thehoneycombfoundationcic.org).*

**‘Workplaces are a type of community, providing opportunities to connect with others. However, not everyone will feel a sense of connection to others or feel that they are able to bring their whole selves to work.’**

The second lesson is the difference between loneliness and chronic feelings of loneliness. We all experience feelings of loneliness and social isolation at times; however, if we experience these feelings frequently, it is likely to impact on our overall health and wellbeing and sense of self.

The third lesson is that many of us find it difficult to speak up about experiences and how they make us feel. One of the reasons for not being able to share experiences of social isolation and loneliness is because of the fear of stigma associated with it and because it is still very much one of those taboo subjects (GOV.UK, 2019).

I can relate to the fear of stigma and taboo associated with social isolation and loneliness, because I have personally experienced it.

I have not always felt lonely, however when my parents died, I felt my feelings of loneliness and social isolation intensify. This life changing event impacted on every part of my life, including work life.

Workplaces can be an important source of support during the most difficult times, especially when we

feel at our most vulnerable, and when we feel lonely and isolated due to a significant life event. Sadly, not everyone experiences a supportive workplace.

Workplaces are a type of community, providing opportunities to connect with others. However, not everyone will feel a sense of connection to others or that they are able to bring their whole selves to work. To create conditions where people feel they belong, there are many things that employers can do. For example, placing people at the heart of their organisations by having people friendly policies — having such policies, may just help to increase feelings of support and connectedness.

Social isolation and loneliness come at a cost, a cost to the individual, to the workplace, as well as to health and social care (New Economics Foundation, 2017; Peytrignet et al, 2020). In the author’s opinion, feelings of social connectedness and workplace belonging is not only good for business and for communities and people we serve, but also positively impacts on physical and psychological wellbeing and the care provided to patients.

## CREATING SUPPORTIVE CULTURES

### Psychological safety

Working in psychologically safe environments provides those spaces where employees feel able to bring their whole selves to work — a space in which people feel valued and included and are able to share their vulnerabilities both inside and

outside of work, without fear of repercussions. Indeed, it is vital to know that you have team members with whom you can share concerns and feel supported. This means having safe and effective ways to speak up and have voices heard. Amy Edmondson, a psychologist who has researched and written extensively on psychological safety, mentions how this produces more productive and efficient workforces (West, 2021: chap 5).

### Compassionate leadership

Professor Michael West in his book, *Compassionate Leadership: Sustaining Wisdom, Humanity and Presence in Health and Social Care*, highlights the need for compassionate and inclusive leadership (West, 2021). Leaders model care and connection for all in the team. Conversations are much easier to have when you know you are going to be supported by your line manager. Thus, line managers should be genuinely interested in individual employees and find ways to provide practical help and support.

When managers are approachable and even share some of their own vulnerabilities, this provides a space where individuals can open up and share their experiences. However, responses need to be authentic and managers should create the right conditions and utilise listening with curiosity and show concern. In turn, this will likely provide more person-centred solutions — but, the concern needs to be genuine.

### Kindness in the workplace

Being surrounded by people who are kind is infectious and creates conditions in which people feel like they belong. Kindness in the workplace is not ‘pink’ and it is not



‘fluffy’. It is a power for care and connection. We can all be a role model for kind behaviours at every level within the organisation and can all be aware of our own behaviours and how they can make others feel.

These ‘kind’ leadership approaches — the practice of personal compassion to ourselves and others — and creating conditions for all to have a voice and be heard can, in the author’s opinion, lead to the workplace providing a sense of purpose and belonging for staff.

Everyone can play a role in responding to loneliness and social isolation by being the best partner, friend and work colleague possible. This provides a listening, caring and supportive space for others to feel connected and experience compassion. Ways to receive and hold that experience ourselves also need to be found. Loneliness and social isolation are faced by many. The good news is that good people and good conversations and compassionate support can help them through. **JCN**

*A special thanks goes to John Walsh for his support with writing this article.*

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### Practice point

Being lonely is a painful experience for those that live it, and they may find it difficult to speak up or feel embarrassment and/or shame, especially within the workplace. Loneliness does not mean that people are unlovable or socially inept.



