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Contents

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t: +44(0) 1789 582000
e: mail@jcn.co.uk
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Is AI transforming how healthcare is delivered?

This issue's 'Community matters' piece discusses the subject of artificial intelligence (AI) and is a 'must read'. Technology is advancing at such a pace so we cannot ignore it and need to find ways to embrace the benefits it brings. This article demonstrates how AI is used in our everyday lives, and to be honest it was a surprise to me just how much we do use it! Examples are given of some uses within healthcare and nursing environments and possible future innovations explored. It is definitely thought provoking, and this feature is clear and explicit, helping us to understand how AI currently supports us and how it could do in the future.

Caring for patients with dementia is very much a part of community nursing and there is no doubt that the condition can negatively effect an individual's quality of life (QoL) on many levels — emotional, social and physical. The article on this subject (*pp. 58–61*) offers practical advice to help address concerns around QoL for patients with dementia and their caregivers, including the use of virtual care platforms, such as telemedicine, remote monitoring of health parameters, and even virtual support groups — again showing how AI is becoming integrated into all areas of healthcare practice.

There is also an insightful case report of a patient with the rare autoimmune disorder, cold agglutinin disease (CAD) (*pp. 24–28*), shedding light on the complexities of managing such a case in a community setting and the significant emotional impact this condition had on the nursing staff involved, due to the constant vigilance needed and unpredictable nature of the disease.

With the new school year imminent, I was interested to read about the work of ERIC, The Childrens Bowel and Bladder Charity (*pp. 16, 18*), given the fact that many children are now starting reception class not toilet trained (one in four according to a recent survey mentioned here). This is a very real issue, causing considerable distress both to the child and their families. Constipation in children is another common but overlooked problem for children, which will not go away by itself and can lead to discomfort, pain, and further complications if not addressed properly. ERIC has many useful resources both for families and healthcare professionals to help you support and improve the wellbeing of children and young people on your caseloads with bladder and bowel problems (see *pp. 62–66*).

Finally, don't forget to take some time off for yourself this summer. Whether it's a short break or a longer holiday, finding time to relax and recharge can make a huge difference.

Annette Bades, editor-in-chief, *JCN*

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Editorial board

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 dietitian with experience in primary and secondary care. While interested in the dietary management of disease in general, my overarching passion is the promotion of evidence-based nutrition among healthcare professionals. This is especially important given the lack of accurate dietary information on the internet and in the media, which patients are often exposed to. I'm grateful to be part of the JCN editorial board to promote and keep nutrition on the agenda.
Patrick Ward-Ongley

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

What does artificial intelligence mean for community nursing?

Whenever scientists try and imagine what the future will look like, they invariably get a little carried away. If past predictions were anything to go by, by this point in the 21st century we should all be whizzing about in driverless cars, feasting on laboratory grown meat and living to improbable ages, our life expectancy artificially extended by stem-cell implants.

But even the most optimistic of scientists get it right sometimes. Thirty years ago, how we laughed when they said we'd all soon be reliant on shiny pocket-sized screens that contained pretty much anything of value in our lives. Or that cash would become obsolete, with all our purchases made with the simple tap of a plastic card (if you think I'm exaggerating, when was the last time you visited a 'cashpoint'?).

Despite the widespread adoption of smartphones and digital banking, there is one innovation that has slowly begun to exert more influence over our daily lives but which few of us understand, let alone know how to use — artificial intelligence, or AI.

Once the subject of hysterical stories about computers taking over the world and armies of sentient robots stealing our jobs, AI has crept into many areas of our lives from the music we listen to, to the face ID that opens our phones, and the digital voice assistants we use around the house.

But while AI is heralded as the future, many of us still don't really understand how it works, let alone what effect it might have on healthcare or the work of community nurses.

Having worked closely with community nurses for a number of years around digital, I often hear views that the variability and nature of the work of community is much less 'digitisable'. As a group, I've found that the experience of technology has been more problematic than other areas in care. I think the growth of AI will change both this perception and offer more positive experiences too.

Whereas in the past clunky systems created manual work, and workarounds, usually taking time away from the human side of things, the current wave of technology offers us new and interesting ways to understand, to interact, and to automate that we're seeing in other areas of society. It will no doubt challenge our norms — such as whether recording an entire care interaction is worthwhile if it automatically transcribes and codifies on behalf of the nurse. Or whether key information raised by the patient flags a clinical risk that the nurse can deal with or escalate in real time.

As health systems like the NHS continue to face demand, workforce and funding challenges, I think this will be both inevitable and bring positives and negatives. As a clinical community, I would encourage you to find ways to get involved and guide these developments on behalf of your profession and the needs of your service users, so AI becomes a change that happens through you, and not to you.

Liam Cahill
Founder, Sector 3 Digital

WHAT IS ARTIFICIAL INTELLIGENCE?

The term AI was first coined in the late 1950s, and by the 1960s scientists were attempting to teach computers to essentially mimic human decision-making. Put simply, AI is the technology used to make a computer 'think' and 'react' in a human way, taking cues from its surroundings and 'deciding' how to react based on the information it has learnt ('What is AI? What does artificial intelligence do?' — www.bbc.co.uk).

Fast-forward to the 21st century, and AI is used in many areas that we take for granted or simply

Healthcare and therefore nursing is constantly changing and evolving. I have been thinking about use of AI and its impact specifically on community nursing and the first thing that occurred to me was the increasing use of the glucose monitoring systems like Libre or Dexcom, which many more of our patients are now using. Many patients who have previously needed daily visits from community nurses to monitor their blood glucose due to failing eyesight or reduced manual dexterity are now self-caring with administration of medication which they can manage independently although they cannot complete the monitoring. This simple device, although expensive, is more cost-effective over time and also reassuring for patients as they can monitor their blood glucose at their own pace. The resulting data can also be analysed giving healthcare professionals a rich source of accurate data to further improve health outcomes. In my practice, this has reduced the number of visits and promoted independence for some patients.

We have also recently supported some of our nurses who require reasonable adjustments in their documentation by encouraging them to dictate to text on their smart phone following a patient visit. The resulting text can then be emailed to themselves securely, edited and uploaded onto the patient's electronic record. This saves time and stress for nurses who before would spend a lot of time writing notes in the car or the patient's home and then transferring those notes onto the patient record later in the day. Again, a simple change which has literally saved hours of time using AI in our daily routines.

There are lots more areas where AI could assist community nursing and make our lives easier. Think of the hours we could save by having an app which maps our journeys each day logging our mileage and submitting the data automatically rather than entering postcode after postcode onto paper or electronic forms to claim mileage at the end of the month. The innovation of a nursing form of Siri or Alexa where you could ask any question and receive fact-checked evidence-based answers in a few seconds would also be beneficial for community nurses, especially newly qualified nurses or those new to the community. There are many ways that AI could enhance our care without replacing the essential part of our care, which can only be administered by a human.

Gail Goddard
Floating district nurse manager and senior lecturer; Queen's Nurse

don't have the time to consider. For example, smartphones use AI to learn about our preferences and dislikes, and recently you may have noticed your phone or laptop providing you with handy ready-made replies to emails or text messages ('Sounds great, I'll see you there!').

Online shopping sites use AI to track what products we might be likely to buy, and digital streaming companies use it to predict what films or music we want to watch or listen to. In travel, flight simulators use AI to train pilots, and farmers can use it to predict the weather.

AI has some slightly more sinister uses as well. Some supermarkets have begun using facial recognition tools powered by AI to extract biometric customer information from CCTV footage and compare it with profiles of known shoplifters ('A day in the life of AI' — www.theguardian.com).

In short, if you thought AI was something that you probably didn't have much to do with in your day-to-day life, think again (or ask Alexa to do it for you).

HOW IS AI USED IN HEALTHCARE?

One of the main benefits of AI is its ability to perform tasks usually considered to require human intelligence. In the realm of healthcare, this is most obvious in areas such as diagnostics, data interpretation and the design of algorithms that can sift through data to identify patterns in illnesses for example. There are two main types of AI:

- Generative AI, which is able to create new content such as pictures and music by 'learning' patterns
- Predictive AI, which is used to make estimations based on large amounts of data such as hospital records.

Therefore, much of the AI currently used in healthcare is predictive AI ('Artificial intelligence: 10 promising interventions for healthcare' — evidence.nihr.ac.uk).

Some specific uses of AI in healthcare include ('Artificial

intelligence'— transform.england.nhs.uk):

- Analysing X-rays such as mammograms — traditionally every mammogram was double-checked for breast cancer by radiologists, a time-consuming process that resulted in delays for women. AI analysis means that each mammogram only needs to be checked by one radiologist, with a second called in only if the AI analysis and the first radiologist 'disagree'
- Developing algorithms from patient data — AI can develop algorithms by 'scanning' or 'reading' thousands of images taken from patients' records. For example, of rashes or moles, to identify conditions such as skin cancer. To protect the privacy of individuals, the AI algorithm does not need to 'know' details such as names or ages, but can work from images alone
- Reading and interpreting brain scans — AI imaging technology can assist clinicians to identify conditions such as acute stroke and Alzheimer's from scans, as well as enabling doctors to instantly share the information between hospitals and speed-up treatment referrals.

AI IN NURSING

As well as being used in healthcare innovations generally, AI is also being used in nursing, and in some cases may benefit community nurses directly.

One example is the idea of 'virtual wards' where patients who might otherwise be in hospital are monitored and even treated remotely at home. In the case of patients with diabetes and hypertension, AI uses an app to turn their smartphone cameras into a diagnostic tool that scans and analyses a urine reagent strip (which is sent to the patient in the post), then tests the albumin and creatinine levels to identify early-stage kidney disease ('Healthy.io: smartphone albuminuria urine self-testing'— transform.england.nhs.uk).

Another AI technology that might have significant implications for community nurses is a predictive system that identifies which people do or do not need to attend A&E. Created by analysing thousands of ambulance and care records, this technology uses patient data such as their mobility, vital signs and presence of chest pain to inform clinicians whether the patient needs critical care (Artificial intelligence: 10 promising interventions for healthcare'— evidence.nihr.ac.uk).

Other AI-driven innovations that might change the practice of many community nurses in the future include documentation software that records and transcribes patient consultations (and filters out any background noise and small talk), then generates an electronic health record. The nurse simply has to approve the transcript and press 'Enter', thereby saving time and increasing patient throughput.

Similarly, community nurses' time management might be transformed by automated monitoring where AI algorithms check patient's vital signs remotely and alert nurses to any anomalies; or medicines management models that 'decide' which drugs will be most effective and assess possible adverse interactions ('What's the future of AI-assisted nursing?'— www.myamericannurse.com).

WHAT ARE THE DOWNSIDES?

Of course, not all of the implications of AI's use in healthcare are positive. For example, there are ethical dilemmas involved such as who or what is responsible if an AI-powered system makes a mistake or misdiagnosis?

Also, there are genuine concerns about job losses following the implementation of AI systems, with particular anxiety around AI's ability to accurately analyse images and scans, with roles such as radiography particularly vulnerable. However, some of these fears can be mitigated by the fact that if AI is used in the right way, it should complement rather than replace the work of humans and can actually free-up clinicians' time to focus on improving services ('What do technology and AI mean for the future of work in health care?'— www.health.org.uk).

It is also important to remember that healthcare and nursing, in particular, is a complicated process, which involves skills such as clinical judgement and critical thinking. Although AI may be useful for supporting nurses in areas such as diagnosis and data analysis, decisions about the actual care that people receive, as well as 'human factors' such as empathy and compassion will always remain the preserve of individual nurses ('Artificial intelligence'— transform.england.nhs.uk).

While none of us really know what the future will hold, one certainty is that AI is going to change healthcare and community nursing with it. Much like the impact of the internet and social media, AI will have benefits such as faster diagnosis, but also downsides such as a lack of 'human' qualities. Rather than replacing community nurses, if used in the right way AI should instead mean that we have more time to do what we do best — focus on the unique needs of our patients. They've yet to come up with an algorithm that can do that. **JCN**

RECOMMENDED READING

Devlin H, Cousins R, Amitrano A (2023) A day in the life of AI. *The Guardian*, 25 October. Available online: www.theguardian.com/technology/ng-interactive/2023/oct/25/a-day-in-the-life-of-ai

Gelinas L (2023) *What's the future of AI-assisted nursing?* American Nurse. Available online: www.myamericannurse.com/whats-the-future-of-ai-assisted-nursing/

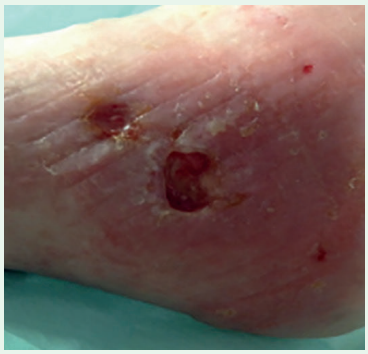
Health Foundation (2023) *What do technology and AI mean for the future of work in health care?* Available online: www.health.org.uk/publications/long-reads/what-do-technology-and-ai-mean-for-the-future-of-work-in-health-care

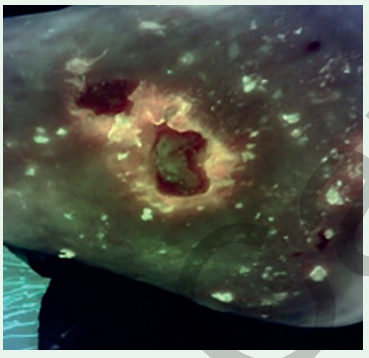
NHS England (2021) *Healthy.io: Smartphone albuminuria urine self-testing.* Available online: https://transform.england.nhs.uk/ai-lab/explore-all-

Within the fields of wound and leg ulcer management, the use of AI to assist in holistic clinical assessment and treatment planning is becoming increasingly important.

At system level, this approach is largely guided by the National Wound Care Strategy Programme (NWCSP) which, through its digital, data and information workstream, provides wound management recommendations in terms of using digital imaging to help standardise the practice of taking and using wound images. The recommendations also promote mechanisms for safeguarding and quality control, offer guidance on lower limb clinical metrics, as well as encouraging the use of digital wound images to support learning (www.nationalwoundcarestrategy.net/digital-data-information/). The recommendations should ensure that clinicians and service providers are able to select high quality and effective systems by using the Register of Wound Management Digital System Suppliers. This will contribute to better organisation of care and help to prevent wounds becoming longstanding or chronic, through collection and provision of data and markers.

But, what does this mean for nurses working in community services and patients who have wounds?





(Pictures shared with permission.)

AI can be used effectively to offer precise and consistent wound measurements including analysis of tissue types on or covering the dermal bed. The picture left shows how the use of a Moleculite camera shines a violet excitation light on a wound. This causes wound components (skin, slough, blood, bacteria, etc) to fluoresce (or emit light) in different colours. These photographs highlight the difference in what can be seen with the naked eye and what can be seen with the camera. Note the biofilm on the wound bed, but also high microbial burden in the surrounding areas of the periwound margins and limb.

LxWxD	2.1x2.0x0.1cm² (LxW=4.2)
Area	3.6cm²
Volume	0.2cm²
Colour	R:17% Y:58% B:25%

LxWxD	1.8x1.9x0.0cm² (LxW=3.42)
Area	2.8cm²
Volume	0.1cm²
Colour	R:45% Y:54% B:1%

(Pictures shared with permission.)

Or, when using the EKare system (https://ekare.ai), it is possible to monitor devitalised tissue in terms of percentage, which is helpful when using debridement. Previously, clinicians would have relied on visual analogue scales to estimate percentages of tissue that was healing and percentages of tissue that was devitalised. The photographs (above) highlight the difference and decrease in devitalised tissue and area of wound bed pre and post debridement.

Georgina Ritchie
Director of education, Accelerate CIC

resources/understand-ai/healthyio-smartphone-albuminuria-urine-self-testing/

NHS England (2023) *Artificial intelligence*. Available online: https://transform.england.nhs.uk/information-governance/guidance/artificial-intelligence/

National Institute for Health and Care Research (2023) *Artificial intelligence: 10 promising interventions for healthcare*. Available online: https://evidence.nihr.ac.uk/collection/artificial-intelligence-10-promising-interventions-for-healthcare/

What is AI? What does artificial intelligence do? Available online: www.bbc.co.uk/newsround/49274918

The importance of DNACPR conversations

Jenny Warren, director of clinical services, Compton Care (specialist palliative and bereavement support)

Having read the 'Community matters' piece in the last issue of the *Journal of Community Nursing* on talking about death and 'do not attempt cardiopulmonary resuscitation' (DNACPR) orders, a subject very close to my heart, I felt compelled to write this editorial to encourage community nurses to always keep this vital aspect of care in mind. Discussing death and DNACPR orders can be challenging. However, these conversations are not just about medical procedures; they are about understanding and respecting patients' wishes, values, and dignity. Engaging in these discussions ensures that patients receive the care they want at the end of their lives, aligning with their personal values and preferences.

As a young community nurse, I only saw a DNACPR form in the context of whether I would need to resuscitate the patient I was caring for or not. I assumed it was a one-stop shop, a very final, black and white decision made that would not change. Even the words 'DO NOT' do not exactly lend themselves to discussion. Add those taboos about talking about death and dying, confusion about responsibility around completion, worries that treatment will be withdrawn if it is in place, it is not surprising that DNACPR gets a bad press.

It is inevitable that at some point the heart will stop and for most of my patients we know it will be in the foreseeable future, and yet still people are referred to my place of work, a hospice, without anyone ever broaching the subject of resuscitation. Through the pandemic we heard of mass DNACPR completions for care home residents. The reality is that many of the care home residents probably would not have had good outcomes from a resuscitation attempt and struggled to tolerate active treatment for reversible causes, but the right to have a say in that was taken from them.

'Patients are often worried, they don't know what might happen to them if they become unwell and what their options might be, but you might be the first person to give them the opportunity to say how they feel and what they want... .'

Even when we consider the need for best interest decisions, surely involving those who are most important to that person is absolutely in their best interests? It is likely that with compassionate discussion with the patient and their family, a DNACPR may still have been the right thing for those patients.

The huge part missing was the conversation.

We have rolled out the 'ReSPECT' plan locally, which stands for recommended summary plan for emergency care and treatment. The principles of ResPECT are embedded in effective and purposeful communication. It is about the individual, it is about affirming appropriate care at the appropriate time. It is having a conversation and asking, 'in this specific situation what do you consider to be most important to you'. 'ReSPECT' even sounds more compassionate.

Community nurses have that privileged role of being with people in the place they call home, often it's the place they feel most safe. Community nurses also have those advanced communication skills to start the conversation. Many community patients have comorbidities, chronic and deteriorating conditions. If you visit a patient, ask yourself the surprise question, 'would I be surprised if this patient died in the next 12 months' and if your answer is 'yes' — that's the time for you to compassionately ask that person about the future.

Patients are often worried, they do not know what might happen to them if they become unwell and what their options might be, but you might be the first person to give them the opportunity to say how they feel and what they want, which is truly an individual approach to advance care planning (ACP).

Talking about death and DNACPR orders is never easy, but it is a critical component of our role as community nurses. Approaching these conversations with empathy, openness, and professionalism, can help to ensure that patients' end-of-life care respects their wishes and upholds their dignity. Let us embrace this responsibility and continue to advocate for patients' rights to make informed decisions about their care. JCN

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1. Agren M (1990) Studies on Zinc in Wound Healing. Linkoping University Medical Dissertations No. 320. Department of Pathology II, Faculty of Health Science. Linkoping, Sweden.

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

A new QNI membership scheme

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

'Membership provides all nurses and allied health professionals of the member organisations with access to a range of support for staff's professional and career development.'

Earlier this year, the Queen's Nursing Institute (QNI) announced the launch of a new membership scheme for organisations that provide community health services in England. This is the first time that the charity has operated such a scheme for organisations.

Membership provides all nurses and allied health professionals of the member organisations with access to a range of support for staff's professional and career development. The programme includes CPD webinars, career development sessions, and a political influencing programme for staff to gain a deeper understanding of how health services are affected by political decision-making at a national level.

The QNI worked with directors of nursing and chief nurses over the last 18 months to develop the scheme and the response from provider organisations has been extremely positive. The new membership scheme is currently open to 'standalone' providers of community services, i.e. those that only provide community services. Integrated provider organisations, such as those that also deliver hospital or mental health care, will be able to join as the scheme develops.

Steph Lawrence MBE, Queen's Nurse, QNI fellow and chief nurse of Leeds Community NHS Trust, has joined the QNI to oversee the scheme. Steph Lawrence commented, 'I am delighted to be working with the QNI on their membership offer and feel I can bring all my community experience to helping support this fantastic initiative.'

In fact, taking a longer view, the QNI did have the equivalent of a membership scheme in the early years of the NHS. District nursing services were mainly provided by independent district nursing associations in cities, towns and villages, and most of these were affiliated to the QNI. Thus, the national standards for district nurse education and training were agreed at national level and then cascaded to service providers. It was a two-way process, as senior nurses from the regions developed and updated the QNI policies to meet developing population healthcare needs.

The QNI has also re-established itself in recent years as a creator of national standards for nurse education and practice; over the last year we have published nine sets of field-specific standards for post-registration specialisms in community nursing. The new Standards have been built around the four pillars (domains) of advanced practice and are mapped to these domains, demonstrating the advanced level of practice for which registered nurses taking specialist practitioner qualifications (SPQs) are being prepared. Service users/experts by experience, representatives from higher education and other institutions, and expert nurses from all four UK countries were involved in the development of the Standards.

The nine fields are: adult social care nursing, community children's nursing, community mental health nursing, district nursing, general practice nursing, inclusion health nursing, health and justice nursing, community learning disability nursing, and community palliative and end-of-life care nursing. Recently, Northumbria University announced that it was developing new SPQ courses in some of these specialisms, mapped to the QNI's Standards, and a number of other universities are working on updating their community SPQs too.

To find out more about the QNI's Standards, go to: https://qni.org.uk/nursing-in-the-community/standards/

A summary of the membership offer for organisations can be found on the QNI website. Member organisations will be able to use a version of the QNI logo on their own websites and promotional materials. For more information, please visit the QNI website: https://qni.org.uk/organisational-membership/ . JCN

More information

To see if your organisation is a member, we are listing new members on our website and encourage any nurse to contact us to find out more about the increasing range of support that we offer for people at any stage of their career: https://qni.org.uk/organisational-membership/current-members/

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1. Velickovic VM, Prieto PA, Krga M, Jorge AM. Superabsorbent wound dressings versus foam dressings for the management of moderate-to-highly exuding venous leg ulcers in French settings: An early stage model-based economic evaluation. Journal of Tissue Viability. 2022;31(3):523–30. **2.** Velickovic VM, Lembelembe J P, Cegri F, Binic I, Abdelaziz AB, Sun S, *et al.* Superabsorbent wound dressing for management of patients with moderate-to-highly exuding chronic leg ulcers: An early stage model-based benefit-harm assessment.The International Journal of Lower Extremity Wounds. 2021.

Find out what's new in paediatric continence

Jackie Fuidge, conference manager, ERIC, The Children's Bowel and Bladder Charity

'Young children face lowered school attendance due to bowel and bladders issues, and difficulties socialising, such as on school trips or sleepovers.'

It is estimated that 1.5 million children and young people (Paediatric Continence Forum [PCF], 2024), that is one in 12, across the UK battle debilitating, misunderstood and sometimes complex bowel or bladder conditions, including bedwetting, daytime wetting, chronic constipation and soiling.

This is a far bigger issue than many might think. Stigma around continence issues means that they are not talked about as much as other health conditions, and some people even delay seeking professional help because of embarrassment, or because they simply do not know what is wrong.

The impact on children and young people, and their families, is huge — from a young age, right through to possible complications in adulthood.

LIFE-ALTERING CONDITIONS

The impact of wee and poo problems is a sad reality that many face. Three children in every primary school class are living with these life-altering conditions each day (Joinson et al, 2018). To add context, that is similar to the number of children and young people living with asthma (NHS England, 2024).

A general increase in later toilet training is being seen, which can cause long-term problems and worries for families of new school starters. In fact, a recent survey highlighted that one in four children starting reception class are not toilet trained, according to teachers (Kindred Squared, 2024).

Young children face lowered school attendance due to bowel and bladder issues, and difficulties socialising, such as on school trips or sleepovers.

Teens face these issues too — and more. ERIC's Young Champions survey, which saw responses from almost 900 young people, highlights issues with toilets in secondary schools and the problems this can cause (www.eric.org.uk). Continence conditions in young people can affect both their mental health and long-term physical health.

The impact on healthcare is significant too. Early diagnosis, intervention and treatment could help relieve stress on children, families and also the healthcare system.

ERIC'S CONFERENCE

Here at ERIC, we know how many children and families are seriously affected by continence conditions and we want to help them. One of our aims is to deliver the best education and learning for healthcare, social care, early years, and education professionals across the children's workforce — including through our professional conference.

ERIC's Paediatric Continence Care Conference is coming up in October

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2024, with the theme: 'Understanding the puzzle and solving it together'.

The face-to-face event is a valuable opportunity to network, exchange ideas and practice with other professionals from all around the UK and beyond. There will also be the chance to speak to many companies in the exhibition area, to find out about products and treatments to support families. We are very grateful to our main sponsor, Coloplast, for their support.

We bring the latest research to the forefront of practice; highlight the impact of bladder and bowel problems on children of all ages and needs; demonstrate the impact of new approaches and services; and provide opportunities for networking and sharing practice.

The programme includes an optional breakfast symposium followed by the morning plenary session packed with the latest research and thought-provoking new approaches, including:

- An innovative new bedwetting treatment service using cutting edge technology
- A talk about barriers to treatment adherence
- Latest research examining the relationships between mental health problems and incontinence.

The afternoon session will offer a range of interactive workshops with each delegate being able to choose two.

A full programme including all the talks and workshops and the expert speakers presenting them can be found on the ERIC website. Highlights include:

- The use of neuromodulation for the treatment of bladder and bowel dysfunction
- Treating constipation, including the importance of toileting routines
- Making pee and poo cool in school!
- Current best practice in nocturnal enuresis management.

ABOUT ERIC

ERIC is the only UK-wide charity dedicated to improving the lives of all children and young people (aged 0–19 years and up to 25 for children with additional needs) with bowel and bladder issues.

Our vision is that children and young people everywhere enjoy good bladder and bowel health. Our mission is to get everyone talking about good bladder and bowel health from birth and taking action.

ERIC provides information and support on continence conditions for parents/carers and professionals. The website is packed with resources like training for professionals, such as our upcoming healthy bladders and bowels or nocturnal enuresis webinars, and downloadable factsheets on common continence conditions to share with parents/carers. Our main factsheets are now available in languages other than English, so they can be shared with more families.

Updates are shared on ERIC's website and social media pages, including vacancies for volunteer helpline staff who work directly with families in need, and the recent campaign to help parents/carers get their children continence-ready for starting school. JCN

More information

ERIC Paediatric Continence Care Conference: 14th October 2024 at the Hilton Birmingham Metropole, 9.30am–4.30pm (optional breakfast symposium starts at 8.30am).

Find all conference details and book your place at: https://eric.org.uk/professionals/paediatric-continence-care-conference/

The cost to attend this year's conference will be £95 per person for payments made by card through our online system. Payment by invoice can also be accepted at a cost of £110 per person.

REFERENCES

Joinson C, Whale K, Randall J (2018) *Young people with continence problems need better support at secondary school*. Available online: www.bristol.ac.uk/policybristol/policy-briefings/young-people-continence-schools/

Kindred Squared (2024) *School Readiness Survey. February 2024*. Available online: https://kindredsquared.org.uk/wp-content/uploads/2024/02/Kindred-Squared-School-Readiness-Report-February-2024.pdf

NHS England (2024) *Childhood asthma*. Available online: www.england.nhs.uk/childhood-asthma/

Paediatric Continence Forum (2024) *Children's Continence Commissioning Guide. A handbook for setting up (commissioning) and running of children's community bladder and bowel services*. Available online: https://paediatriccontinenceforum.org/resources

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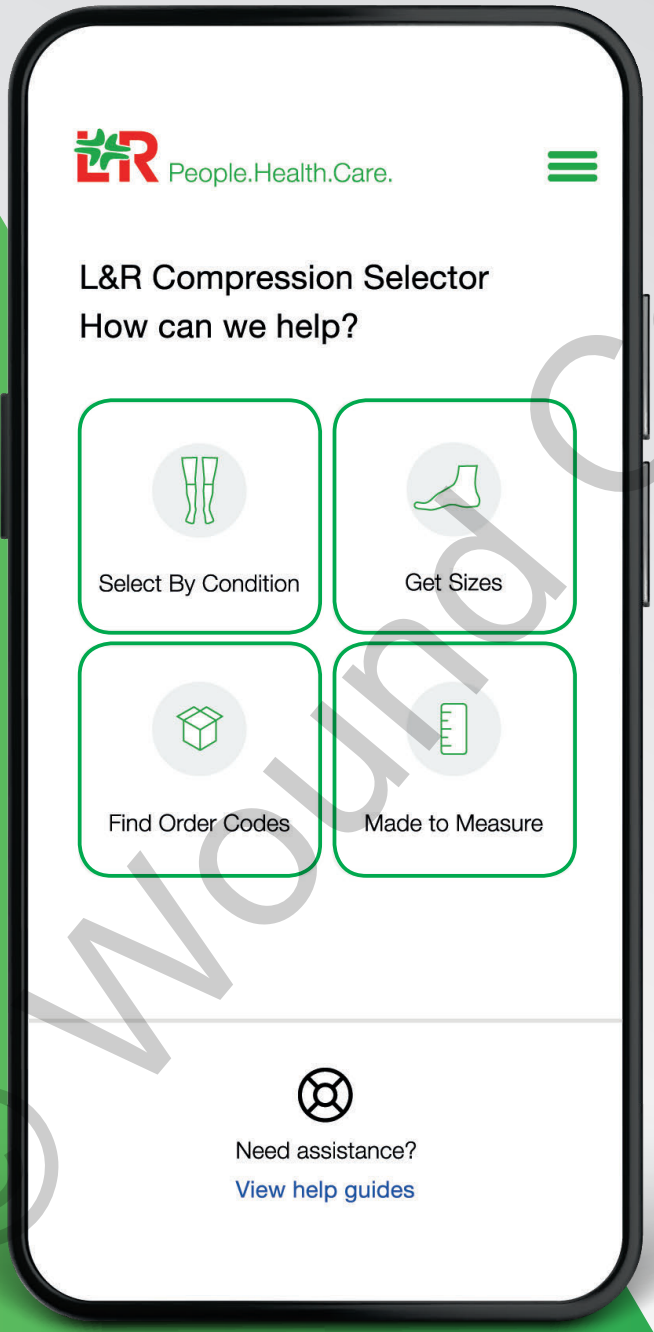

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New approach to cancer symptoms campaign

Andy Glyde, early diagnosis campaign strategy lead, Bowel Cancer UK

'... too few people are still being diagnosed at the earliest stages. In England, less than four in 10 bowel cancers are diagnosed at stages 1 or 2.'

The importance of early diagnosis in cancer is better understood today than it has ever been. Spotting cancer in its earliest stages offers better treatment options and improved survival (Cancer Research UK, 2024). This is particularly stark for bowel cancer, where more than nine in 10 people survive when diagnosed at stage 1, dropping dramatically to less than one in 10 at stage 4.

Yet, too few people are still being diagnosed at the earliest stages. In England, less than four in 10 bowel cancers are diagnosed at stages 1 or 2.

The reasons for this are complex, which means that there is no single solution. We need to work across the pathway, from ensuring primary care is supported to recognise and refer in a timely way, through to diagnostic services having the capacity they need to meet demand for cancer tests.

Another important aspect is the patient interval — the time period from first symptom to first GP appointment. International studies show this tends to be longer in the UK than comparable nations with better bowel cancer survival (Weller et al, 2018). In a nutshell, we need to get people to spot symptoms and take action when they have them.

However, it is not just about telling people about the symptoms of bowel cancer, in the hope they retain the information for that time when they realise they have been pooing more or less often, or have found some blood in their poo. Behaviour is more nuanced than this, and so the approach to encouraging timely presentation of symptoms needs to be too.

Last summer, Bowel Cancer UK launched its new five-year strategy, 'On a Mission'. Restating its vision for a world where nobody dies of bowel cancer, early diagnosis was placed at the heart of the work that needs to be done. We want to see a big change so that more than seven in 10 bowel cancers are diagnosed at stages 1 or 2 by 2028, in line with NHS England's targets (NHS England, 2019).

One way we think we can get there is by supporting timely presentation, which is where our new campaign — 'Tell Your GP Instead' — comes in. Targeting those people least likely to contact their GP even if they have symptoms, the campaign seeks to chip away at the deeply entrenched barriers to early diagnosis.

Over an 18-month period, Bowel Cancer UK developed the campaign based on behavioural science, as well as insights from people affected by bowel cancer, alongside target audiences. From there, we were able to identify the key barriers to address, namely:

- Embarrassment
- Fear of cancer
- Fatalism
- Worry about wasting GP time
- Awareness of symptoms.

Then we sought to better understand our target audiences. Based on attitudes, two key groups were found. These are 'stoics', who are fatalistic about their health and do not like to bother their GP, and 'healthcare sceptics', who are less trusting of healthcare professionals. Both are over 50, tend to be in lower socioeconomic groups, and live in urban areas. Healthcare sceptics are heavily skewed to ethnic minority communities.

Where this campaign differs most from other cancer campaigns is in its delivery. Traditionally, these campaigns run over a short burst, normally four to six weeks, with the advertising delivering a big peak in awareness, which usually translates into higher GP presentations during that period. But the effect is never sustained, meaning it needs to be repeated, which can be prohibitively expensive.

Instead, this campaign is working for a longer period, running in a two-week-on/two-week-off pattern. This will deliver a lower awareness peak but will allow for better targeting and a repeated message. This is better for the target audiences because it means we can erode those deeply entrenched attitudes getting in the way of timely presentation. An additional positive side-effect is that it will also relieve the impact on primary care by spreading out the demand over a longer time.

'Tell Your GP Instead' was launched in May. It shows conversations about bowel cancer symptoms happening in unusual places, including with a supermarket cashier, with a plumber, and a pet cat. The call to action is for people to tell their GP instead and ask for an at-home test (a faecal immunochemical test [FIT]).

Early campaign testing found that people liked the idea of FIT and felt it was an enabler to take action. But, they did not like the language, hence the need to explain it in a different way. In doing so, people are being provided with the words they can use to start a conversation with their GP about their symptoms.

The campaign is running nationwide in newspaper adverts, as well as in 18 communities across the UK through out-of-home ads (e.g. bus stops), local newspaper and radio ads. It is also running online, seeking to disrupt some of the self-diagnosis behaviours that exist.

Alongside this, Bowel Cancer UK has thought about how it can improve the way we talk about symptoms and help-seeking. The website has been updated with new language that is already catching people's attention at the right time.

We are looking forward to seeing what impact the campaign is having. In lieu of being able to access real time presentation and referral data, attitudes will be tracked to see if the dial is starting to shift for stoics and sceptics.

Tell Your GP Instead is still only one part of the solution. It is a key element of the wider early diagnosis programme at Bowel Cancer UK, which includes awareness roadshows touring the UK, and work with corporate partners, such as Andrex, where we are working together to tackle embarrassment around poo and going to the toilet.

More information

For more information about Tell Your GP Instead, visit: www.bowelcanceruk.org.uk/campaigning/tell-your-gp-instead/

'Bowel Cancer UK's Professionals Network brings together primary care health professionals to improve the treatment, care and support for people with bowel cancer in the UK.'

We know we need to support the healthcare professional community. That is why we are engaging and educating primary care professionals across the UK, with free online learning modules, best practice guidance and resources for healthcare professionals and patients.

Bowel Cancer UK's Professionals Network brings together primary care health professionals to improve the treatment, care and support for people with bowel cancer in the UK. You will receive updates about Bowel Cancer UK's latest education, support for patients, as well as news and updates in bowel cancer care. Join the network at: www.bowelcanceruk.org.uk/how-we-can-help/for-health-professionals/professionals-network/

We hugely value the work of nurses across the NHS, particularly those who support the diagnosis, treatment and care of people affected by bowel cancer. We know that we need to work together to achieve a world where nobody dies of bowel cancer. JCN

REFERENCES

Cancer Research UK (2024) *Early diagnosis data hub*. Available online: https://crukcancerintelligence.shinyapps.io/EarlyDiagnosis/

NHS England (2019) *NHS Long Term Plan*. Available online: www.longtermplan.nhs.uk/

Weller D, Menon U, Zalounina Falborg A, et al (2018) Diagnostic routes and time intervals for patients with colorectal cancer in 10 international jurisdictions; findings from a cross-sectional study from the International Cancer Benchmarking Partnership (ICBP). *BMJ Open* 8: e023870

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Cold agglutinin disease: a case report

Justine Hendley

This case report is to help raise awareness of a rare autoimmune disorder, cold agglutinin disease (CAD), which is characterised by the premature destruction of red blood cells (haemolysis) (National Organisation for Rare Disorders [NORD], (2020). It can have a severe physical and psychological impact on those suffering with it. Caring for patients with CAD can also be extremely challenging and even traumatic for clinicians. The importance of good multidisciplinary team (MDT) working both within hospital and when discharging a patient to a community healthcare setting is also highlighted (NORD, 2020), as well as the importance of clear communication for the patient from medical staff on the expectations of treatment and prognosis. Approximately one person in 300,000 gets CAD, which is more prevalent in those aged 60 years and older. Women are also more likely to get it than men (Smith, 2021).

KEYWORDS:
- Cold agglutinin disease
- Pain and trauma
- Tissue viability
- Community care

Cold agglutinin disease (CAD) is a rare autoimmune disorder in which the body's immune system mistakenly attacks and destroys its own red blood cells (RBCs) in response to cold temperatures. Symptoms of CAD can make you feel weak and tired. Patients can experience dizziness, headaches, sore back, legs or joints, ringing in the ears, irritability or changes in behaviour, pale or yellow skin, vomiting and/or diarrhoea, cold feet and hands, chest pain and irregular heartbeat (Smith, 2021). The disease is more prevalent in individuals over the age of 60 and is more commonly diagnosed in women than men.

Justine Hendley, sister, community wound healing team, Coventry and Warwickshire Partnership NHS Trust

'Patient x had 100% gangrenous necrotic hands, feet, knee, and an area of necrosis to the side of his face, and critical limb ischaemia.'

This article is a personal account of the author's experience of managing a patient with this condition and her shock at the devastating impact on the person's life and emotional affect on herself as a tissue viability nurse and other nursing staff involved in the patient's care.

CASE REPORT — OVERVIEW

Patient x, an 82-year-old male, had recently been discharged from hospital to a nursing home following a fall and long lie at home. He had 100% gangrenous necrotic hands, feet, knee, and an area of necrosis to the side of his face, and critical limb ischaemia (CLI). Critical limb ischaemia significantly increases the risk of major medical complications, including death. Within one year of developing CLI, almost one in three people have an amputation, and one in four die, most commonly from heart disease or a stroke (Cleveland Clinic, 2022). Treatment options for CLI include conservative management, revascularisation, or amputation. However, the links between treatment decisions and quality of life require further investigation (Monaro et al, 2017).

In this case, amputation was not advised by vascular surgeons and a conservative management approach was put in place. Patient x sadly passed away six months later in the nursing home, following his final discharge from hospital. Staff were left feeling not only severely saddened, but also relieved that this man was finally out of severe pain and no longer psychologically traumatised by the reality of staring hour after hour, day after day, at his fixed necrotic hands in front of his face, alongside staring down his body to his necrotic feet and ankles, unable to mentally process that these were still attached and part of his body.

Past medical history (PMH)/ initial presentation

Patient x initially presented to his GP in 2015 at the age of 75 with Raynaud's symptoms, which can mimic CAD (Sweeney and Reagan, 2023). He had been experiencing these symptoms since the age of 68. He described his symptoms at this point as: 'When exposed to the cold my fingers and toes become particularly painful and go dusky, sometimes purple/blue, at other times black. Following this, my skin will peel. Occasionally, my nose and ears are also affected. The pain and colour will ease when I'm warmer'. Symptoms of CAD can be triggered

or worsened by cold temperatures or viral infections (Cunha, 2023).

Otherwise, his GP noted that he was well in himself. His weight was steady and he had noticed no lumps and was not suffering from any sweats. He was not prone to infection, nor had he had any joint problems. Patient x had no past medical history of note at that time. He occasionally took ibuprofen for the pain in his fingers, but was not on any regular tablets or medicines. He had no known allergies, was a lifelong non-smoker and drank only moderately.

Patient x was a retired electronics engineer working in aviation, who carried on working up until the age of 69. He enjoyed working out but had been unable to attend the gym because there was no heating there. He lived alone. His GP referred him to a haematologist who started to investigate the possibility of either CAD or cryoproteins associated with a paraprotein.

Medical examination/ investigations/results

In 2015, when patient x was 75 years old, a haematologist completed a haemolysis, lymphoproliferative and myeloma screen. This was prompted due to the presenting Raynaud's symptoms at his GP appointment of purplish, cold feet, which had been set off by the cold and become very severe. The GP therefore referred patient x to the haematologist with his consent. Recommendations were also made at this time by the associate specialist in haematology to refer him to rheumatology, as it was felt by the associate specialist that they may have helpful advice about any underlying conditions and possible treatments.

He was followed up at a six–eight-week outpatient appointment. The haematologist noted that patient x was enjoying the warmer weather and had less in the way of pain and duskiness in his digits. Unfortunately, his full blood count (FBC) sample had clotted at his last visit. However, they were able to determine that he was direct Coombs test (DCT) positive. Renal and bone function were normal, but he did have a raised bilirubin at 51, possibly going along with haemolysis. There was no cryoglobulin or cryoprecipitate, but he did have a small IgM paraprotein of 6.4g/L. His bloods were repeated and arrangements made for a computed tomography (CT) scan of his chest/abdomen/pelvis to look for any underlying lymphoproliferative disorder. It was considered by the consultant haematologist that he may need a bone marrow biopsy, but patient x was not keen on this at that time.

He was followed up again two months later by the consultant haematologist. His blood counts were better with haemoglobin 144. Patient x cancelled the CT scan appointment, as he was worried about the radiation dose and was still concerned about having a bone marrow biopsy. As he was completely asymptomatic at that point (July, 2015), further discussions were postponed until September 2015. Patient x was advised to get his bloods checked (immunoglobulins and FBC) a week before this next follow-up. They would then again discuss a bone marrow biopsy. Information sheets were given to the patient (but his notes did not state what these were).

It was noted that patient x had not yet been seen by a rheumatologist, so the haematologist again recommended this referral to the GP.

Initial hospital admission in 2021

It was not until August 2021, when patient x was 81 years of age, that he was admitted to hospital with shortness of breath, feeling generally weak, weight loss and reduced appetite. His haemoglobin (HB) was 42 and he received a blood transfusion. A CT TAP (thorax, abdomen and pelvic) was performed, but showed no malignancy. An endoscopy was also carried out showing no bleeding. He received one dose of rituximab while in hospital, due to suspected CAD, and plans were made to receive further doses in the haematology day unit. Rituximab is currently used for the treatment of non-Hodgkin lymphoma and refractory rheumatoid arthritis (RA), and has been shown to induce remission in >50% of CAD patients (Malesci and La Montagna, 2008).