# Helping Patients with Dressings or PICC lines to Shower and Bathe with Confidence

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Leg Circumference (5cm above ankle bone)	Model	PIP Code
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23 - 34cm (9-13")	MP25 Medium to Large	416-6484



Patient Height	Patient Weight	Model	PIP Code
5'5" (165 cm) and above	Up to 10 Stone (64kg)	MP76 Slim Leg	333-7581
	10 - 16 Stone (64 - 102kg)	MP80 Average Build	320-0045
	16 - 22 Stone (102 - 140kg)	MP180 Large Leg	320-0060
Under 5'5" (165cm)	Up to 10 Stone (64kg)	MP76S Slim Leg Short	333-7599
	10 - 16 Stone (64 - 102kg)	MP80S Short Leg	320-0052
	16 - 22 Stone (102 - 140kg)	MP180S Large Leg Short	320-0078



Limbo Model	Upper Arm Circumference	PIP Code
M45	22 - 25cm	N/A*
MP65	25 - 29cm	386-4303
MP75	30 - 39cm	386-4311
M85	39 - 54cm	N/A*

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# ICHTHOPASTE<sup>◇</sup> VISCOPASTE<sup>◇</sup> PB7 ZIPZOC<sup>◇</sup>

## Zinc Oxide Paste Bandages - Trusted Wound and Skin Care for Your Patients

When the skins' integrity has been lost due to ulceration, chronic oedema or dermatological conditions, our zinc paste bandages and medicated stocking provide a protective barrier, reduce inflammation<sup>1</sup>, and help to break the itch-scratch cycle<sup>2</sup>. The application of topical zinc oxide helps to correct a local zinc deficit, soothing red and irritated skin, supporting re-epithelialisation<sup>1</sup>.

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**ZIPZOC** (zinc impregnated medicated stocking) **Abbreviated prescribing information.** Refer to summary of product characteristics before prescribing.  
**Composition:** A sterile rayon stocking impregnated with an ointment containing 20% Zinc Oxide. Each stocking (80cm x 7cm) contains about 41.5g of ointment. **Therapeutic indications:** Aid to the treatment of chronic leg ulcers and other associated skin conditions. Where chronic venous insufficiency exists, the medicated stocking can be used as a primary contact layer under compression bandaging or hosiery. **Method of Administration:** Because ZIPZOC is preservative free, it must be changed no less frequently than weekly. For topical application, ZIPZOC should be applied to cover the lower leg from the base of the toes to below the knee. All folds should be smoothed out. To protect clothing, a suitable outer bandage should be worn. If chronic venous insufficiency exists, ZIPZOC may be used as a primary contact layer under compression therapy and may be left in situ for one week, before re-application.  
**Contra-indications:** Arterial leg ulcers. Known hypersensitivity to zinc oxide or the excipients in the ointment. **Special Warnings and Special Precautions:** None known. **Interactions:** None known. **Pregnancy and Lactation:** There is no evidence to suggest ZIPZOC should not be used during pregnancy. **Undesirable Effects:** The skin of leg ulcer patients is easily sensitised to some topical medications. ZIPZOC contains no preservatives thereby reducing the risk of skin reactions. Reported reactions include, rash, erythema, itching and maceration of the wound edge. If the outer bandage is inappropriate or the medicated stocking is not changed with sufficient frequency it can cause the stocking to dry out. **Excipients:** Liquid Paraffin Ph. Eur. White Soft Paraffin BP. **Incompatibilities:** None reported. **Shelf Life:** 3 years. **Storage:** At or below 30°C. Keep all medicines out of the reach of children. **Packaging:** Polyethylene aluminium foil laminated pouches, each pouch containing a single medicated stocking. The outer carton will contain either 4 or 10 pouches. **Legal Category:** P **Market authorization number:** PL44616/0002 **Date of first authorisation/renewal of the authorisation:** 01 October 2006 **Date of revision of text:** 26 October 2018 **Trade Mark of Evolan Pharma AB** **Date of preparation:** October 2018