Patient x again refused to have a bone marrow biopsy. He was considered fit for discharge and returned to his own home. Upon discharge, he declined to have any further doses of rituximab and voiced that he did not wish to attend any more haematology clinic appointments. The only rationale he gave for this was that the dose of rituximab he received while in hospital had made him feel 'very unwell'. He did, however, consent to receiving a telephone call instead from his consultant haematologist. Contact numbers were given to him for the 24-hour haematology ward should he require it, but he never contacted them.

At his next telephone consultation with the haematologist he voiced that he had 'felt rough and could not stand the journey to the clinic or day unit', but he also did not want any more rituximab as he felt that it made him ill and he was unsure as to its purpose. The haematologist tried to reiterate that they were giving him this treatment to try to stop red cell breakdown and that, without it, there was a risk of admission to hospital with severe anaemia in the coming weeks. Patient x decided he was going to try and build his strength naturally and told the haematologist that he was eating better than he did when in hospital. He did not want to come to the hospital for a blood test, but accepted a telephone call with the haematologist in three weeks' time. Unfortunately, patient x did not answer the calls from his haematologist for virtual reviews at this time or at a re-attempt in March 2022. A letter was also sent to his address to advise him to make contact.

Final hospital admission in 2023

Patient x was admitted one final time to hospital in January 2023 at the age of 82 years, following a fall and long lie in his own home. He initially presented with new onset confusion, feeling disorientated and with a reduced appetite. He looked cachexic,

also called wasting syndrome or anorexia cachexia syndrome — a complex problem which is more than just a loss of appetite (Cancer Research UK, 2023). His catheter was draining very dark urine, alongside his noted necrotic limbs. It was noted by the medical/nursing staff within the accident and emergency department that the skin on both his hands and feet looked cold and dusky, described as having ischaemic limbs. The tissue viability nurse (TVN) at the hospital gave advice to all nursing staff for any areas of necrotic tissue to be kept dry and dressed in either an iodine containing surgical dressing or a non-adherent wound contact layer.

As his limbs, hands, knee, feet, and face were ischaemic, the following tests were undertaken:

- CT scan of his head showed hyperattenuating and enhancing space-occupying lesions seen adjacent to the posterior aspect of the left lateral ventricle with surrounding vasogenic oedema
- CT TAP showed no obvious signs of neoplasm, benign looking liver cysts, and multiple gallstones
- Magnetic resonance imaging (MRI) scan of his head showed patchy enhancing lesion, differentials included lymphoma and primary glial tumour in this order.

He had a markedly distended urinary bladder with a long-term indwelling catheter *in situ*. Advice was given in the discharge letter from the senior house officer (SHO) at the hospital for a fast track discharge to another hospital in the short term while patient x was waiting for a nursing home bed, to check whether the catheter had been clamped. It was noted that he had an enlarged prostate.

He was then discharged from this hospital to a long-term bed in a local nursing home (see below 'Community care').

Treatment plan in hospital

Patient x was readmitted to hospital in May 2023 from the nursing home due to confusion and shivering. He was diagnosed with *Escherichia coli* bacteriemia and urosepsis (catheter-associated urinary tract infection [CAUTI]). Hospital records noted a background of CAD and ischaemic limbs with necrotic tissue to both hands and feet. Patient x spiked a temperature and was started on intravenous (IV) meropenem and clindamycin with IV fluids and received a blood transfusion. He was then transferred to a haematology ward where he had a three-unit blood transfusion. He was seen by physiotherapy while on the ward and hand splints were given, which he was advised to wear, with nursing staff carrying out two hourly skin checks. However, he declined to wear the hand splints. He was then reviewed by both plastic and vascular teams and a conservative management plan was agreed upon to move forward to discharge to a nursing home.

'The decision was taken to opt for a conservative management plan, as this was considered more suitable for the patient's overall health and wellbeing.'

Patient x's case was discussed with the neurosurgery department/ward regarding the enhancing lesion seen on CT/MRI of his head, but it was decided that the patient was not fit for biopsy. The decision was taken to opt for a conservative management plan, as this was considered more suitable for the patient's overall health and wellbeing.

The haematology consultant explained to the patient that he was not fit for biopsy of the brain lesion and that he would not regain function in his hands or feet to live independently, and recommendations were given for full-time nursing care. He was reviewed by a tissue viability nurse in the hospital and advice was given to nursing staff via the discharge letter back to the nursing home to keep all areas of necrosis dry to reduce the risk of infection/sepsis. If any areas began to exude, inadine or silver dressings were recommended to dry up the wounds. He was then discharged to a local nursing home for palliative care.

Community care

Patient x was admitted to the local nursing home in February 2023. The necrotic tissue to his hands, feet, knee, and right cheek were 100% dry necrosis at this point, encompassing the full surface area of both his hands, fingers, feet, and toes. Nurses within the home had been dressing the areas with a primary wound contact layer, sterile dressing pads and securing with a lite bandage. They contacted the patient's GP in March 2023 due to an area on the left wrist becoming moist with purulent exudate. The GP prescribed a course of antibiotics and an end-of-life pathway was implemented by nursing and care staff. It was at this point in March 2023 that the nursing home referred to the community tissue viability team for wound care advice.

The author and a fellow tissue viability nurse arrived at the nursing home the same day that the urgent referral asking for wound care advice was received. This was five weeks after the patient had been admitted to the nursing home.

Patient x was bedbound and the whole surface area of both hands was 100% necrotic tissue in a fixed position. He was now fully dependent on the nurses and care staff to meet his activities of daily living, including being fed due to the inability to use his hands. He was no longer able to walk or weight bear because of the necrotic tissue encompassing the whole surface area of his feet to his malleolus. It was not long ago that he had been leading a fully independent life.

The author carried out a wound assessment and wrote a tissue viability report for the nursing home. Again, as per the tissue viability nurse in the hospital, it was advised that all wounds be kept dry. The wound care plan in the community recommended inadine as the primary dressing and sterile absorbent pads for his hands. Initially, these were secured with a

light stockinette and soft, absorbent retention bandages around the wrist (his left wrist had started to become moist and sloughy) to create a light glove-like structure. The hope was that this would not only dry up the moist area to the wrist, but also reduce the psychological trauma of having his necrotic hands so visible to him.

However, patient x was unable to tolerate the bandages in this way, due to pain. Therefore, his hands were left exposed and only the moist, sloughy left wrist area was covered and lightly bandaged with a loose stockinette to secure the dressing.

The necrotic areas to the right side of his cheek, knee and both ankles and the whole of his feet remained dry and 100% necrotic tissue. Thus, no dressings were recommended and staff were to continue to monitor his skin integrity throughout the day.

The psychological trauma on patient x was very apparent at the initial community assessment. While chatting with the author, he asked: 'when can I get these gloves and boots off?' The nursing home nurse looked at a loss as to what to say, and so the author sat with him and explained that he was not wearing gloves or boots, but these were his hands and feet and the result of his fall and condition. He sat up in bed, silenced for some time and simply said, 'ok'.

Psychology referral was offered for support, however he declined. The author then referred him to the local palliative care support team. Although he was in a nursing home, due to the rarity of his condition and its management, it was felt that this was essential for his quality of life as he was then on an end-of-life care pathway.

He was nursed by care home staff on a full replacement airwave mattress with cot sides with soft bumpers in place. Soft pillows were also in place at the end of his bed to reduce the risk of his feet encountering the foot of the bed. He was only on paracetamol 1g QDS (four times daily) and 5–10mg liquid morphine PRN (as required) at this point for pain control. His pain score was 4/10 both throughout the day and night (where 0=no pain and 10= worst pain possible).

'Improved MDT working and an MDT meeting between all involved in his care, both in the hospital and those that would be taking over care in the community, would have enabled a smoother discharge to community services.'

There was also some confusion and lack of clarity between the patient and nursing home staff around the option of limb amputation — patient x talked about this as being a possibility for him several times. However, the tissue viability team clarified that this was not the case as a conservative management pathway had been advised by consultants at the hospital. Management of necrosis secondary to CAD is usually conservative — to keep warm and avoid exposure to the cold, including cold foods and drinks (Nakagawa et al, 2022).

A joint visit was carried out by the tissue viability and palliative care nurses in April 2023. Wound care plans were unchanged. The area of necrosis to the right side of his face had fallen off naturally and no wound was present underneath. His feet and hands remained 100% necrotic tissue and dry, with a moist sloughy area still present to his left wrist. Conversations around psychological support were revisited. However, patient x stated that he was 'not ready to talk about it'.

During the final three months of his life, the community tissue viability team continued to both review patient x in person as well as keep a virtual oversight of him through regular conversations with the nursing home staff and manager. Fears were regularly raised by the nursing home staff around what action they should take if either the limb (hand) fell off and/or the tissue was to deglove. This was a very real risk, considering after his final discharge from hospital he experienced some confusion, which was thought to be possibly due to a urinary tract infection (UTI). The care home had been given a large sharps bin from the hospital and been advised by the hospital infection control team that if this was to occur, to seal the limb in the sharps bin and send to the hospital, due to it potentially being a body part for disposal. The community tissue viability team also advised the nursing home staff to ensure that they had dark-coloured towels, either red or black to hand, in case of a catastrophic bleed occurring. This never happened.

In the final four days of patient x's life, the palliative team started a syringe driver of 5mg morphine sulphate and 5mg midazolam, alongside stat doses of morphine administered when needed and a titrating increasing dose if required. The tissue viability nurses also spent time with staff reassuring them of wound care plans and recommended to the nursing home manager that the staff were likely to need psychology support, reflection time as a team following the care and death of patient x, due to the rare and traumatic nature of CAD.

RECOMMENDATIONS FOR CHANGES IN PRACTICE

Following review of patient x's journey from his initial diagnosis of CAD and his fall, from the initial GP appointment to hospital consultations, and then on to community nursing services, the author noted the following learning, which informed recommendations for improving practice and care for patients with CAD.

Patient x was never seen by a rheumatologist and it was unclear whether a referral was completed. It would have been beneficial to have their medical opinion and knowledge regarding his condition and possible treatment options.

There was no MDT meeting arranged. Improved MDT working

and an MDT meeting between all involved in his care, both in the hospital and those that would be taking over care in the community, would have enabled a smoother discharge to community services. This was much needed being a rare condition and situation. As a result, the nursing home staff had a lack of knowledge as to the risks of a catastrophic bleed and actions to take should this occur. As said above, there was also noted confusion for both the patient and nursing home staff on the care plan or option of amputation. If a MDT meeting had taken place, this lack of clarity could have been avoided and CAD better understood by all. This would have helped to reduce nursing home staff anxieties on actions to take should his limbs deglove, as well as the holistic approaches to care, such as staying away from cold foods and drinks (Smith, 2021) and keeping him warm with plenty of blankets.

No psychology services appear to have been considered while in hospital. There was a lack of documentation of any conversations taking place between hospital medical staff and the patient about the plan for conservative management. A psychology assessment in hospital, if patient x had consented, could have helped him with the clear disassociation he experienced with his necrotic limbs.

A clear/direct referral pathway was required from hospital to the community tissue viability nurses, as this referral was received via the nursing home. This resulted in an urgent, unplanned visit from the community tissue viability team. A direct referral from the hospital to the community tissue viability nurses would have enabled a planned community assessment to be allocated and carried out, as well as more time to gain knowledge of CAD before the initial tissue viability nurse assessment. It would also have improved clarity on the conservative management pathway, alongside holistic approaches to care

There is no established standard of care for CAD treatment and CAD cohort studies are limited by the rarity of the condition (Mullins et al, 2017).

CONCLUSION

The recommendations for change in practice highlight the importance of maintaining high standards of care, particularly regarding communication within MDT practices for patients with CAD. Effective communication is crucial to support the physical, emotional, and psychological health and wellbeing of these patients.

Furthermore, it is essential to ensure that both the patient and all involved in their care have a thorough understanding of holistic approaches to managing this rare disease and the potential risks associated with falls. Such comprehensive knowledge helps to anticipate and mitigate risks, promoting a more patient-centred approach to care. JCN

KEY POINTS

- Cold agglutinin disease (CAD) is a rare autoimmune disorder in which the body's immune system mistakenly attacks and destroys its own red blood cells (RBCs) in response to cold temperatures.
- It can have a severe physical and psychological impact on those suffering with it. Caring for patients with CAD can also be extremely challenging and even traumatic for clinicians.
- Approximately one person in 300,000 gets CAD, which is more prevalent in those aged 60 years and older.
- Symptoms of CAD can make you feel weak and tired.
- There is no established standard of care for CAD treatment and CAD cohort studies are limited by the rarity of the condition.
- Effective communication is crucial to support the physical, emotional, and psychological health and wellbeing of these patients.
- Good multidisciplinary team (MDT) working both within hospital and when discharging a patient to a community healthcare setting is vital, as well as the importance of clear communication for the patient with CAD from medical staff on the expectations of treatment and prognosis.

REFERENCES

Cancer Research UK (2023) *Cachexia (wasting syndrome)*. Available online: www.cancerresearchuk.org/about-cancer/coping/physically/diet-problems/types/cachexia

Cleveland Clinic (2021) *Critical limb ischemia: causes, symptoms and treatment*. Available online: https://my.clevelandclinic.org/health/diseases/23120-critical-limb-ischemia

Cunha JP (2023) *Cold agglutinin disease*. MedicineNet. Available online: www.medicinenet.com/cold_agglutinin_disease/article.htm

Malesci D, La Mongagna G (2008) Occurrence of cold agglutinin disease in RA patient during etanercept therapy successfully treated with rituximab. *Rheumatology* 47(5): 734–5

Monaro S, West S, Gullick J (2017) An integrative review of health-related quality of life in patients with critical limb ischaemia. *J Clin Nurs* 26(19–20): 2826–44

Mullins M, Jiang X, Bylsma LC, Fryzek JP, Reichert H, Chen EC, et al (2017) Cold agglutinin disease burden: a longitudinal analysis of anemia, medications, transfusions, and health care utilization. *Blood Adv* 1(13): 839–48

Nakagawa H, Kato C, MiyataY (2022) Necrosis secondary to cold agglutinin disease. *CMAJ* 194(14):

National Organisation for Rare Disorders (2020) *Cold Agglutinin Disease*. Available online: https://rarediseases.org/rare-diseases/cold-agglutinin-disease/

Smith M (2021) *What is cold Agglutinin disease?* WebMD. Available online: https://www.webmd.com/women/what-is-cold-agglutinin-disease#1

Sweeney J, Reagan J (2023) *Cold agglutinin disease*. Cancer Therapy Advisor. Available online: www.cancertherapyadvisor.com/home/decision-support-in-medicine/hematology/cold-agglutinin-disease/

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ARION SLIDE SOLUTIONS

Suprasorb® Liquacel Pro and Suprasorb® Liquacel Ag: preparing wounds to heal

Andrew Kerr

Patients with chronic wounds present a growing challenge to community practitioners. Adding to this growing burden is the fact that inconsistent and sub-optimal wound care is delivered in some cases resulting in hard-to-heal wounds that could heal with evidence-based care. Holistic patient assessment is an important first step in establishing the cause of the wound and identifying any barriers to healing. Wound bed preparation is a concept which prepares the wound for closure by systematically identifying potential barriers to non-healing within the wound, including the presence of devitalised tissue, excess exudate, increased wound bioburden, infection, inflammation and biofilm. Dressings are a key part of wound bed preparation in the community setting, and it is important that community practitioners are mindful of the properties and mode of action of products they use, so that optimal outcomes can be achieved. Suprasorb® Liquacel Pro is a hydroactive gelling fibre dressing and Suprasorb® Liquacel Ag is a hydroactive dressing with silver nanoparticles that can be used as part of wound bed preparation to promote a moist wound healing environment.

KEYWORDS:
■ Chronic wounds ■ Wound bed preparation ■ Moist wound healing ■ Suprasorb® Liquacel Pro and Suprasorb® Liquacel Ag

The financial burden that chronic wounds place on the NHS has been widely publicised (Guest et al, 2015; 2020). In the year 2017/18, wound management cost the NHS approximately £8.3 billion (Guest et al, 2020). The majority of this sum was spent on district and community nursing visits (Guest et al, 2020). Of the total cost, £5.6 billion was spent on wounds that remained unhealed over the year of the study, versus a cost of £2.7 billion spent on wounds that healed (Guest et al, 2020). Individually, the average cost of an unhealed wound was £3700 — 2.5 times the cost of managing a healed wound (£1500) (Guest et al, 2020).

Andrew Kerr, director, Lower Limb Consultancy Services Ltd; honorary tissue viability clinical nurse specialist, Sandwell and West Birmingham Hospitals NHS Trust

This annual resource use and cost of management is incurred until wound closure is achieved (Guest et al, 2020). Unfortunately, in some cases, chronic wounds can be present for months or years when, in fact, most chronic wounds can be healed promptly with appropriate treatment (Holloway, 2021).

While it is recognised that several factors contribute to the increasing number of people with chronic wounds, such as complex comorbidities and advancing age, in combination with community staff shortages and operational procedures hindering community services (Wounds UK, 2022), it is clear that NHS resources can be saved by healing wounds in a timely fashion, where possible (Atkin et al, 2019).

Guest et al (2015; 2020) highlighted that hard-to-heal wounds may in part be a consequence of inadequate care delivery among community practitioners; a conclusion drawn from a lack of differential diagnosis and incomplete note keeping, making it difficult to see how appropriate patient care and wound management could be delivered (Guest et al, 2015; 2020). When records were present, it appeared that dressing and bandage types were switched at successive dressing changes, indicating confusion with the wound management plan among clinicians delivering care (Guest et al, 2020).

Unfortunately, the delivery of sub-optimal care that is not evidence-based can result in increased morbidity and decreased quality of life for people with wounds (Atkin et al, 2019). This can increase the risk of complications such as infection, which in some patients, such as those with diabetes-related foot ulcers, can be limb-threatening (International Wound Infection Institute [IWII], 2022).

WOUND HEALING

To achieve healing, it is important firstly to identify the underlying cause of the wound and any factors that may impede the healing process; these can be patient-, environment-, and wound-related (Wounds UK, 2018). This can be achieved by carrying out a holistic patient assessment that identifies any underlying pathophysiological cause of the wound, as well as any risk factors for non-healing, including physical, spiritual and social barriers (Atkin et al, 2019; Loi and Minhas, 2021). Local wound factors should

also be considered and barriers to healing addressed using evidenced-based wound care solutions. Taking a systematic approach to wound assessment and implementing effective management can be facilitated by wound bed preparation (Atkin et al, 2019).

WOUND BED PREPARATION AND MOIST WOUND HEALING

Wound bed preparation is a concept that enables clinicians to systematically identify and address where possible any local wound factors that may be resulting in non-healing (Atkin et al, 2019). Several acronyms exist to guide wound bed preparation, the most well known being TIME:

- T Tissue management
- I Infection/inflammation
- M Moisture balance
- E Wound edge and epidermal advancement (Atkin et al, 2019).

Using the acronym helps clinicians to check all aspects of the local wound environment that may be delaying healing and which need addressing for optimal outcomes (Atkin et al, 2019; Dowsett 2023).

An update of TIME to TIMERS has been proposed. This includes repair and regeneration 'R' and the use of advanced therapies when needed, and 'S' for social and patient-related factors. This in part recognises the role of engaging patients in their healing journey and working in partnership when possible, enabling patients to become a stakeholder in their own health care (Atkin et al, 2019).

In the community setting, dressings play an integral role in wound bed preparation. The selection of a dressing is important to promote a moist wound healing environment and to facilitate wound bed preparation through the removal of local barriers to healing, such as devitalised tissue, excess exudate and bioburden (Dowsett, 2023). It is important that clinicians can assess local wound conditions, identify possible barriers to healing, and select an appropriate dressing to meet the management goals of the individual patient with a wound.

T: Tissue management

The wound bed and edges should be checked for the presence of devitalised tissue (also known as non-viable, non-vital or dead tissue), which includes slough, necrotic tissue, debris, microorganisms and biofilm (Tettelbach et al, 2024). If present, devitalised tissue needs to be removed to create an optimal wound-healing environment and to reduce the risk of infection (Tettelbach et al, 2024). Devitalised tissue can be removed through cleansing and debridement of the wound bed and surrounding skin (Murphy et al, 2020; Tettelbach et al, 2024).

Numerous debridement methods exist, but in the community setting, mechanical and autolytic debridement are most commonly available and their combined use is recommended for optimal results (Tettelbach et al, 2024).

Mechanical debridement involves the physical removal of devitalised tissue and debris from the wound bed. Debridement pads (also available in a wand shape) can be used to help reduce the risk, or signs of wound infection and can also be effective in disrupting wound biofilm (Atkin et al, 2019; Tettelbach et al, 2024).

Autolytic debridement is a natural process in which immune cells selectively target and degrade devitalised tissue, leading to its softening and eventual detachment (Atkin et al, 2019; Tettelbach et al, 2024). Wound dressings can be used to promote moisture balance in the wound, so that it is neither too wet nor too dry, to optimise autolysis (Tettelbach et al, 2024). A dressing that can remove debris without drying out and adhering to the wound bed during wear is crucial.

Autolytic debridement is typically indicated for non-infected wounds since it can take several days (Atkin et al, 2019; Tettelbach et al, 2024), but it can also be used in combination with antimicrobial therapy (Tettelbach et al, 2024). A combination of cleansing, mechanical and autolytic debridement is recommended to achieve optimal results (Tettelbach et al, 2024). However, if significant autolysis is not observed within one to two weeks, another method of debridement should be considered, e.g. sharp or surgical, for which referral may be needed (Tettelbach et al, 2024).

Red Flag

It is unacceptable for people to suffer from chronic wounds for prolonged periods without diagnosis, assessment or referral, as in the majority of cases they can be healed with appropriate management, treating the cause and any associated symptoms. (Holloway, 2021). Patients with chronic wounds should undergo holistic assessment at regular intervals to identify barriers to healing, which should be addressed where possible with an appropriate treatment plan and may require referral to the multidisciplinary team (MDT).

I: Infection/inflammation

Infection and inflammation are both conditions that prevent healing (Atkin et al, 2019). Although inflammation is a crucial part of the wound healing process, persistent wound inflammation is often present in chronic wounds and is associated with biofilm — thought to be present and responsible for non-healing in 78% of chronic wounds (Malone et al, 2017). The presence of destructive proteases can also cause chronic inflammation and contribute to tissue damage in both the wound and periwound skin (Cutting et al, 2015).

Signs and symptoms of inflammation include redness, oedema, heat and pain, although these may be less notable in some patients because of skin pigmentation or underlying disease processes such as diabetes (Atkin et al, 2019). Blood tests for inflammatory markers may help in these individuals (Atkin et al, 2019). A large volume or purulent exudate may also indicate chronic inflammation (Atkin et al, 2019).

Wound bed preparation can help to reduce inflammation and optimises conditions for healing by removing damaged tissue and foreign materials and reducing bacterial bioburden

(Dowsett, 2023). Biofilm should be suspected in wounds where best practice has been carried out but without any change of conditions, and there are no signs or symptoms of infection (Murphy et al, 2020). Mechanical debridement can be used to disrupt and remove biofilm, and a dressing with antimicrobial properties, such as silver, can be applied to prevent biofilm from re-forming and to maintain a healing environment (Murphy et al, 2020). This approach is known as biofilm-based wound care (Malone and Swanson, 2017).

Chronic wound exudate often contains high levels of proteases, inflammatory cytokines and bacteria which can perpetuate inflammation. Using an absorbent dressing that can effectively manage chronic wound exudate is beneficial in reducing inflammation and promoting wound healing (Wounds UK, 2019).

There may be overt (obvious) or covert (subtle) signs of local wound infection. Identifying these signs is key for timely intervention and effective wound management. Overt indicators include, increased redness, oedema, pain, heat and purulent exudate. Whereas covert signs may include increased exudate, wound discolouration, friable granulation tissue, recurrent devitalised tissue, malodour and wound deterioration (IWII, 2022). The presence of local wound infection should be managed by cleansing and debridement, followed by use of topical antimicrobial dressings, such as a silver dressing, to reduce bioburden. Antimicrobial dressings should be used in line with local policy and appropriate antimicrobial stewardship (IWII, 2022). If infection is spreading or systemic, it is essential to refer the patient for oral or intravenous (IV) antibiotic therapy.

M: Moisture balance

A moist wound healing environment is known to result in faster healing (Winter, 1962). However, balance is needed — too wet may lead to maceration and wound enlargement, while a dry wound can lead to desiccation, which can significantly impair the wound healing process. Chronic wound exudate contains dysregulated proteases that can result in skin damage if not managed appropriately (Wounds UK, 2013). Therefore, management should aim to absorb exudate and foreign materials, locking it away from both the wound bed and healthy skin to prevent further damage. Primary and/or secondary dressings should also be able to retain excess exudate to prevent leakage (Wounds UK, 2013). For people with venous leg ulcers, the dressing selected may need to exert these properties under compression therapy (Wounds UK, 2013). Wear time and absorbency of the dressing should be considered at each dressing change (Wounds UK, 2013).

E: Wound edge and epidermal advancement

The majority of wounds heal by epithelial cell migration from the healthy skin around the wound (Atkin et al, 2019). Therefore, the wound edge should be monitored and, when required, devitalised tissue removed. If necessary, the wound margins should be refashioned so that they are flat and not rolled to promote healing (Tettelbach et al, 2024). Damage from wound exudate should be avoided by selection of a dressing with suitable absorbency.

This article will now focus on Suprasorb® Liqacel Pro, a gelling fibre dressing, and Suprasorb® Liqacel Ag, a gelling fibre dressing with silver. This will highlight the properties that make them valuable tools to aid wound bed preparation and manage bacterial burden and biofilm.

SUPRASORB® LIQUACEL PRO AND SUPRASORB® LIQUACEL AG

Suprasorb® Liquacel Pro

Suprasorb® Liquacel Pro is a hydroactive gelling fibre dressing (*Figure 1*) that promotes a moist wound healing environment and aids wound bed preparation in both shallow and cavity wounds when there is moderate-to-heavy exudate.

The dressing is made up of 80% gel-forming sodium carboxymethylcellulose fibres (CMC fibres), which enable the dressing to form a gel on contact with wound exudate, and 20% lyocell fibres, which give the dressing tensile strength. Lyocell is a particularly soft, eco-friendly, semi-synthetic fibre made from sustainably sourced wood cellulose, usually eucalyptus trees.

Figure 1.
Suprasorb® Liquacel Pro, a hydroactive gelling fibre dressing, available as a flat dressing and ribbon.

Gel formation and exudate management

When Suprasorb® Liquacel Pro comes into contact with wound exudate, a gel is formed, which maintains a moist wound environment that supports autolytic debridement. The gelled dressing conforms to the wound bed, preventing leakage and leaving no space or gaps for bacteria to grow (Data on file, 2024).

Bacteria and cell debris present in the wound are absorbed vertically and held securely in the dressing. This confines exudate to the soaked area of the dressing, moving it away from the wound and surrounding skin. Suprasorb® Liquacel Pro retains fluid under compression (Data on file, 2024). Exudate and bacteria are removed during dressing changes, thus helping to reduce the microbial burden of the wound (*Figure 2*).

Suprasorb® Liquacel Pro has reinforced lyocell fibres and tight needling which together enhance tensile strength. This means that the dressing can be removed in one piece during dressing changes, even when saturated (Data on file, 2024). This avoids dressing breakage and fibres being left behind in the wound, which can result in non-healing (Tettelbach et al, 2024).

Furthermore, as the gelled fibres of the dressing remain structurally intact, little shrinkage of the dressing

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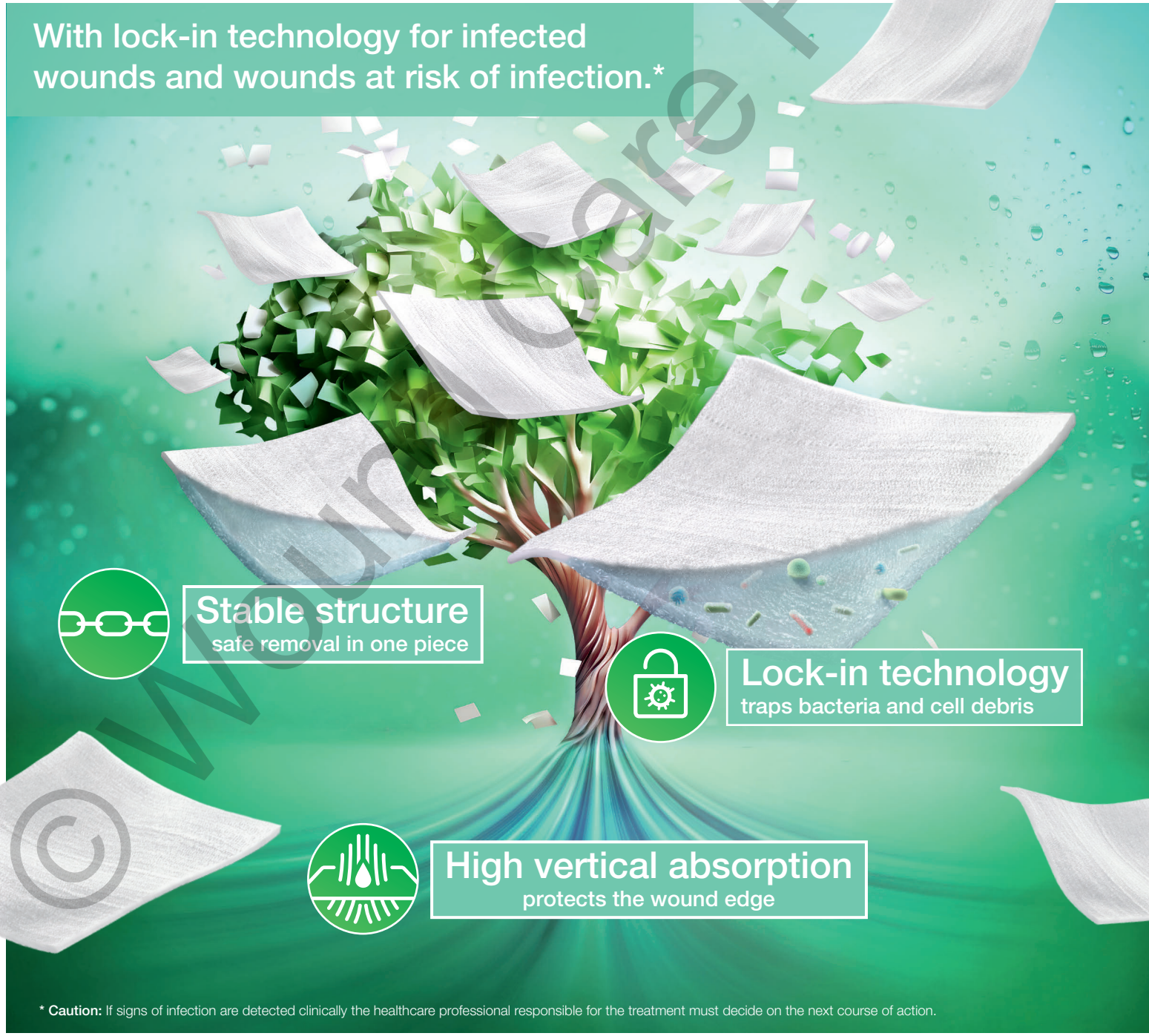

* **Caution:** If signs of infection are detected clinically the healthcare professional responsible for the treatment must decide on the next course of action.

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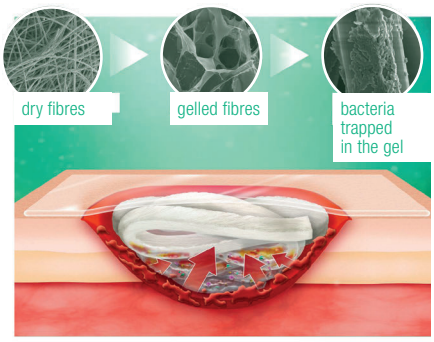

Figure 2.
Mode of action of Suprasorb® Liquacel Pro.

occurs during wear time, meaning that the wound bed remains covered (Data on file, 2024).

Suprasorb® Liquacel Ag

Suprasorb® Liquacel Ag is an antimicrobial hydroactive silver dressing that is composed of 60% CMC fibres and a 40% blend of lyocell and silver fibres (with 1.1% silver nanoparticles).

Absorbency

Suprasorb® Liquacel Ag performs in the same way as Suprasorb® Liquacel Pro; when in contact with wound exudate, a gel is formed, which maintains a moist wound environment and supports autolytic debridement.

As for Suprasorb® Liquacel Pro, fluid is absorbed vertically into the dressing and locked away from the wound. Suprasorb® Liquacel Ag traps wound exudate, cell debris and bacteria and is removed in one piece during dressing changes (*Figures 2* and *4*).

Silver nanotechnology

The silver component of Suprasorb® Liquacel Ag gives the dressing antimicrobial properties. The strengthening lyocell fibres throughout the dressing contain 1.1% silver nanoparticles, which provide a sustained and consistent antimicrobial effect (Data on file, 2022a). The silver nanoparticles within Suprasorb® Liquacel Ag have been developed to achieve a balance between effective antimicrobial action and minimal cytotoxicity, ensuring that the dressing is gentle both on the wound and surrounding intact skin (Data on file, 2022a; Data on file, 2022b). Suprasorb® Liquacel Ag is effective against 99.99% of common wound pathogens, including *meticillin-resistant Staphylococcus aureus* (MRSA) (Data on file, 2020) (*Figure 4*).

Figure 3.
Suprasorb® Liquacel Ag, a gelling hydrofibre dressing with silver.

Mete et al (2024) carried out an observational study in six European woundcare centres where eight wound managers treated 81 patients with Suprasorb® Liquacel Ag, performing at least four dressing changes over seven to 28 days. The authors made several observations:

- Over the study period, signs of infection, such as redness, overheating, tissue dysfunction, swelling, pain, and wound odour were significantly reduced by an average of 2.64 on the visual 0–10 analogue scale (VAS)
- The dressing conformed to the wound in 98.8% of cases
- Signs of biofilm were reduced in 60% of the treated wounds that initially showed signs of biofilm at the beginning of the treatment
- Dressings did not adhere in 95% of cases
- In all cases, wound exudate was successfully directed into the secondary dressing, Suprasorb® Liquacel Ag could be removed intact and dressing changes were atraumatic.

The study concluded that Suprasorb® Liquacel Ag is effective for managing infected, at risk of infection, or wounds where biofilm is suspected.

Indications and contraindications

Suprasorb® Liquacel Pro and Suprasorb® Liquacel Ag can be used for the management of shallow and cavity wounds in the presence of a moderate-to-heavy volume of wound exudate.

Suprasorb® Liquacel Pro is indicated for:

- Leg ulcers
- Diabetes-related foot ulcers
- Pressure ulcers
- Postoperative wounds
- Second-degree burns
- Abrasions/lacerations
- Oncological wounds.

Where wounds are infected, or at risk of infection, Suprasorb® Liquacel Ag may be used in line with local antimicrobial policies and clinical assessment findings.

Suprasorb® Liquacel Pro and Suprasorb® Liquacel Ag are not intended for use on heavily bleeding wounds, inside internal body cavities, or on closed wounds (Suprasorb® Liquacel Pro Instructions for Use [IFU]; Suprasorb® Liquacel Ag IFU).

Formulation

Both dressings are available as flat or rope dressings for cavity wounds. Both dressing types can be cut to the required size. Once applied to the wound, Suprasorb® Liquacel Pro and Suprasorb® Liquacel Ag should be covered with a secondary dressing which is suitable for the wound conditions (e.g. Suprasorb® P Sensitive foam, or Vliwasorb® Pro superabsorbent, L&R).

The dressings can remain in place for up to seven days and can be used under compression.

Biofilm-based wound care

Where biofilm is suspected, Suprasorb® Liquacel Pro and Suprasorb® Liquacel Ag can be used as part of biofilm-based wound care. This may include mechanical wound debridement using monofilament fibre technology to remove debris, slough, bacteria and biofilm from the wound where appropriate (e.g. Debrisoft® pad or Debrisoft® Lolly, L&R). This should be followed by the application of Suprasorb® Liquacel Ag, or in line with local policies and clinical assessment. Edward-Jones (2022) reported that silver nanotechnology was effective against biofilm and a broad spectrum of pathogens including MRSA. An *in-vitro* study by King et al (2023) demonstrated that the silver nanoparticles in Suprasorb® Liquacel

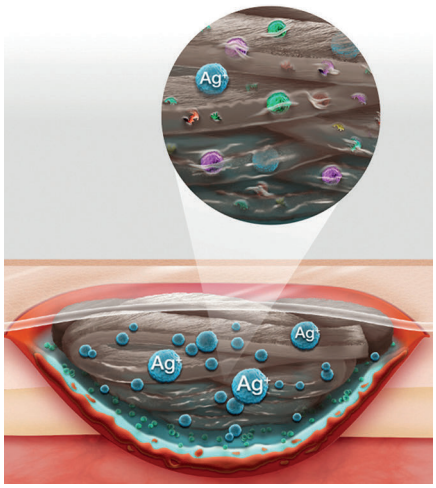

Figure 4.
Mode of action of Suprasorb® Liquacel Ag.

Ag was effective in preventing biofilm for both gram-positive and gram-negative bacteria.

REASSESSMENT

Wound healing and the condition of the wound are not static, so reassessment is regularly needed to ensure that management plans remain appropriate and effective (Atkin et al, 2019). Most chronic wounds have more than one local wound factor that may need addressing to create an environment conducive to healing. As the wound is a symptom of underlying conditions and general patient wellbeing, management needs to occur as part of a holistic care plan, not in isolation.

CONCLUSION

Chronic wounds pose a significant financial burden on the NHS, with the bulk of costs arising from hard-to-heal wounds in the community, with community and district nursing visits making up the largest spend (Guest et al, 2020). Chronic wounds inflict suffering on patients who live with symptoms such as excess exudate, odour, and increased risk of complications, i.e. infection and biofilm development (Atkin et al, 2019; Dowsett, 2023). However, with appropriate care, many chronic wounds could be healed in a timely fashion saving NHS resources and reducing the burden for patients (Guest et al, 2020). Wound bed preparation is a structured approach to wound care, enabling clinicians to systematically assess and address various factors that contribute to non-healing. This proactive approach can help in identifying potential issues early, thereby improving the chances of successful wound healing and reducing the risk of complications. Within the community setting, dressings are a key part of wound management so it is important that clinicians recognise the role they play and know what properties to select for the wounds they are treating.

Suprasorb® Liquacel Pro and Suprasorb® Liquacel Ag are hydroactive fibre dressings that have demonstrated numerous properties which create an effective wound healing environment and prepare the wound bed for healing in a variety of wound types. JCN

REFERENCES

Atkin L, Bucko Z, Conde Montero E, et al (2019) Implementing TIMERS: the race against hard-to-heal wounds. *J Wound Care* 28(3 Supple 3): S1–S49

Cutting KF, Vowden P, Wiegand C (2015) Wound inflammation and the role of a multifunctional polymeric dressing. *Wounds Int* 6(2): 42–6

Data on file (2020) *VENGATR-25*

Data on file (2022a) *VENAGTR-69*

Data on file (2022b) *VENAGTR-6*

Data on file (2024) *Comparison of the fluid handling properties of Suprasorb Liquacel Pro and Suprasorb Liquacel Ag with marketed products*

Dowsett C (2023) A multidimensional approach to wound bed preparation using UrgoClean Ag. *Wounds UK* 19(4): 78–85

Edward-Jones V (2022) Silver nanoparticles: an overview of scientific toxicity and safety data and introduction of a new dressing, Venus Ag. *Wounds UK* 18(4): 22–9

Guest JF, Ayoub N, McIlwraith T, et al (2015) Health economic burden that wounds impose on the National Health Service in the UK. *BMJ Open* 5: e009283

Guest JF, Fuller GW, Vowden P (2020) Cohort study evaluating the burden of wounds to the UK's National Health Service in 2017/2018: update from 2012/2013. *BMJ Open* 10: e045253

Holloway S (2021) The language of non-healing wounds. *Wounds UK* 17(3): 9

International Wound Infection Institute (2022) *Wound Infection in Clinical Practice*. Wounds International, London

King E, Wynn-Jones G, Kettlewell G (2023) *Antibiofilm performance of silver nanoparticles and new silver nanoparticle wound dressing*. Poster presentation, Symposium on Advanced Wound Care (SAWC), 2023, Las Vegas

Loi S, Minhas A (2021) Importance of wound bed preparation in the management of chronic wounds. *J General Practice Nurs* 7(4): 48–52

Malone M, Bjarnsholt T, McBain AJ (2017) The prevalence of biofilms in chronic wounds: a systematic review and meta-analysis of published data. *J Wound Care* 26(1): 20–25

Malone M, Swanson T (2017) Biofilm-based wound care: the importance of debridement in biofilm treatment strategies. *Br J Community Nurs* 22(Sup6): S20–25

Mete E, Westermann G, Rainer C, Roes C (2024) *Observational, international, multicentre, single-arm study to assess the performance, safety and handling of new antimicrobial hydro-active fibre dressing*. Poster presentation, European Wound Management Association (EWMA), 2024, London

Murphy C, Atkin L, Swanson T, et al (2020) International consensus document. Defying hard-to-heal wounds with an early antibiofilm intervention strategy: wound hygiene. *J Wound Care* 29(Suppl 3b): S1–28

Tettelbach WH, Ciprandi G, Downie F, et al (2024) International consensus document. Best practice for wound debridement. *J Wound Care* 33(Suppl 6c): S1–32

Winter G (1962) Formation of the scab and the rate of epithelialisation of superficial wounds in the skin of young domestic pigs. *Nature* 193: 293–4

World Union of Wound Healing Societies (2019) *Consensus document. Wound exudate: effective assessment and management*. Wounds International, London

Wounds UK Best Practice Statement (2013) *Effective exudate management*. Wounds UK, London

Wounds UK (2018) *Best practice statement. Improving holistic assessment of chronic wounds*. Wounds UK, London

Wounds UK (2019) *Identifying and managing inflammation Made Easy*. Wounds UK, London

Wounds UK Best Practice Statement (2022) *Active treatment of non-healing wounds in the community*. Wounds UK, London

Low back pain in primary and urgent care

Kirsty Armstrong

Diagnosis of low back pain can be intriguing and complex. Careful history-taking and physical examination are essential to ensure red flags (serious issues) are not missed, that treatment is appropriate, evidence-based and timely, and that follow-up and review are well documented and understood by the patient. This article covers some of the more common causes of back pain in primary and urgent care.

KEYWORDS:
■ Low back pain ■ History-taking ■ Physical examination
■ Diagnosis ■ Treatment ■ Safety netting

Low back pain is a common condition which can range from mild discomfort to severe, debilitating pain and is a leading cause of disability worldwide (Wu et al, 2020). It affects people of all ages, with most people experiencing it at least once in their lives (World Health Organization [WHO], 2023). Six hundred and nineteen million people globally were affected with low back pain in 2020, a number which is estimated to increase to 843 million by 2050, due to population growth and ageing (WHO, 2023).

While the following list is not exhaustive, some of the most common causes for back pain include:

- Spinal metastases with a known or unknown primary cause (cancer)
- Urinary tract infection (UTI), whether this is acute, chronic or recurrent
- Renal stones or calculi
- Infection in the vertebrae, bones, ligaments or muscles
- Skeletal fractures, e.g. non-pathological fractures (no trauma) or pathological fractures following trauma
- Functional back pain (FBP) — also known as non-specific back pain
- Referred pain from elsewhere in the back or from the front, e.g. a dissecting aortic aneurysm (vascular)
- Muscular or ligament issues
- Osteoporosis
- Osteomyelitis
- Osteoarthritis
- Shingles which affects the skin but can present as back pain
- Trauma or lesions/deformity affecting the vertebrae/discs leading to cauda equina symptoms, e.g. changes to urination or elimination with or without paraesthesia (usually in the 'saddle' area)

(National Institute for Health and Care Excellence [NICE], 2023).

HISTORY-TAKING

Using a pain assessment mnemonic, such as OPQRSTU (onset, provoking or palliating factors [what makes it worse or better?], quality and quantity [if it is pain, is it burning, aching, sharp dull?], region or radiation, severity on a scale of 1–10 with 1 being the least and 10 the worst pain, time [hourly, daily, have you had it before?] and treatment, understanding [what do you think it is?] (Freise, 2023) is helpful to ensure that the questioning of symptoms is complete. The mnemonic that is most useful is the one that you remember and feel confident and comfortable with. There is also SOCRATES (site, onset, character, radiation, associations, time course, exacerbating/relieving factors, severity) (Geeky medics, 2024), which is one of many other alternatives.

As an aide memoire, using SAMOSADIET (Lewis, 2014) is useful to tie the history together and complete the picture of the patient's problem alongside focused history-taking and physical assessment. As an example, here is the mnemonic SAMOSADIET with considerations of how this might be applicable to the patient when considering some of the common causes of back pain:

- Smoking: this can affect the integrity of the vertebral discs making them drier and less flexible, therefore increasing the likelihood of spinal pathology (Elmasry et al, 2015)
- Alcohol: this may be relevant if the patient has had a fall while intoxicated (NHS Inform, 2023)
- Medications: are there any medications that reduce bone density such as steroids? This would make a non-pathological fracture more likely. Osteoporosis will also make the bones more brittle. It is also important to know what medications the patient is currently taking to enable understanding of past medical history and medical conditions (Bickley, 2023). Drug history

Kirsty Armstrong, advanced nurse practitioner in out of hours care, urgent care and GP extended access

including over-the-counter and prescribed medications and recreational drugs should be taken into account. Intravenous (IV) drug users are at high risk of infections due to being immunocompromised (Lavender and McCarron, 2013). Consider also medications that can cause the patient to fall and injure themselves, e.g. anti-hypertensives in a dehydrated elderly patient

- Occupation: a heavy manual job, such as construction which involves heavy lifting, can increase the chances of trauma and back problems. However, a sedentary job can also lead to loss of mobility and stiffness, which in itself can contribute to back problems. Access to facilities such as toilets for site workers can affect the bladder — not passing urine when needed can increase the chances of UTI (NICE, 2023)
- Social: where does the patient live and who with? Are they a carer? Do they live up many flights of stairs and a non-functional lift with lots of heavy shopping to carry, or children and buggies to manoeuvre? It is also important to bear in mind that social deprivation affects coping mechanisms around back pain (Karran et al, 2020)
- Allergies: these are essential to consider if a patient needs prescribing (Bickley, 2023)
- Diet: does the patient have a healthy diet, e.g. fresh, non-processed food, fruit and vegetables? Are they a good weight, overweight, slight, which may impact on posture and spinal pathology (NICE, 2023)
- Immunisations: these are a good indicator of health beliefs and self-care and so are relevant when considering infections, such as tuberculosis (TB), which can affect the spine (Abraham and Sheeran, 2015)
- Exercise: this is relevant to back pain, as too much or too little exercise can impact daily functioning (Keele University, 2021)
- Travel: useful when considering exotic infections with unknown symptoms and periods of immobility on long trips which can contribute to factors such as thrombosis and coagulation/vascular problems (Bickley, 2023).

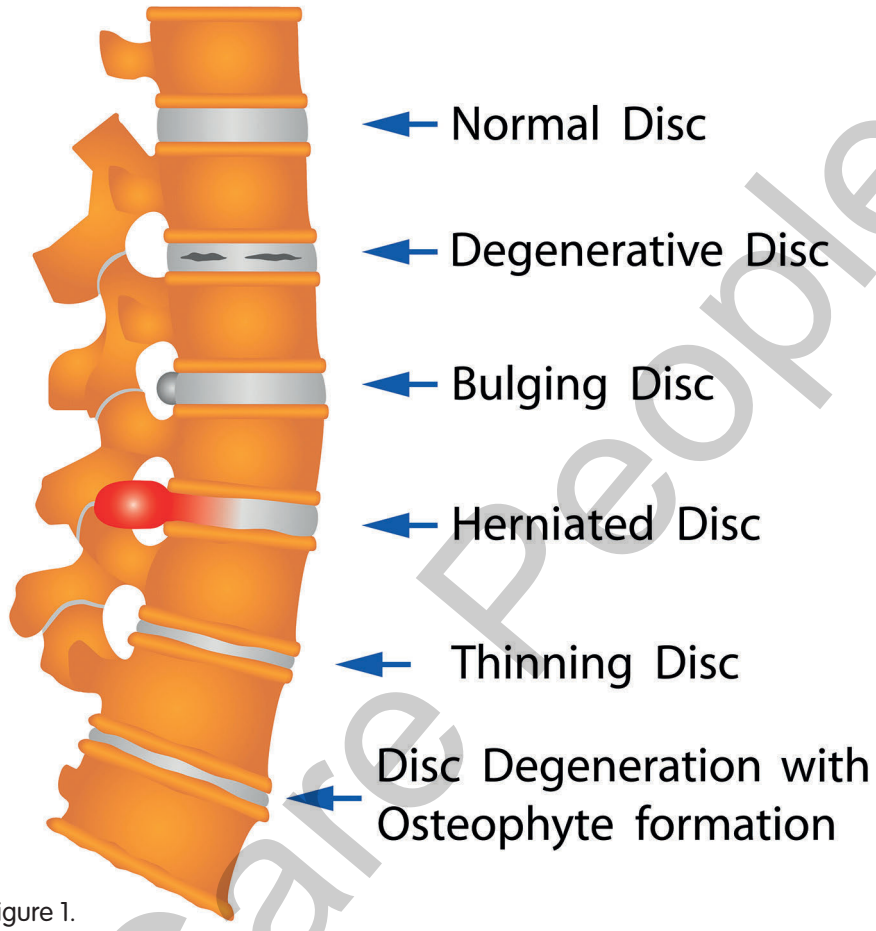

Figure 1.
Examples of disc problems.

Table 1: Useful for personal medial and family history

J	Jaundice			
A	Anaemia			
MI	Myocardial infarction	Heart disease		
T	TB	Thyroid disorders		
H	Hypertension			
R	Renal	Respiratory disorders	Rheumatic fever	Rheumatoid disorders
E	Epilepsy	Eczema		
A	Asthma			
D	Diabetes			
S	Stroke	Circulatory disorders	Skeletal problems, e.g. sciatica	
C	Cancer			
MH	Mental health	Anxiety	Depression	

To continue with the questioning, check family history of common illnesses and also personal medical history. In the author's clinical experience, the mnemonic JAMITHREADSCMH can be helpful (Queen Mary's, University of London, n.d.) (*Table 1*).

History-taking specific to back pain

To complete the history, consider any recent or past trauma which may need some careful listening and probing as smaller incidents can be forgotten but have a long-

Table 2: Signs and symptoms of cauda equina syndrome which may overlap with those for sciatica (NICE, 2023)

Red flags for sciatica	Red flags for cauda equina syndrome
▸ Bowel/bladder dysfunction (most commonly urinary retention) ▸ Progressive neurological weakness ▸ Saddle anaesthesia ▸ Bilateral radiculopathy ▸ Incapacitating pain ▸ Unrelenting night pain ▸ Use of steroids or intravenous drugs	▸ Bilateral sciatica ▸ Severe or progressive bilateral neurological deficit of the legs, such as major motor weakness with knee extension, ankle eversion, or foot dorsiflexion ▸ Gait disturbance or difficulty walking ▸ Difficulty initiating micturition or impaired sensation of urinary flow. If untreated, this may lead to irreversible urinary retention with overflow urinary incontinence ▸ Loss of sensation of rectal fullness. If untreated, this may lead to irreversible faecal incontinence ▸ Perianal, perineal, or genital sensory loss (saddle anaesthesia or paraesthesia) ▸ Laxity of the anal sphincter • Consider an assessment of anal tone, but note that this does not need to be performed in primary care ▸ Erectile dysfunction

term impact, e.g. falls on hard steps or lifting, even if light loads.

Check for any changes to passing urine or dysuria (Public Health England [PHE], 2018), which could indicate a UTI or bowel changes — including urinary retention in older males due to constipation. It is also vital to check that there are no changes in bowel habits.

Saddle anaesthesia or paraesthesia includes perineal tingling, pins and needles, loss or lack of sensation and, alongside urinary and bowel changes, is a red flag for cauda equina syndrome (*Table 2*).

For those with chronic back problems — be these urinary or functional — including low back pain, healthcare professionals should ask about triggers, e.g. hormonal changes, changes in diet, different work patterns, or changes in environment — all of which may contribute to worsening or lessening of symptoms (Keele University, 2021).

PHYSICAL EXAMINATION

Initially, healthcare professionals should watch the patient walk into the room (if not, then gait needs to be part of assessment) and be aware of their body language (e.g. stooping, limping, facial grimaces, clutching at body parts) (Bickley, 2023). It may be possible in the work area to offer pain relief, which will facilitate rather than hinder examination (although, in the author's clinical experience, patients may wish you to see how much pain they are in).

'Saddle anaesthesia or paraesthesia includes perineal tingling, pins and needles, loss or lack of sensation and, alongside urinary and bowel changes, is a red flag for cauda equina syndrome.'

Asking the patient to 'hop' onto the couch gives a good indication of mobility and pain levels if FBP is a possibility (Bickley, 2023). *Table 3* outlines risk factors for FBP.

Checking range of movement is also essential but can be brief and assessed in further detail if you find an abnormality (Bickley, 2023).

Sensation needs to be evaluated if there is any chance of impairment. This can be done with a small piece of cotton wool, or just a light touch, and at the same time strength and tone can be elicited (Bickley, 2023).

If FBP is suspected, sensation and pulse are essential, as is checking the pulses to the feet to see if they are warm and well perfused (NICE, 2023).

Skin should be examined — is it red hot or tender, do you notice any rash? Is this unilateral (likely to be shingles), or more widespread and scattered (derm.net, 2023).

However, if the issue is not thought to be FBP, vascular problems, urinary symptoms and past medical history of note should be explored, considering the list of common causes of back pain at the beginning of this article.

INVESTIGATIONS ACCORDING TO POSSIBLE DIAGNOSIS

When assessing a possible UTI (patients often complain about pain in the kidney/loin area), dip the urine to look for nitrites, in particular, as these are indicative of bacterial UTIs, as certain bacteria, such as *Escherichia coli* can convert urinary nitrates into nitrites. It is also important to consider other factors for comprehensive evaluation, such as blood, leucocytes (white blood cells) and protein (see below), for both UTI or renal colic, which is typically characterised by sudden, severe

Table 3: Risk factors for FBP (NICE, 2023)

▸ Age: 24–45 years
▸ Male sex
▸ Lifting, 'heavy' physical work
▸ Previous back pain
▸ Being overweight
▸ Smoking
▸ Being pregnant
▸ Long-term use of medication that is known to weaken bones, such as corticosteroids
▸ Stress
▸ Depression

flank pain due to kidney stones (PHE, 2018).

Blood in the urine can indicate UTI, but a lot of blood (Ribena-coloured urine) plus severe pain rather than dysuria is more likely to indicate renal colic. Protein/leucocytes in the urine may indicate an infection or inflammation in the urinary tract. However, they can also be associated with vaginal or penile discharge and so UTI should be excluded, particularly when there is vulval discomfort when urine passes across the vulva.

Vital signs, such as temperature, will give a guide to infection. Raised heart rate and blood pressure may be due to pain rather than a pre-existing condition, but this information should have been elicited in the history-taking (using National Early Warning Score 2 [NEWS2]; NICE, 2020).

Respiratory rate and oxygen saturations are needed to complete the clinical picture and use of NEWS2 will help to gauge the severity of the patient's condition (NICE, 2020).

Chronic conditions, such as pre-existing back pain or recurrent UTIs, need careful management and attention to detail (PHE, 2018), particularly if the patient is presenting in different settings at different times or has been lost to follow-up.

Contrary to popular opinion, X-ray of the back will reveal little other than an obvious fracture. Serious, ongoing, non-resolving conditions may require further imaging, but local protocol and specialist advice should be sought in the first instance. If osteoporosis is a possibility, appropriate imaging such as a Dexa scan, further investigations, and specialist advice will be needed (NHS, 2022).

'Chronic conditions, such as pre-existing back pain or recurrent UTIs, need careful management and attention to detail (PHE, 2018), particularly if the patient is presenting in different settings at different times... .'

As an exhaustive list of conditions that can lead to back pain will not be covered in this article, see the references listed at the end.

TREATMENT ACCORDING TO POSSIBLE DIAGNOSIS

Should a urinalysis be positive, follow local and national antibiotic guidelines with awareness around chronic conditions, catheterised patients, and patients over the age of 65 for whom the guidelines are different (PHE, 2018). A mid-stream specimen of urine is indicated in some situations, such as recurrent UTIs or inconclusive dipsticks — in the author's clinical opinion, the PHE algorithm is useful for this

Red Flags **For any condition with back pain (NICE, 2023)**

- Fever, night sweats and pain that cannot be controlled with antipyretics/analgesia
- Not passing urine, vomiting and unable to keep fluids down
- Pain not managed in primary or urgent care and needs referral into a pain management clinic
- End-of-life care — part of which is low back pain
- Not improving within parameters — so consider what the outcome should be and what it actually is. If concerned, confer with a more senior colleague or specialist — particularly the patient with a past medical history of cancer or immunocompromised
- Perineal, anal, vulval numbness or loss/change in sensation alongside back pain — consider cauda equina syndrome, a surgical emergency often needing prompt decompression to prevent permanent nerve damage
- Sciatica (shooting pains or numbness in the leg) which has become too severe to manage or is now in both legs
- Back pain that is accompanied by neck pain and a positive Kernig's sign. A positive test is when the patient is unable to straighten their legs when the neck is flexed due to meningeal irritation. This could indicate a brain bleed, such as a subarachnoid haemorrhage (SAH)
- Dropping blood pressure and noticeable mass in the abdomen could be a dissecting aortic aneurysm — do not examine, patient needs expert help immediately
- The younger patient (<25) presenting with sudden onset back pain (possible ankylosing spondylitis).

Patient story

Mr Jones is aged 56 and a builder. He has had some low back pain recently and a past medical history of disc problems.

You are telephone triaging him and he complains of numbness around the anal area, shooting pains into both legs, constipation and dribbling when passing urine — all in the last 24 hours after he lifted a heavy bag of concrete. At the time this hurt, but now he has only these other symptoms and feels a change of sensation 'down below'.

He takes statins for his high cholesterol and ramipril for blood pressure.

What further questions do you need to ask him? What are your top three differentials? How should he be managed and in what time frame?

Yellow Flags

- Beliefs that may affect the best progress (Abraham and Sheeran, 2015; Bickley, 2023)
- The patient has poor or unreasonable expectations about improvement and pain control
- The patient is not wanting to contribute to treatment, e.g. mobilising and is concerned that moving will make it worse. For instance, not attending for physiotherapy or follow-ups/appointments and not completing the recommended exercises. It is essential that the patient has an understanding of the condition and that mobility is vital — lying in bed for six weeks is no longer the recommended treatment
- The patient feels that they need more empathy and that the clinician does not understand the condition — linked to first point
- Social problems, such as poor or currently inappropriate housing, or the patient is unable to cope with current situation
- Depression and anxiety causing distress and inability to manage every day situations and now also physical problems
- Obesity preventing full rehabilitation and interaction and hindering mobility.

(PHE, 2018). In some cases of chronic urinary problems, referral onwards might lead to an ultrasound of the kidneys, bladder and urethra. This should also reveal any calculi.

If working in a clinical area that is able to offer further investigations, bloods may be of use such as a full blood count (FBC) with white blood cell differentials and C-reactive protein (CRP, to check for inflammation). CRP is sensitive as an inflammatory marker but cannot tell you where the inflammation is (https://labtestsonline.org.uk).

Osteoarthritis (OA) is a degenerative condition (NHS, 2023) which can lead to pain and loss of mobility and is best managed by adequate pain relief, plenty of exercise to promote mobility, and physiotherapy if needed (Keele University, 2021; NICE, 2023). The 'wear and tear' of OA is different for everybody and the management plan needs to reflect this (NICE, 2023).

Osteomyelitis needs to be treated with great care and specialist advice and treatment should be sought (NICE, 2023).

Patients with a past medical history of cancer, particularly those who are known to metastasise readily (prostate, lung and breast cancer) should be referred into the two-week wait pathway if presenting with a sudden new onset back pain with minimal triggers (such as just turning over in bed) (Lustberg, 2012).

SAFETY NETTING AND GIVING WORSENING CARE ADVICE

It is important to consider the parameters and general progression of the presenting complaint and what you would expect with rehabilitation and in what time period (Edwards et al, 2022). Advice should also be given on worsening symptoms and the 'who, when, where, why' to go if the condition worsens, or if the patient is anxious (UK Health Security Agency [UKHSA], 2020).

Long-term management of chronic conditions such as FBP must include advice on maintaining back health (Keele University, 2021) with, for example, pilates, yoga, regular exercise. With FBP consider smoking cessation (patients who smoke will have drier discs so are more susceptible) and weight reduction if needed (NICE, 2023). With a UTI diagnosis, advise on voiding after intercourse, drinking plenty of fluids, possible herbal supplements, and correct post void wiping for females (from front to back) (PHE, 2018).

Recurrence of any condition should prompt scrutiny of previous assessments, history-taking, treatments and investigations — do not rely on the work or assessment of other clinicians, as they can be wrong (PHE, 2018). Investigations should not be repeated unless there are obvious anomalies.

Information/education given should always be evidence-based. NHS websites contain good links, videos, resources for patients which they can look at for further guidance and it may be helpful to introduce patients to self-help groups to encourage interaction and education on the condition.

CONCLUSION

This article has discussed some of the common presentations related to lower back pain in primary and urgent care. There is no substitute for good history-taking, performing a thorough physical assessment and having a working knowledge of the evidence base for tests/investigations and treatment of some of these conditions. If in doubt, speak to more senior colleagues or specialists for advice on management and healthcare professionals should always work within their competency (Nursing and Midwifery Council [NMC], 2015). JCN

Box 1 Definition of musculoskeletal back pain

- Back pain is a symptom
- Simple low back ache is also called uncomplicated or non-specific low back pain and will vary with posture, activity, time and treatment — also called functional back pain (FBP), as it affects function
- Sciatica is a lay term for pain extending into the leg (buttock, thigh, calf or heel)
- Classification of FBP:
  - Acute (less than six weeks)
  - Sub-acute (six to 12 weeks
  - Chronic (more than 12 weeks).

REFERENCES

Abraham C, Sheeran P (2015) The health belief model. In: Conner M, Norman P, eds. *Predicting and Changing Health Behaviour*. Edn 3. McGraw-Hill, California, USA

Bickley LS, Szilagyi PG (2023) *Bates' guide to physical examination and history taking*. 13th edn). Lippincott Williams & Wilkins

Dermnet. *Herpes zoster*. Available online: https://dermnetnz.org/topics/herpes-zoster

Edwards PJ, Silverston P, Sprackman J, Roland D (2022) Safety-netting in the consultation. *BMJ* 378: e069094

Elmasry S, Asfour S, de Rivero Vaccari JP, Travascio F (2015) Effects of tobacco smoking on the degeneration of the intervertebral disc: a finite element study. *PLoS One* 10(8): e0136137

Freise G (2023) *How to use OPQRSTU as an effective patient assessment tool*. Available online: www.ems1.com/ems-products/education/articles/how-to-use-opqrst-as-an-effective-patient-assessment-tool-yd2KWgJIBdtd7D5T/

Geeky medics (2024) *SOCRATES and other mnemonics*. Available online: https://geekymedics.com/the-socrates-acronym-in-history-taking/ (accessed 7 May, 2024)

Karran E, Grant A, Moseley L (2020) Low back pain and the social determinants of health: a systematic review and narrative synthesis. *Pain* 161(11): 2476–93

Keele University (2021) *STarT Back Screening Tool*. Available online: https://startback.hfac.keele.ac.uk/

Lavender T, McCarron B (2013) Acute infections in intravenous drug users. *Clin Med (Lond)* 13(5): 511–13

Lewis,SJ (2014) SAMOSADIET. Cited in: Armstrong K (2014) Common skin conditions in community and primary care. *Br J Community Nurs* 19(10): 482, 484–8

Lustberg MB, Reinbolt RE, Shapiro CL (2012) Bone health in adult cancer survivorship.*J Clin Oncol* 30: 3665–74

NHS Inform (2023) *Alcohol and falls in the elderly*. Available online: www.nhsinform.scot/healthy-living/preventing-falls/causes-of-falls (accessed 7 May, 2024)

NHS (2022) *Causes of back pain*. Available online: www.nhs.uk/conditions/back-pain/

NHS (2023) *Osteoarthritis*. Available online: www.nhs.uk/conditions/osteoarthritis/

Nursing and Midwifery Council (2015) *Code of conduct*. Available online: www.nmc.org.uk/standards/code/

National Institute for Health and Care Excellence (2020) *National Early Warning Score systems that alert to deteriorating adult patients in hospital*. Available online: www.nice.org.uk/advice/mib205/resources/national-early-warning-score-systems-that-alert-to-deteriorating-adult-patients-in-hospital-pdf-2285965392761797

National Institute for Health and Care Excellence (2023) *How should I assess a person with low back pain?* Available online: https://cks.nice.org.uk/topics/back-pain-low-without-radiculopathy/diagnosis/assessment/

Public Health England (2018) *Diagnosis of urinary tract infections: quick reference guide for primary care*. Available online: https://assets.publishing.service.gov.uk/media/5f89809ae90e072e18c0ccc2/UTI_diagnostic_flowchart_NICE-October_2020-FINAL.pdf

Queen Mary's, University of London (no date) *History taking template*. Available online: https://qmplus.qmul.ac.uk/pluginfile.php/267359/mod_page/content/12/History%20taking%20template.pdf

UK Health Security Agency (2020) *Urinary tract infection — diagnostic tools for primary care*. Available online: www.gov.uk/government/publications/urinary-tract-infection-diagnosis (accessed 29 April, 2024)

Williams B (2022) The National Early Warning Score: from concept to NHS implementation. *Clin Med* 22(6): 499–505

World Health Organization (2023) *Low back pain. Key facts*. Available online: www.who.int/news-room/fact-sheets/detail/low-back-pain

Wu A, March L, Zheng X, et al (2020) Global low back pain prevalence and years lived with disability from 1990 to 2017: estimates from the Global Burden of Disease Study 2017. *Ann Transl Med* 8(6): 299

Revalidation Alert

Having read this article, reflect on:

- Common causes for back pain
- What good history-taking should cover
- How you perform a thorough physical assessment
- Your knowledge of red flags for cauda equina syndrome.

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

KEY POINTS

- Diagnosis of low back pain can be intriguing and complex.
- Low back pain is a common condition which can range from mild discomfort to severe, debilitating pain and is a leading cause of disability worldwide.
- Careful history-taking and physical examination are essential to ensure red flags (serious issues) are not missed, that treatment is appropriate, evidence-based and timely, and that follow-up and review are well documented and understood by the patient.
- Saddle anaesthesia or paraesthesia includes perineal tingling, pins and needles, loss or lack of sensation and, alongside urinary and bowel changes, is a red flag for cauda equina syndrome.
- For those with chronic back problems — be these urinary or functional — including low back pain, healthcare professionals should ask about triggers.
- If in doubt, speak to more senior colleagues or specialists for advice on management.

Laryngeal cancer: an overview

Margaret Perry

Laryngeal cancer falls under the umbrella term of head and neck cancers and is the second commonest cancer type within this group. The condition often presents with symptoms shared with those of other less serious diseases, making diagnosis challenging. This article hopes to give nurses and non-medical prescribers an overview of symptoms, diagnosis, treatment, and prognosis with the aim of raising awareness and helping to get an earlier diagnosis of this devastating disease.

KEYWORDS:
■ Laryngeal cancer ■ Symptoms ■ Diagnosis ■ Treatment
■ Prognosis ■ Quality of life

Laryngeal cancer develops in the larynx (commonly called the voice box) and falls under the umbrella term of head and neck cancers, which includes cancer of the tongue, mouth and lips, salivary glands, nose, sinuses, and the nasopharynx as well as the larynx. Laryngeal cancer is the second most common form of head and neck cancer (Koroulakis and Agarwal, 2022), and has variable signs and symptoms some of which are shared with those of other common conditions. This article hopes to raise awareness of this potentially fatal disease with the aim of giving nurses and non-medical prescribers more knowledge and confidence in assessing and getting a diagnosis and treatment for patients presenting with symptoms of this condition.

Margaret Perry, locum advanced nurse practitioner

PREVALENCE RATES

Prevalence rates vary around the world but approximately 2000 new cases are diagnosed in the UK each year (National Institute for Health and Care Excellence [NICE], 2021). Laryngeal cancer is four times more common in men than in women, with nearly three quarters of cases diagnosed in those aged 60 or older (Willacy, 2023). Laryngeal cancer is rare in patients younger than 40 years of age, with incidence increasing among the older population, rising to a peak in the eighth decade (Jones et al, 2016). Patients affected by laryngeal cancer are more than twice as likely to be from lower social class V than from classes I and II, which has been attributed to the greater likelihood of tobacco and alcohol use among this patient group (Williamson et al, 2012).

'It is thought that repeated exposure of the head and neck mucosa to various aerosolised carcinogens, leads to genetic mutations which make cells within a particular mucosal area more susceptible to tumour formation.'

PATHOPHYSIOLOGY

The larynx plays a vital role in several functions, including swallowing, breathing and speaking, and anatomically is broadly divided into three main areas:

- Supraglottis: this is the area above the level of the vocal cords
- Glottis: this is at the level of the vocal cords
- Subglottis: this forms the area below the level of the vocal cords (Cancer Research UK, 2021).

The process by which cancer develops is highly complex and involves several processes. It is thought that repeated exposure of the head and neck mucosa to various aerosolised carcinogens, leads to genetic mutations which make cells within a particular mucosal area more susceptible to tumour formation (Saran et al, 2023). The histologic progression occurs from normal laryngeal mucosa to dysplastic mucosa, to carcinoma *in situ* and then to invasive carcinoma, in a multistep process of accumulated genetic events that lead to the development of laryngeal tumours (Johnson, 2023).

TYPES

Most tumours are squamous cell carcinoma (SCC) and most patients

Red Flags

- Approximately 2000 new cases diagnosed each year in the UK
- Rare in patients under 40 years of age
- Increased prevalence in older adults peaking in the eighth decade
- More common in males and among those from social classes IV and V (i.e. those in partly skilled and unskilled occupations).

Table 1: Other risk factors for laryngeal cancer (Liberale et al, 2023)

Possible risk factor	Additional information
Opium	Opium has been identified as a carcinogenic agent in humans and has been cited as a possible causative agent in laryngeal cancer, although there is limited information
Helicobacter	Helicobacter is associated with several gastrointestinal diseases, such as ulceration and gastritis. Its association with malignancy is under scrutiny as while a link is suspected, results have been inconclusive
Agent orange	This is a known pollutant used as a herbicide and was commonly used during the Vietnam war. A greater risk of laryngeal cancer has been identified among war veterans exposed to this substance, hence raising interest in its association
Microbiome	The microbiome is composed of the microorganisms which inhabit our bodies. They are now believed to have a role in influencing the immune system and affecting metabolism. Alcohol and smoking alter the healthy microbiome and may lead to promoting cancer development

are unfortunately diagnosed at advanced stages (i.e. over 75% at stage III or stage IV), while chondrosarcomas (develops in cartilage), leiomyosarcomas (cancer originating in the connective or supporting tissues), and melanomas only account for 2–5% of all laryngeal cancers (Ciolofan et al, 2017).

RISK FACTORS

Multiple factors have been studied and there are numerous risk factors associated with the development of laryngeal carcinoma. As with many other cancers, age is one of the key causes. Others are as follows: (Liberale et al, 2023)

- Smoking: this is thought to be influential as a cause for many cancers. The carcinogenic impact of smoking and its effect on the risk of laryngeal cancer is now well established (Ramroth et al, 2011). However, cigar and pipe smokers have a less well-established relationship with the development of this cancer type
- Alcohol consumption: this is also an important risk factor and appears to have a dose dependent effect. When alcohol abuse is combined with smoking, the individual risk of developing laryngeal cancer is significantly increased, up to 177 times greater when compared to individuals who neither consume alcohol nor smoke (Bilano et al, 2015)
- Human papillomavirus (HPV): this infection has been found in both benign and malignant laryngeal lesions and is commonly found in younger patients and non-smokers with laryngeal cancer. HPV-16 has been frequently seen in laryngeal cancer specimens and has shown a strong association with the development of squamous cell laryngeal carcinoma (Liberale et al, 2023). HPV-18, another high-risk virus, has also been frequently isolated
- Epstein Barr virus (EPV): the role of EBV is controversial and it is now thought that both HPV and EBV are viruses capable of promoting carcinogenesis and tumour progression.

There are several other factors under scrutiny for their possible impact on the development of laryngeal cancer, which are shown in *Table 1*.

SIGNS AND SYMPTOMS

Malignant tumours affect the physiology of the larynx but the most frequently reported symptoms of laryngeal malignancies include hoarseness, sore throat, dysphagia and/or painful swallowing, impairment in voice quality, otalgia, cough, and haemoptysis (Nocini et al, 2020). Warning signs vary according to the site and location of the malignancy (see below).

Supraglottic tumours

These represent approximately one-third of all laryngeal cancers (Salvador Coloma and Cohen, 2016). They are often asymptomatic until they have reached an advanced stage and are associated with cervical lymph node metastatic spread (Williamson et al, 2012). These tumours affect the voice when they have spread to the vocal cords, causing hoarseness later in the disease progression.

Glottic tumours

These are the most common and prevalent form of laryngeal cancers, representing approximately two-thirds of all cases (Salvador Coloma and Cohen, 2016). They are more likely to be detected earlier because of their effect on voice quality, manifesting as hoarseness of the voice and often metastasise late as the vocal cords themselves are poorly supplied by the lymphatic system (Williamson et al, 2012).

Subglottic tumours

This is the rarest type, representing less than 2% of all laryngeal cancers (Salvador Coloma and Cohen, 2016). They often cause breathing symptoms due to laryngeal obstruction but only affect the voice when they have spread to the vocal cords, presenting with hoarseness later and are therefore commonly associated with poor prognosis if the patient presents with hoarseness alone (Williamson et al, 2012).

DIAGNOSIS

It is not uncommon for patients who develop early symptoms to delay seeking medical advice and therefore presenting at a much later stage with symptoms of pain, swallowing difficulty, a palpable neck mass, or in extreme cases, airway compromise (Jones et al, 2016). If laryngeal cancer is suspected, NICE guidelines suggest urgent referral on a two-week wait for any patient aged

Red Flags

- Tobacco smoking is a major factor in the development of laryngeal cancer
- The impact of cigar and pipe smoking is less known
- When combined with excess alcohol intake, risk is massively increased
- HPV and EBV are both thought to be capable of promoting carcinogenesis and tumour progression.

45 years or older presenting with persistent unexplained hoarseness or an unexplained lump in the neck (NICE, 2021). Flexible laryngoscopy is commonly used to assess the larynx and allows an evaluation of the function and exact location of the tumour. Fine needle aspiration of a neck mass is preferable to an open biopsy, because the latter increases the risk of local and regional recurrence (Pynnonen et al, 2017). Additional investigations are shown in *Table 2*.

STAGING AND GRADING

Staging

Cancer staging is applicable to all cancers and is used to determine tumour size and the degree of spread, and to plan treatment and provide an indication of prognosis (Brierley et al, 2016). There are currently two methods in use (Cancer Research UK, 2022).

TNM stages for cancer of the larynx (tumour, node, and metastases)

This system gives an indication of the size of the tumour and whether it has spread, either to the lymph nodes or to more distant sites such as the lungs or liver. Further information using a numbering system assigns the tumour to a stage — from 1 to 4, with stage 1 indicating an early stage and stage 4 an advanced stage.

Grading

Grading the cancer cells gives the oncologist an indication of how cells under microscopic examination differ in appearance from normal cells. These are generally graded as follows:

- Grade 1 (low grade): cells are well differentiated and look like normal cells
- Grade 2 (intermediate grade): cells are moderately differentiated and look somewhat like normal cells
- Grade 3 (high grade): these cells are poorly differentiated and are grossly abnormal in comparison to normal healthy cells.

TREATMENT AND MANAGEMENT

Treatment and management are under the care of the multidisciplinary team, whose core function is to determine a treatment plan using input from a group of healthcare professionals. This will include input from a variety of specialists including oncologists, maxillofacial surgeons, radiologists, specialist nurses and several others.

Surgery and radiotherapy are two commonly used treatments with the choice dependent on the location of the tumour and stage of the disease.

Early stage supraglottic carcinoma (stages 1 and 2)

Radiotherapy is effective for stage 1 cancer in the supraglottic region and improves functional outcomes and quality of life and is better at preserving voice quality (Salvador-Coloma and Cohen, 2016). Surgery is also effective with results comparable to those of radiotherapy (Simpson Jones et al, 2004). Although radiotherapy or surgery alone is sufficient for the treatment of node negative T1–2 supraglottic cancers, for patients with node positive cancers (stages T1 and T2, N1 stages III–IV) concurrent platinum-based chemoradiotherapy or surgery followed by postoperative radiotherapy is recommended if performance status is sufficient to tolerate this treatment (Jones et al, 2016). *Table 3* gives a simple explanation of the TNM system.

Table 2: Additional investigations for diagnosis of laryngeal cancer (Cancer Research UK, 2021)

Test	Additional information
Ultrasound scan	This uses high frequency sound waves to get a picture of the area under investigation
Videostroboscopy	This involves insertion of a long, thin, flexible tube to examine the voice box while the patient is speaking
Computed tomography (CT) scan	This uses X-rays to take pictures from different angles and a computer. Once the images have been taken, the computer puts them together to form a three-dimensional image
Magnetic resonance imaging (MRI) scan	This can produce images from all over the body and can show up abnormal areas in various parts of the body, including the lymph nodes
Positron emission tomography (PET)-CT scan	This uses low dose radiation and may be used to give more detailed information about abnormal areas found on MRIs, CT scans or X-rays

Practice point

Performance status is a score used to estimate a patient's ability to perform basic activities of daily living (e.g. eating, bathing, getting dressed) and is useful in determining best treatment options and in shaping prognosis (West, 2015).

Early stage glottic carcinoma (T1–T2)

In the UK, cancers at this stage are usually treated with radiotherapy, with partial laryngeal surgery in reserve or transoral laser microsurgery (Jones et al, 2016) (a minimally invasive procedure used to remove small or medium sized tumours through the mouth). One treatment only is advised, as combining surgery with radiotherapy can impact on functional outcomes (and perhaps survival in the context of incompletely resected tumour) when combination therapies are used (Jones et al, 2016).

Subglottis

Cancers in this region are asymptomatic early in the disease process, but behave more aggressively and are frequently diagnosed late. However, if diagnosed early, radiotherapy is an option (MacNeil et al, 2018). Other treatment options for primary subglottic carcinoma include surgery (laryngectomy or partial laryngectomy), radiation (with or without chemotherapy), or combination therapy (MacNeil, 2018).

Glottis

Patients with early-stage cancer should be treated using a larynx preserving approach, either radiotherapy or transoral laser surgery (see above) (Salvador-Coloma and Cohen, 2016).

Treating advanced stage cancers

The term advanced laryngeal cancer generally denotes those at stages

Table 3: TNM system explained (National Cancer Institute, 2022)

T (tumour)	Information	N (node)	Information	Metastases	Information
T0	Primary tumour cannot be found	N0	No spread to nearby lymph nodes	MO	Cancer has not spread to other parts of the body
T1, 2, 3, 4	Refers to the size and/or extent of the primary tumour. The higher the number, the larger the tumour or degree of spread. Can be subdivided further (e.g. T3a, T3b) to give more detail	N1, 2, 3	Refers to the number and location of lymph nodes that contain cancer. The higher the number, the more lymph nodes contain cancer cells	M1	Cancer has spread to other parts of the body

3 or 4 and is assigned by virtue of advanced T classification (T3 or T4), N classification (N1–3) or M classification (Sheahan, 2014). In years gone by, total laryngectomy was the gold standard treatment, however it is associated with significant functional and psychological sequelae (Sheahan, 2014). Preservation of the larynx is now preferred with chemotherapy and radiotherapy. However, a minority of patients with T3–T4 primary site disease may be suitable for specialised organ-preservation procedures, such as a supracricoid partial laryngectomy (involves removing part of the larynx, vocal cords, epiglottis and thyroid cartilage but leaving the cricoid cartilage intact) (Sperry et al, 2013). Fernandez et al (2023) suggested that surgical treatment associated with complementary radiation therapy offers better survival rates in advanced laryngeal cancer patients.

PROGNOSIS AND SURVIVAL RATES

Despite advances in available treatments, the five-year survival rate for all stages of laryngeal cancer varies widely according to the tumour site and stage at diagnosis (Bradford et al, 2020). In addition, there are other multiple factors which affect outcomes.

Ageing is associated with decreased organ function, more comorbidities, and cognitive dysfunction, which can affect the immune system, response to treatment and prognosis (Sommers et al, 2017). Additional prognostic factors include patient age, nutritional status, physical performance status, comorbidities, as well as the tumour site, stage and grade (Kim et al, 2023). In terms of overall survival, older age (>60 years), a history of smoking, a history of alcohol consumption, a high Charlson comorbidity index score (*Table 4*), a high TNM stage (3 and 4), nodal involvement, and poor pathological differentiation, have all been found to increase risk of death (Kim et al, 2023).

CONCLUSION

Laryngeal cancer is a devastating diagnosis for anyone affected. The early signs and symptoms may easily be mistaken for other less serious diseases, so patients may delay getting medical advice believing the cause to be harmless. This results in later presentation and delayed diagnosis which impacts on outcomes. Clinicians assessing patients with symptoms may find making a diagnosis challenging. It is hoped that this article has raised awareness among nurses and non-medical prescribers enabling earlier recognition and referral with the aim of improving outcomes in the future.

REFERENCES

Bilano V, Gilmour S, Moffiet T, et al (2015) Global trends and projections for tobacco use, 1990–2025: An analysis of smoking indicators from the WHO Comprehensive Information Systems for Tobacco Control. *Lancet* 385: 966–76

Bradford CR, Ferlito A, Devaney KO, et al (2020) Prognostic factors in laryngeal squamous cell carcinoma. *Laryngoscope Investig Otolaryngol* 5(1): 74–81

Brierley J, Gospodarowicz M, O'Sullivan B (2016) The principles of cancer staging. *Ecancermedicalscience* 10: ed61

Cancer Research UK (2021) *Tests for laryngeal cancer*. Available online: www.cancerresearchuk.org-about-cancer/laryngeal-cancer/getting-diagnosed/tests-diagnose

Cancer Research UK (2022) *Survival for laryngeal cancer*. Available online: www.cancerresearchuk.org/about-cancer/laryngeal-cancer/survival

Ciolofan MS, Vlăescu AN, Mogoantă CA, et al (2017) Clinical, histological and immunohistochemical evaluation of larynx cancer. *Curr Health Sci J* 43: 367–75

Fernandez EM, Palacios-Garcia JM, Morenajo-Luna R, et al (2023) Survival analysis in patients with laryngeal cancer: A retrospective cohort study. *Life (Basel)* 13(2): 295

Johnson JT (2023) *Malignant tumours of the larynx*. Medscape. Available online: https://emedicine.medscape.com/article/848592-overview#a9

Jones TM, De M, Foran B, et al (2016) Laryngeal cancer: United Kingdom National Multidisciplinary guidelines. *J Laryngol Otol* 130(Suppl 2): S75–S82

Kim DH, Won Kim S, Han JS, et al (2023) The prognostic utilities of various risk factors for laryngeal squamous cell carcinoma: A systematic review and meta-analysis. *Medicina (Kaunas)* 59(3): 497

Revalidation Alert

Having read this article, reflect on:

- Your knowledge of risk factors for laryngeal cancer
- The signs and symptoms of laryngeal cancer
- Different sites and locations for malignancy
- Why laryngeal cancer is often diagnosed late
- Treatment and management for laryngeal cancers.

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

Table 4: Charlson comorbidity index (MD Calc, 2023)

Issue	Additional information	Score
Age	50–59 years of age 60–69 years of age 70–79 years of age 80 plus years of age	+1 +2 +3 +4
Myocardial infarction (MI)	History of probable or definite MI changes and/or enzyme changes	No: 0; Yes: +1
Chronic heart failure (CHF)	Exertional or paroxysmal nocturnal dyspnoea which has responded to medication (diuretics, digitalis, etc)	No: 0; Yes: +1
Peripheral vascular disease	Intermittent claudication, past bypass surgery for chronic arterial insufficiency, history of gangrene, acute arterial insufficiency or untreated abdominal or thoracic aneurysm	No: 0; Yes: +1
Cerebrovascular accident (CVA) or transient ischaemic attack (TIA)	History of CVA with minor or no residual TIAs	No: 0; Yes: +1
Dementia	Chronic cognitive deficit	No: 0; Yes: +1
Chronic obstructive pulmonary disease (COPD)	Includes COPD, emphysema, and chronic bronchitis	No: 1; Yes: +1
Connective tissue disease	Autoimmune conditions (e.g. rheumatoid arthritis, scleroderma)	No: 1; Yes: 2
Peptic ulcer disease	Past treatment for ulcer disease or bleeding ulcer	No: 0; Yes: +1
Liver disease	Severe: cirrhosis and portal hypertension with variceal bleeding history Moderate: cirrhosis and portal hypertension. No bleeding history Mild: chronic hepatitis or cirrhosis without portal hypertension	None: 0 Mild: + 1 Moderate to severe +3
Diabetes mellitus	None or diet controlled Uncomplicated End organ damage	0 +1 +2
Hemiplegia	Following CVA	No: 0; Yes: 1
Moderate to severe chronic kidney disease (CKD)	Severe: on dialysis	No: 0; Yes: 2
Solid tumour	Tumour which has no fluid or cysts	No: 0 Localised: +2 Metastatic: +6
Leukaemia		No: 0; Yes: +2
Lymphoma		No: 0; Yes: +2
Acquired immunodeficiency syndrome (AIDS)		No: 0; Yes: +6
NB: 0 points + estimated 10-year survival 98%. The higher the score, the higher the predicted mortality rate.		

Koroulakis A, Agarwal M (2022) *Laryngeal cancer*. StatPearls. Available online: www.ncbi.nlm.nih.gov/books/NBK526076/

Liberale C, Soloperto D, Marchioni A, et al (2023) Updates on laryngeal cancer: Risk factors and oncogenesis. *Int J Mol Sci* 24(16): 12913

MacNeil SD, Patel K, Liu K, et al (2018) Survival of patients with subglottic squamous cell carcinoma. *Curr Oncol* 25(6): e569–e575

MD CALC (2023) *Charlson comorbidity index (CCI)*. Available online: www.mdcalc.com/calc/3917/charlson-comorbidity-index-cci

National Cancer Institute (2022) *Cancer staging*. Available online: www.cancer.gov/about-cancer/diagnosis-staging/staging

National Institute for Heath and Care Excellence (2021) *Head and neck cancers: recognition and referral*. Available online: https://cks.nice.org.uk/topcs/head-neck-cancers-recognition/background-information

Nocini R, Molteni G, Mattiuzzi C, et al (2020) Updates on laryngeal cancer epidemiology. *Chin J Cancer Res* 32(1): 18–25

Pynnonen MA, Boyd Gillepsie M, Roman B, et al (2017) Clinical practice guideline: Evaluation of a neck mass in adults. *Otolaryngol Head Neck Surg* 157(2suppl): S1–S30

Ramroth H, Dietz A, Becher H (2011) Intensity and inhalation of smoking in the aetiology of laryngeal cancer. *Int J Environ Res Public Health* 8(4): 976–84

Salvador-Coloma C, Cohen E (2016) Multidisciplinary care of laryngeal cancer. *J Oncol Pract* 12(8): 717–24

Saran M, Georgakopoulos B, Bordoni B (2023) Anatomy, head and neck, larynx vocal cords. StatPearls. Available online: www.ncbi.nlm.nih.gov/books/NBK535342/

Sheahan P (2014) Management of advanced laryngeal cancer. *Rambam Maimonides Med J* 5(2): e0015

Simpson Jones A, Fish B, Fenton JE, et al (2004) The treatment of early laryngeal cancers (T1–T2 N0): surgery or irradiation? *Head Neck* 26(2): 127–35

Sommers LW, Steenbakkers R, Bijl HP, et al (2017) Survival patterns in elderly head and neck squamous cell carcinoma patients treated with definitive radiation therapy. *Int J Radiat Oncol Biol Phys* 98: 793–801

Sperry SM, Rassekh CH, Laccourreye MD, et al (2013) Supracricoid partial laryngectomy for primary and recurrent laryngeal cancer. *JAMA Otolaryngol Head Neck Surg* 139(11): 1226–35

West H (2015) Performance status in patients with cancer. *JAMA Oncol* 1(7): 998

Willacy H (2023) *Throat cancer*. Available online: https://patient.info/cancer/throat-cancer-laryngeal-cancer

Williamson JS, Biggs TC, Ingrams D (2012) Layrngeal cancer: an overview. *Trends Urol Men's Health*. Available online: https://wchh.onlinelibrary.wiley.com/doi/pdf/10.1002/tre.295

Weight management for those with low energy requirements

Carolyn Taylor

Maintaining an ideal weight is difficult for many people. For those who have reduced energy requirements, such as people with a spinal cord injury (SCI), maintaining a healthy weight can be more challenging. There are many barriers, including difficulties with increasing energy expenditure. This article discusses these challenges along with the increased health risks of diabetes and coronary heart disease seen within this population. Through a review of the literature, some practical solutions are provided. These include having weight management programmes starting soon after injury, education including carers', and focusing on behavioural change techniques as part of a multidisciplinary approach to encouraging a healthy lifestyle, lifelong.

KEYWORDS:
■ Weight management ■ Spinal cord injury ■ Challenges
■ Solutions ■ Energy expenditure ■ Prevention of weight gain

If you look at the weight management industry and anything in the popular press, there are a myriad of tips and hints to lose weight, including reported unbelievable success stories of diets endorsed by celebrities. Weight gain is a growing problem. Figures for the general population in 2019 were that 64% were overweight and 28% had obesity (House of Commons Library, 2003). If weight loss or preventing weight gain was easy, these figures would be different and the weight management industry would not need to promote the next best answer to weight loss and maintaining an ideal body weight.

For a number of people, their clinical conditions means that achieving and maintaining an ideal weight is more difficult. This is not only due to the effect that their condition has on energy expenditure, but also because obesity has a massive effect on quality of life and long-term health. This is on top of any psychological impact that weight and body composition may have on body image, as well as having to come to terms with physical changes from their clinical condition, such as spinal cord injury (SCI). For example, SCI is a condition where there is a reduction in energy expenditure (Farkas et al, 2019).

This article considers what can be done to support a better weight management programme for people whose energy expenditure is reduced, or the ability to exercise is limited, such as those who are wheelchair bound, using SCI as the condition. However, the learning from this can relate to other conditions not covered in this article, i.e. those with lower limb amputations and people struggling with chronic fatigue (Evans et al, 2009) and potentially, more recently, Long Covid. Motor neurone disease (MND) can affect swallowing and so alternative nutritional support is required to prevent rapid weight loss (De Silva et al, 2022). There are other neurological conditions, such as MND or conditions with high amounts of uncontrolled spasm, where alternative nutritional support is required to prevent weight loss. (De Silva et al 2022). This article focuses solely on those whose energy requirements are low.

Spinal cord injury is a disability which usually presents as a sudden loss of function below the affected part of the spinal cord (Qin et al, 2010). For those with other neurological conditions, the change may be more progressive allowing for a more gradual adaption to changing body composition. Following SCI or other neurological conditions, there can be a loss of muscle mass. Where the injury is due to trauma, the loss of muscle is dramatic and fast resulting in rapid weight loss (Thibault-Halman et al, 2011). Clinical guidelines are that people who lose more than 5% of their body weight in three to six months are at risk of malnutrition (British Association for Parenteral and Enteral Nutrition [BAPEN], 2003). The rapid weight loss people with SCI experience in the first three months can exceed this level, with reports of up to 10–15kg weight loss over this time (Laven et al, 1989). This should encourage the clinical team to try to prevent such rapid weight loss. The author's clinical experience also demonstrates that patients and their families find this rapid weight loss worrying and also want to prevent it, so that rehabilitation is not compromised or the risk of skin damage resulting in complications, such as pressure ulcers, increased.

However, it is not clear what

Practice point

Weight loss involves eating less than the body needs and overcoming hunger sensations for potentially a long period of time.

Carolyn Taylor, specialist dietitian for spinal cord injuries, Sheffield Teaching Hospital NHS Foundation Trust

an acceptable weight loss should be in the initial weeks and months following injury. It may be that by preventing dramatic weight loss, healthcare professionals are actually predisposing patients to being overweight in the longer term (Crane et al, 2011). By encouraging the use of high calorie snacks to prevent weight loss, less healthy eating dietary patterns might set in, which patients then have to change when they are discharged home. With other neurological conditions, such as multiple sclerosis (MS), individuals may be concerned that weight loss indicates a deterioration in their clinical condition and so, in the author's clinical experience, they try and prevent it — again by eating higher calorie snacks.

When reviewing the literature, there are no weight management programmes for patients less than one year post injury. This is perceived to be due to the ongoing body composition changes that are happening in the acute phase following injury. However, research has shown that weight gain is at its fastest in the first year following injury and after this time it is generally at a slower rate (de Groot et al, 2010). In the author's clinical opinion, although it would seem prudent to try and prevent this initial weight gain, this is often at a psychologically challenging time when people are dealing with life-changing injuries. A recent literature review could not find any research into how best to support those in the initial post injury phase (Madigan et al, 2024). Pellegrini et al (2021) found that healthcare professionals are concerned about talking to newly injured patients about the likelihood of developing obesity in later years, as they have too many other changes to face during the acute phase.

CONSEQUENCES OF WEIGHT GAIN

To understand changes in energy requirements, it is necessary to consider body composition. Muscle has a higher metabolic demand and therefore when people have less muscle present energy needs are reduced (Farkas et al, 2019; Ma et al, 2022). When physical mobility is also reduced, there is a further reduction in energy needs. If there is no nerve supply to the muscle, the excess fat cannot be made into muscle as it will shrink and weaken due to disuse (atrophy). Furthermore, without impact exercises, bone will not be stimulated to increase in density (Gorgey et al, 2014). If energy intake continues at pre-injury levels, increased adiposity occurs. This results in people with SCI having a higher fat mass for the same body weight as the general population (Buchholz and Bugaresti, 2005). A higher fat mass predisposes the SCI patient to greater risk of diseases associated with obesity, such as diabetes and coronary heart disease (Myers et al, 2007; Cragg et al, 2013). Indeed, SCI patients have a two-fold increase in the risk of diabetes and 40% mortality associated with coronary heart disease (Myers et al, 2007; Cragg et al, 2013). Furthermore, patients have reported to the author that increased weight reduces mobility, which can:

- Put strain on carers who are helping with transfers
- Increase risk of pressure ulcers
- Increase isolation — patients have reported to the author that increasing weight means that they struggle to mobilise in their wheelchair or get out of their house.

This is alongside the psychological impact of changes to body image. A carer the author recently worked with reported, 'As my husband has been getting older and putting on weight, I have been getting older as well but becoming weaker making managing his weight and helping with transfers has become more difficult for us'.

Ideal body weight is often classified using body mass index (BMI) ranges, which is a relationship between weight and height. A healthy weight is classified as a BMI between 24.9kg/m^2. In view of the increased risk of conditions associated with obesity, it has been suggested that BMI ranges are changed for those with a SCI, with the healthy range becoming greater than 22kg/m^2 (Silveira et al, 2017). However, following a recent service evaluation the author completed at a local spinal injuries unit, 60% of patients already had a BMI greater than 25kg/m^2. Using these SCI cut-offs would mean the majority of patients are already overweight, tending towards obesity, after their initial injury.

CHALLENGES OF WEIGHT REDUCTION

Managing weight changes therefore becomes important and challenging. Those who have tried to lose weight themselves or supported others will know that weight loss is difficult. The National Institute for Health and Care Excellence (NICE, 2023) recommends that for the general population an energy deficit of 600kcals/d should be followed for weight loss. It is unclear if this target is the same for people with SCI or other neurological conditions. However, when energy requirements are low, it follows that there should be an even lower calorie intake to reduce weight — the ultimate aim being for a lower ideal body weight. It is for this reason that there is a trend in the literature towards preventing weight gain as a more realistic proposition.

As said, people with SCI have reduced energy requirements due to reduced muscle mass and energy expenditure. The author's experience is that people with SCI are often keen to know exactly what their calorie requirements are. SCI consists of injury to different levels of the spinal cord, each associated with different vertebra of the spinal column. This results in different amounts of possible movement. There is also the severity of the injury to consider, which is classified according to the American Spinal Injury Association (ASIA) score, the international standard for neurological classification of SCI. The score (A–E) will determine how complete the neurological injury is and what motor or sensory sparing there is. These differing parameters result in different energy needs, as possible muscle mass will vary leading to individual levels of physical ability. This is indicated in the need for different energy requirements for

people with para- and tetraplegia (Shea et al, 2018).

For each individual patient, a body composition of fat and muscle mass should ideally be obtained and the frequently cited option for this is the dual energy X-ray absorptiometry (DEXA) scan (Messina et al, 2020). However, this is unlikely to be available within normal clinical practice on a regular basis. Surrogate measures can therefore be used, including bioelectrical impedance or skinfold measurements. Due to differences in body composition relating to differing levels of SCI and the lack of SCI-specific normal ranges, these measurements are best used for monitoring each individual's progress, rather than as a comparison against a benchmark. When complex and expensive equipment, such as indirect calorimetry, is not available, predictive equations are often used to estimate energy expenditure.

Generally, the accepted energy requirements for SCI are 23–28kcals/kg body weight. However, there is evidence that these overpredict energy requirements for people with SCI (Farkas et al, 2021). Farkus et al (2021) suggested that individual indirect calorimetry is required to more accurately predict individual energy needs. While useful in the research setting, these types of measurements are not routinely undertaken as part of clinical practice within the UK. The energy needs of a 70kg male who is tetraplegic to maintain weight would be around 23kcal/kg, which is equivalent to 1610kcals. If this man was 1.7m, his BMI would be 24kg/m^2. This would be within the normal range for someone who was able bodied, but for a person with SCI efforts may be required to reduce their weight to fit the suggested healthy ranges for SCI. Taking the NICE recommendations of a daily deficit of 600kcals/d would result in energy needs of 1000kcals/d. In this example, as the man is a tetraplegic, his ability to increase energy needs with activity will be significantly reduced.

To complicate matters further, rapid weight loss can reduce skin integrity and result in increased risk of pressure ulcers (NICE, 2014a). Reasons for this could be associated with loss of fat layers in the skin, or due to a nutritionally inadequate diet. Using very low calorie diets (800kcals/d or less) could increase this risk further and should only be considered with appropriate support and monitoring, especially focusing on micronutrients which are essential to skin integrity (Multidisciplinary Association of Spinal Cord Injury Professionals [MASCIP], 2018). There is a risk that these very low calorie diets are not nutritionally adequate for prolonged periods.

Exercise is often considered to help stimulate weight loss. While there is evidence that increasing physical activity improves lean body mass and flexibility, which in turn can help to maintain independence for longer and reduce mortality, there is limited evidence that exercise reduces body weight (Shojaei et al, 2017). There is also evidence that people with SCI are less likely to undertake physical activity than the general population (Ginis et al, 2018). Specific barriers include local gyms not having wheelchair accessible equipment, or staff who feel comfortable supporting people with disabilities (Vissers et al, 2008). For example, a person with SCI reported to the author that to use a swimming pool they had to get changed into their swimming costume in the disabled area and then go through the main reception to access the swimming pool. They felt that this was humiliating and therefore were unlikely to use that swimming pool again. Overcoming such barriers and dietary changes should be considered to support these patients.

There are guidelines to help promote physical activity (Ginis et al, 2018) and an increasing breadth of evidence-based resources available (www.wheelpower.org.uk/getting-started/physical-activity-after-a-spinal-cord-injury/). As discussed earlier, changes may need to start when the patient is first injured to prevent weight gain.

The complexity of weight reduction for people with SCI is highlighted in *patient story one*.

An additional point to consider is that people with SCI will also have a neurogenic bowel so may not be able to tolerate a high fibre intake associated with the traditional low calorie, healthy diet. For these patients, a gradual reduction in fibre content may be required.

Patient story one

A man who had had SCI for 15 years was struggling with shoulder pain and had been advised to lose weight to help alleviate this pain. However, while trying to support dietary changes, he decided it would be better to change to using an electric wheelchair. The concern was that his physical activity was going to drop even further, resulting in weight gain. However, once he got his electric wheelchair, he actually lost weight. The independence the electric wheelchair gave him improved his self-confidence, his ability to get out and about, and therefore reduced his snacking, which he had not really realised he was doing due to boredom and depression. This demonstrates how dietary intake and subsequent weight management are intertwined with many factors.

WHAT ARE POSSIBLE SOLUTIONS?

MASCIP has supported the publication of guidance for weight management for SCI (MASCIP, 2018). This involved collaboration between dietitians, physiotherapists, psychologists, medical staff and patient representatives to develop consensus recommendations on various elements related to weight management. In particular, it included:

- Classification of obesity
- Nutrition education
- Dietary interventions
- Behavioural therapy
- Physical activity interventions

- Medical and surgical interventions
- Implications on bowel management.

While these guidelines were being produced, it was noted that evidence was lacking and some parallels had to be drawn from the NICE recommendations for the general population, rather than SCI-specific evidence. One area of interest was the use of commercially available weight management programmes which have reported successes in general obesity management. The author has experience of SCI patients attempting to utilise these to support weight loss. However, they have had problems with being weighed, with only stand-on scales available. They have also reported that the leaders of the groups have little knowledge of their nutritional requirements. The MASCIP recommendations highlighted that specialist support would ideally be required for those with a disability, as specialists would have the knowledge to deal with the intricacies of the clinical condition (MASCIP, 2018). For example, they comprehend that reduction in energy intake can help to support weight management, but that target weight loss is appropriate to ensure maintenance of skin integrity. MASCIP (2018) suggested that the target weight loss should be around 0.5–1kg weight loss a week, with a target of 10% weight loss in a six-month period.

A recent systematic review (Madigan et al, 2024) indicated that such weight management programmes enable 30% of patients to achieve more than a clinically relevant 5% weight loss level, not the 10% recommended above. The programmes included in the systematic review were a combination of calorie-restricted diet with increasing physical activity. These results indicate how difficult weight loss is with this population and again raise the question that preventing weight gain may be a more realistic proposition.

Evidence for obesity management and weight loss in the general population includes recommendations for behavioural change techniques for long-term compliance and maintenance of lost weight (NICE, 2014b). The MASCIP guidelines (2018) also highlight that behaviour change techniques are likely to be beneficial for the SCI population. These can help with adjusting dietary intake and physical activity levels.

There is limited evidence of the benefit of other weight management techniques, such as use of very low calorie diets or meal replacement programmes. However, there is evidence of the success of bariatric surgery with this population. A systematic review documented that bariatric surgery produced the greatest permanent weight reduction in SCI (Shojaei et al, 2017). This may seem a radical and costly management technique. There are also some emerging studies into the benefit of newly available obesity drugs (Cirnigliaro, 2023). Both of these management strategies have been approached with caution with this patient cohort due to the neurogenic bowels that people with SCI experience. From the author's discussions with clinical experts, including active researchers and consultants, there is a concern that with already slower bowel movement, potentially altered appetites and risk of autonomic dysreflexia, that these treatments may be contraindicated. Further research is required to understand the benefit of these drugs for this patient population.

CONCLUDING THOUGHTS

In the UK, the SCI population has lifelong support from specialist spinal injury centres around the country. However,the limited number of these centres means that geographically patients are often some distance away. Accessing specialist support recommended for weight management can involve considerable travel. If weight management services require weekly reviews, this involves a great deal of commitment.

Support more locally would be beneficial, using local services and experience. One option is the tier 3 weight management programmes delivered locally. These services focus on weight reduction rather than preventing weight gain, but may be helpful provided that consideration is given as to how people can be weighed and how their specific needs are catered for.

A study by LaVela (2022) highlighted that some healthcare professionals felt that there was no evidence available on how to support these patients, highlighting how ongoing education is not only required for patients, but also the staff supporting them. In addition, as said, focus needs to be more on preventing weight gain rather than achieving weight loss. Educating staff to discuss this appropriately with newly injured patients is helpful so that they feel supported in all aspects following the life changes they are experiencing. Pellegrini et al (2021) reported one healthcare professional as saying:

> *A lot of patients use food as their only form of pleasure because they've lost other forms of pleasure and sensation of their body. Even us as human beings that don't have something that traumatic, we turn to food as a comfort. Food is so much more than just nutrition. There's so many more things involved, so when that's something that you get instant gratification from when so many other things have gone bad in your life, I think that's a big barrier.*

The benefits of addressing increasing weight can be seen in *patient story two*.

Weight maintenance is complex, but by understanding the intricacies of specific requirements associated with SCI and other disabilities it is possible to have a successful outcome. JCN

REFERENCES

British Association for Parenteral and Enteral Nutrition (2003) *Malnutrition Universal Screening Tool (MUST)*. Available online: www.bapen.org.uk/pdfs/must/must_full.pdf

Buchholz AC, Bugaresti JM (2005) A review of body mass index and waist circumference as markers of obesity and coronary heart

This young lady had a high tetraplegic injury. As her weight increased, her breathing was affected and she started to need more support for ventilation. As a high tetraplegic, she was unable to increase her physical activity. Her weight gain and need for ventilation affected her psychologically. She was proud of her physical appearance, but the introduction of tracheostomy tubes was a difficult change for her to accept. By focusing on careful weight management, through consideration of her energy intake, she was able to reduce her weight, her breathing improved, and requirement for ventilation was reduced again. This not only improved her health and breathing, but also her psychological state to cope with the SCI.

disease risk in persons with chronic spinal cord injury. *Spinal Cord* 43(9): 513–8

Cirnigliaro CM, La Fountaine MF, Sauer SJ, Cross GT, Kirshblum SC, Bauman WA (2023) Preliminary observations on the administration of a glucagon-like peptide-1 receptor agonist on body weight and select carbohydrate endpoints in persons with spinal cord injury: A controlled case series. *J Spinal Cord Med* 9: 1–8

Cragg J, Noonan VK, Dvorak M, Krassioukov A, Mancini GBJ, Borisoff JF (2013) Spinal cord injury and type 2 diabetes: results from a population health survey. *Neurology* 81(21): 1864–68

Crane DA, Little JW, Burns SP (2011) Weight gain following spinal cord injury: a pilot study. *J Spinal Cord Med* 34(2): 227–32

De Groot S, Post MWM, Postma K, Sluis TA, Van der Woude LHV (2010) Prospective analysis of body mass index during and up to 5 years after discharge from inpatient spinal cord injury rehabilitation. *J Rehabil Med* 42: 922–8

De Silva S, Turner BJ, Perera ND (2022) Metabolic dysfunction in motor neurone disease: shedding light through the lens of autophagy. *Metabolites* 12(7): 574

Evans KM, Flanagan DE, Wilkin TJ (2009) Chronic fatigue: is it endocrinology? *Clin Med (Lond)* 9(1): 34–8

Farkas GJ, Pitot MA, Berg AS, Gater DR (2019) Nutritional status in chronic spinal cord injury: a systematic review and meta-analysis. *Spinal Cord* 57: 3–17

Farkas GJ, Sneij A, Gater DR Jr (2021) Energy expenditure following spinal cord injury: a delicate balance. *Top Spinal Cord Inj Rehabil* 27(1): 92–9

Ginis KAM, van der Scheer JW, Latimer-Cheung AE, et al (2018) Evidence-based scientific exercise guidelines for adults with spinal cord injury: an update and a new guideline. *Spinal Cord* 56: 308–21

Gorgey AS, Dolbow DR, Dolbow JD, Khalil RK, Castillo C, Gater DR (2014) Effects of spinal cord injury on body composition and metabolic profile — part 1. *J Spinal Cord Med* 37(6): 693–702

House of Commons Library (2023) *Obesity statistics*. Available online: https://researchbriefings.files.parliament.uk/documents/SN03336/SN03336.pdf

LaVela SL, Pedersen J, Ehrlich-Jones L, Heinemann AW (2022) Informal caregivers' self-identified roles in facilitating health-promoting behaviours for weight management in community-dwelling care recipients living with spinal cord injury in the United States. *Health Soc Care Community* 30(5): e1585–98

Laven GT, Huang C-T, DeVivo MJ, Stover SL, Kuhlemeier KV, Fine RR (1989) Nutritional status during the acute stage of spinal cord injury, 1989. *Arch Phys Med Rehabil* 70(4): 277–82

MaY, de Groot S, Hoevenaars D, Achterberg W, Adriaansen J, Weijs PJM, et al (2022) Predicting resting energy expenditure in people with chronic spinal cord injury. *Spinal Cord* 60(12): 1100–07

Madigan CD, King JA, Taylor C, et al (2024) A systematic review and qualitative synthesis of weight management interventions for people with spinal cord injury. *Obes Rev* Jun 9: e13785 [online ahead of print]

Messina C, Albano D, Gitto S, Tofanelli L, Bazzocchi A, Ulivieri FM, Guglielmi G, Sconfienza LM (2020) Body composition with dual energy X-ray absorptiometry: from basics to new tools. *Quant Imaging Med Surg* 10(8): 1687–98

Multidisciplinary Association for Spinal Cord Injury Professions (2018) *MASCIP Guideline for weight management in individuals with spinal cord injury*. Available online: www.mascip.co.uk/wp-content/uploads/2019/10/03-May-2018-Wong-et-al-MASCIP-Weight-Management-Guidelines-for-People-with-a-Spinal-Cord-Injury.pdf

Myers J, Lee M, Kiratli J (2007) Cardiovascular disease in spinal cord injury: an overview of prevalence, risk, evaluation, and management. *Am J Phys Med Rehabil* 86(2): 142–52

National Institute for Health and Care Excellence (2014a) *Pressure ulcers: prevention and management*. Clinical guideline [CG179]. Available online: www.nice.org.uk/guidance/cg179

National Institute for Health and Care Excellence (2014b) *Weight management: lifestyle services for overweight or obese adults*. Public health guideline [PH53]. Available online: www.nice.org.uk/guidance/ph53

National Institute for Health and Care Excellence (2023) *Obesity: Identification, assessment and management*. Available online: www.nice.org.uk/guidance/cg189

Pellegrini CA, Burkhart L, Jones K, LaVela SL (2021) Health provider identified barriers and facilitators to weight management for individuals with spinal cord injury. *Spinal Cord* 59(10): 1061–71

Qin W, Bauman WA, Cardozo C (2010) Bone and muscle loss after spinal cord injury: organ interactions. *Ann NY Acad Sci* 1211: 66–84

Shea JR, Shay BL, Leiter J, Cowley KC (2018) Energy expenditure as a function of activity level after spinal cord injury: the need for tetraplegia-specific energy balance guidelines. *Front Physiol* 19(9): 1286

Shojaei MH, Alavinia SM, Craven BC (2017) Management of obesity after spinal cord injury: a systematic review. *J Spinal Cord Med* 40(6): 783–94

Silveira S, Ledoux T, Robinson-Whelen S, et al (2017) Methods for classifying obesity in spinal cord injury: a review. *Spinal Cord* 55: 812–17

Thibault-Halman G, Casha S, Singer S, Christie S (2011) Acute management of nutritional demands after spinal cord injury. *J Neurotrauma* 28: 1497–1507

Vissers M, Van den Berg-Emons R, Sluis T, Bergen M, Stam H, Bussmann H (2008) Barriers to and facilitators of everyday physical activity in persons with a spinal cord injury after discharge from the rehabilitation centre. *J Rehabil Med* 40(6): 461–7

Addressing mental health inequalities

Sabrina Garnowski

This article explores the multifaceted landscape of mental health inequalities and proposes a comprehensive approach for community nurses to address these disparities. Drawing on legislative measures, healthcare delivery reforms, and community engagement initiatives, the article emphasises the pivotal role of nurses in advocating for equitable access to mental health services and promoting inclusive care practices. Key considerations include the impact of social determinants of health, the need for collaborative multidisciplinary approaches, and the importance of addressing systemic factors perpetuating inequality within the healthcare system.

KEYWORDS:
■ Mental health ■ Inequalities ■ Community nursing
■ Prescribing practices ■ Legislative measures

The pursuit of equitable healthcare lies at the heart of modern society's moral imperative, enshrined in legislation such as the Equality Act (2010), which safeguards individuals against discrimination based on characteristics like age, disability, and gender identity. However, despite legislative efforts, health inequalities persist, manifesting as avoidable disparities in health outcomes among different demographic groups. The National Health Service (NHS) *Long Term Plan* (NHS England, 2019a) underscores a commitment to addressing these disparities by prioritising the most marginalised communities, including ethnic minorities, those with disabilities, and individuals facing socioeconomic challenges. Similarly, the community mental health framework (CMHF) (NHS England, 2019b) emphasises the need for tailored approaches to mental healthcare delivery, advocating for collaboration between healthcare providers and community organisations.

'Nurses, as frontline healthcare professionals, play a crucial role in championing inclusivity and challenging discrimination in healthcare settings.'

Nurses, as frontline healthcare professionals, play a crucial role in championing inclusivity and challenging discrimination in healthcare settings. The Nursing and Midwifery Council (NMC, 2020) emphasises the importance of nursing practice that upholds dignity, respect, and inclusivity for all patients, irrespective of their background or identity. Moreover, nurse prescribers are tasked with considering and respecting the diverse values and beliefs of patients regarding their health and treatment options, thereby promoting equality and cultural competence in medication management (Royal Pharmaceutical Society [RPS], 2021).

Despite these efforts, the intersection between mental health and inequality remains stark. Individuals with long-term physical health conditions, such as diabetes or cardiovascular disease, are disproportionately affected by mental health issues like depression, yet only a fraction of them access treatment (Public Health England [PHE], 2016). Furthermore, overprescribing of psychotropic medications for common mental health conditions by general practitioners underscores systemic challenges in mental health care delivery (Pilling et al, 2011). This overreliance on pharmacological interventions can lead to adverse outcomes, particularly for vulnerable populations such as adults with learning disabilities (NHS England, 2022). Professor Joanna Moncrieff's advocacy for patient autonomy and critical evaluation of psychiatric treatments highlights the need for a nuanced approach to prescribing in mental health care (Middleton and Moncrieff, 2019).

Multidisciplinary collaboration between mental health prescribers, general practitioners, and other healthcare disciplines is essential to ensure holistic care for individuals with complex needs (NMC, 2018). Moreover, the promotion of health behaviour change through interventions like motivational interviewing (MI) underscores the importance of empowering patients to actively participate in their treatment journey (Hart et al, 2016; PHE, 2016). Addressing health inequalities requires a comprehensive understanding of the social determinants of health and a commitment to providing equitable

Sabrina Garnowski, specialist clinical practitioner, Devon Partnership NHS Trust. Sabrina works as part of her contract in Tiverton Primary Care Network (wholly deployed to the PCN under the additional roles reimbursement scheme [ARRS]); Queen's Nurse

access to healthcare services for all individuals, regardless of their background or circumstances. As nurses continue to advocate for inclusivity and equity in healthcare, they serve as catalysts for positive change in the pursuit of health justice for all.

Health inequalities are not limited to mental health but extend to physical health conditions as well, exacerbating disparities in healthcare access and outcomes. Obesity, for example, is not only a physical health concern, but also correlates with various mental health disorders, including mood and anxiety disorders (Lin et al, 2013). Furthermore, the use of certain medications, such as antipsychotics and antidepressants, can contribute to weight gain, posing additional challenges for individuals struggling with their mental health (Goldberg and Ernst, 2019). Prescribers must navigate these complexities, considering both the physical and psychological implications of their treatment decisions. For individuals with eating disorders like anorexia nervosa and bulimia nervosa, prescribing medications associated with weight gain can exacerbate their condition and perpetuate feelings of stigma and shame (Treasure et al, 2003). This underpins the importance of a holistic approach to prescribing, which takes into account the individual's mental and physical wellbeing, as well as their personal values and preferences regarding treatment options (Dent et al, 2012; RPS, 2021).

The challenges of healthcare delivery are further compounded for marginalised and transient populations, such as Travellers and individuals experiencing homelessness. These communities often face barriers to accessing healthcare services, including limited access to medical records and frequent relocations, which disrupt continuity of care (Goward et al, 2006; Greenfields and Brindley, 2016). Consequently, they are at higher risk of mental health issues, including anxiety, depression, and suicide (Van Cleemput, 2018). Addressing the unique needs of these populations requires a coordinated approach involving healthcare providers, social services, and community organisations. Psychosocial interventions, tailored to the specific needs and circumstances of these individuals, can play a crucial role in promoting mental wellbeing and facilitating engagement with healthcare services (Keogh et al, 2020).

Moreover, substance misuse presents a complex challenge at the intersection of mental health and inequality. Approximately 40% of individuals with psychosis engage in substance misuse at some point in their lives, complicating both pharmacological and psychological treatment interventions (National Institute for Health and Care Excellence [NICE], 2011). Comorbid mental health issues in substance misusers are common, highlighting the need for integrated care approaches that address both substance use disorders and underlying mental health conditions (Oluyase et al, 2019). Prescribers should be vigilant in assessing the risks and benefits of medication use in this population, considering the potential for misuse and adverse drug interactions (General Medical Council [GMC], 2023). Multidisciplinary collaboration between mental health specialists, addiction services, and primary care providers is essential to ensure comprehensive and coordinated care for individuals with dual diagnoses.

In addition to addressing health disparities at the individual level, it is imperative to recognise and challenge systemic factors that perpetuate inequality within the healthcare system. The biomedical model, which emphasises the biological aspects of illness while overlooking social determinants of health, has historically dominated psychiatric practice (Wade and Halligan, 2017). However, this reductionist approach fails to account for the complex interplay between biological, psychological, and social factors that contribute to mental health and illness. Alternative frameworks, such as the biopsychosocial model, present a more holistic view of mental health, encompassing social and environmental influences on wellbeing (Engel, 1977, cited in Wade and Halligan, 2017).

Practice point

Power dynamics in PTMF = the various ways in which power relations operate within social structures and interpersonal relationships, usually characterised by dominance or subordination.

Johnstone et al's Power Threat Meaning Framework (PTMF) offers another perspective, emphasising the broader context of distress and unusual experiences beyond individual pathology (Johnstone et al, 2018). This framework delves into how social inequalities, power dynamics, and adverse life events shape individuals' responses to distressing situations. In challenging conventional psychiatric diagnoses, Johnstone et al (2018) propose the PTMF as an alternative, highlighting psychological distress as a meaningful response to life's challenges. The author's clinical perspective echoes these sentiments, suggesting a shift towards more inclusive frameworks for understanding mental health.

By adopting a holistic perspective, healthcare providers can better address the underlying determinants of mental health inequalities and develop more effective interventions that target social as well as biological factors.

Diagnostic practices within psychiatry also warrant critical examination, as diagnostic labels can both reflect and perpetuate social stigma and inequality (Hearing Voices Network, 2013; Perkins et al, 2018). The Diagnostic and Statistical Manual of Mental Disorders (DSM) and the International Classification of Diseases (ICD) are widely used diagnostic tools that shape understanding of mental illness and inform treatment decisions (American Psychiatric Association, 2013; World Health Organization [WHO], 2019). However, these classifications are not immune to bias and cultural influences, leading to disparities in diagnosis and treatment across

different populations (Perkins et al, 2018). Moreover, diagnostic labels can carry significant social implications, affecting individuals' self-perception, access to resources, and experiences of stigma and discrimination (Cooke et al, 2014). Therefore, it is essential for healthcare providers to critically evaluate the role of diagnostic labels in mental healthcare and consider alternative approaches that prioritise the individual's unique experiences and needs.

OVERPRESCRIBING

The issue of overprescribing in mental healthcare highlights the need for greater scrutiny of prescribing practices and a shift towards more judicious and evidence-based prescribing (Chief Pharmaceutical Officer [CPO], 2021). Overprescribing of psychotropic medications, particularly in primary care settings, has been linked to a range of adverse outcomes, including medication dependence, adverse drug reactions, and increased mortality (Pilling et al, 2011; CPO, 2021). Limited access to psychological therapies has been identified as a contributing factor to overreliance on medication, particularly for milder mental health conditions (Clare and Oyebode, 2023a, b, c). Therefore, in the author's opinion, efforts to address overprescribing must include investments in mental health services that prioritise non-pharmacological interventions, such as psychotherapy and counselling, as well as initiatives to enhance prescribers' awareness of the risks and benefits of medication use. This is especially crucial in light of cases like that of Oliver McGowan, a young man with autism who tragically died due to overprescribing of antipsychotic medication, underscoring the dire consequences of inappropriate prescribing practices and the urgent need for systemic reforms.

In response to this tragedy, the UK government introduced the Oliver McGowan Mandatory Training in Learning Disability and Autism package, aimed at improving healthcare professionals' understanding of the unique needs of individuals with learning disabilities and autism, including appropriate prescribing practices. This training package has had a significant impact on prescribing behaviour, leading to increased awareness and sensitivity among healthcare professionals and contributing to a reduction in inappropriate medication use among vulnerable populations (National Development Team for Inclusion [NDTi], 2022).

Moreover, the intersectionality of mental health and social inequality necessitates a nuanced understanding of how structural factors, such as race, ethnicity, gender, sexuality, and socioeconomic status, intersect to shape individuals' experiences of mental illness and access to care (Chrisp, 2023). For example, research has consistently shown disparities in mental health outcomes and treatment access among minority populations, highlighting the need for culturally responsive and inclusive approaches to mental healthcare (NHS England, 2021a).

MULTIDISCIPLINARY WORKING AND PEER SUPPORT

Another critical aspect of addressing mental health inequalities is the need to promote collaborative and multidisciplinary approaches to care. Mental health issues often intersect with various social and health-related concerns, such as housing instability, substance abuse, and physical health conditions (Khan et al, 2022). Therefore, effective treatment requires coordinated efforts across different healthcare disciplines, as well as collaboration with social service agencies and community organisations. Fostering partnerships between mental health providers, primary care physicians, social workers, and other stakeholders, can help to ensure that individuals receive comprehensive and integrated care that addresses their unique needs and circumstances.

Moreover, empowering individuals with lived experience of mental illness to play active roles in their care can enhance treatment outcomes and promote social inclusion (Davidson et al, 2016). Peer support programmes, in which individuals with shared experiences provide guidance, encouragement, and practical assistance to others facing similar challenges, have been shown to improve mental health outcomes and reduce feelings of isolation and stigma (Davidson et al, 2016). In the author's clinical experience, incorporating peer support into mental health services can harness the power of shared experience to foster resilience, recovery, and community connection among individuals with mental illness.

Practice point

Healthcare providers should be attuned to the unique social and cultural contexts in which mental health issues arise and tailor their interventions accordingly, ensuring that marginalised and underserved communities receive equitable and effective care.

TRAUMA-INFORMED PRACTICE

Adoption of trauma-informed practice is paramount in addressing mental health inequalities within community nursing. Trauma-informed care recognises the prevalence and impact of trauma on individuals' lives and acknowledges how traumatic experiences can contribute to health disparities. By understanding the complex interplay between trauma, mental health, and social determinants, nurses can provide care that is sensitive to the unique needs and experiences of trauma survivors. Trauma-informed approaches prioritise safety, trustworthiness, collaboration, empowerment, and cultural humility, creating a supportive environment where individuals feel validated and respected (Harris and Fallot, 2001).

In communities disproportionately affected by trauma, such as those experiencing poverty, violence, or systemic discrimination, trauma-informed care can help mitigate the adverse effects of trauma and promote healing. By addressing the root causes of trauma and providing trauma-sensitive interventions, nurses can contribute to reducing mental health inequities and foster resilience among marginalised populations (Najavits, 2002).

Furthermore, trauma-informed practice intersects with efforts to address health disparities by recognising that trauma can exacerbate existing inequalities in healthcare access and outcomes. For example, individuals who have experienced trauma may face barriers to seeking and engaging in healthcare services due to mistrust, fear, or past negative experiences (Substance Abuse and Mental Health Services Administration [SAMHSA], 2014). By adopting trauma-informed approaches, nurses can create environments that minimise re-traumatisation and enhance accessibility for underserved populations (SAMHSA, 2014).

The impact of trauma extends beyond mental health and can significantly affect physical health. Research has shown that trauma exposure is associated with a higher risk of various physical health conditions, including cardiovascular disease, chronic pain, autoimmune disorders, and gastrointestinal problems (Courtois and Ford, 2013). Trauma can dysregulate the body's stress response systems, leading to long-term physiological changes that increase susceptibility to illness and disease.

In clinical practice, nurses may encounter patients with trauma histories presenting with somatic symptoms or unexplained physical complaints. These manifestations of trauma-related distress can sometimes be misinterpreted as purely medical issues, leading to underdiagnosis or inadequate treatment. Therefore, it is essential for nurses to adopt a trauma-informed lens when assessing and managing patients' physical health concerns, recognising the interconnectedness of mind and body (Fallot and Harris, 2009).

Furthermore, trauma diagnoses, such as post-traumatic stress disorder (PTSD) or complex PTSD, can have profound implications for individuals' physical wellbeing. Studies have shown that individuals with PTSD are at higher risk of developing comorbid medical conditions, experiencing more severe symptoms, and exhibiting poorer treatment outcomes compared to those without PTSD (Barry et al, 2018; NHS England, 2021a). Additionally, trauma-informed care involves recognising the impact of trauma on individuals' health behaviours and healthcare utilisation patterns, such as avoidance of medical care or engaging in high-risk behaviours as coping mechanisms (NICE, 2018).

Photograph: PeopleImages.com - Yuri A/Shutterstock

Incorporating trauma-informed principles into community nursing practice requires ongoing education, training, and organisational support. Overall, trauma-informed practice is an essential component of addressing mental health inequalities and advancing health equity within communities. By recognising and responding to the impact of trauma, nurses can play a crucial role in promoting healing, resilience, and recovery for individuals and communities affected by adversity.

SOCIAL DETERMINANTS OF HEALTH

In addition to individual-level interventions, structural reforms are needed to address the root causes of mental health inequalities and promote health equity at the population level. This includes efforts to address social determinants of health, such as poverty, racism, and discrimination, which disproportionately impact marginalised communities and contribute to disparities in mental health outcomes (Office for Health Improvement and Disparities, 2022).

In the author's clinical opinion, policies aimed at reducing income inequality, improving access to affordable housing, job training programmes, and community development initiatives, as well as combating systemic racism, can help create the conditions for mental well-being and ensure that all individuals have the opportunity to thrive.

MENTAL HEALTH PROMOTION AND PREVENTION

Furthermore, investing in mental health promotion and prevention initiatives can help reduce the burden of mental illness and prevent the onset of more severe conditions. Early intervention programmes that identify and address mental health concerns in their early stages can prevent the escalation of symptoms and improve long-term outcomes for individuals and communities (PHE, 2016). This includes promoting mental health literacy and awareness, providing education and training on coping skills and stress management, and implementing screening programmes to identify individuals at risk of mental health problems (Barry et al, 2018).

Prioritising mental health promotion in schools, workplaces, and communities can foster resilience, build coping skills, and create supportive environments that promote mental wellbeing for all.

One crucial aspect of addressing mental health inequalities is ensuring equitable access to mental health

services. Historically, marginalised communities, including people of colour, LGBTQ+ individuals, and those experiencing poverty, have faced barriers to accessing quality mental healthcare due to factors such as stigma, discrimination, and systemic inequities in healthcare delivery (Sue et al, 2009).

To address this, it is essential to implement policies and practices that promote inclusivity, cultural competence, and accessibility within mental health services. This can involve initiatives such as diversifying the mental health workforce to better reflect the communities they serve, providing language interpretation services for individuals with limited English proficiency, and offering culturally tailored treatment options that acknowledge and respect the values, beliefs, and preferences of diverse populations (Kirmayer et al, 2011).

Additionally, efforts to expand mental health coverage and reduce financial barriers to care can help ensure that all individuals have the opportunity to access the care that they need. While the NHS provides free healthcare, including mental health services, there are still financial barriers for some individuals accessing certain types of care or support services, such as private therapy or specialised treatments not covered by the NHS (NHS England, 2021b).

RESEARCH

Lastly, it is essential to engage in ongoing research and evaluation to assess the effectiveness of interventions aimed at reducing mental health inequalities and identify areas for improvement. By collecting data on mental health outcomes, service utilisation, and social determinants of health, progress can be tracked over time to identify disparities that require targeted interventions (PHE, 2016).

Moreover, involving communities and stakeholders in the research process can ensure that interventions are culturally responsive and address the specific needs and priorities of diverse populations.

CONCLUSION

Addressing mental health inequalities requires a commitment to ongoing advocacy and social change. This includes efforts to challenge stigma and discrimination, advocate for policies that promote mental health equity, and amplify the voices of individuals with lived experience of mental illness (Corrigan et al, 2012).

By raising awareness, mobilising communities, and advocating for change at local, national, and global levels, a more just and equitable society where mental health is valued, supported, and prioritised for all can be created. JCN

REFERENCES

American Psychiatric Association (2013) *Diagnostic and Statistical Manual of Mental Disorders*. 5th edn

Barry LC, Wakefield DB, Trestman RL, Conwell Y, Walkup JT (2018) The impact of post-traumatic stress disorder on physical health. *J Clin Psychiatry* 79(2)

Case A, Kraftman L (2022) *Health Inequalities: The IFS Deaton Review*. Available online: https://ifs.org.uk/sites/default/files/2022-11/Health-inequalities-The-IFS-Deaton-Review-of-Inequalities.pdf

Chief Pharmaceutical Officer (2021) *Good for you, good for us, good for everybody — a plan to reduce overprescribing to make patient care better and safer, support the NHS, and reduce carbon emissions*. Department of Health and Social Care. Available online: www.gov.uk/government/publications/national-overprescribing-review-report

Chrisp P (2023) *Adults with depression who want to quit antidepressants should be given support on how to do it safely over time, says NICE*. News NICE, 17 January 2023 Available online: www.nice.org.uk/news/nice-draft-quality-standard-depression-adults-update-2023

Clare H, Oyebode F (2023a) *Is Psychiatry Working? Crisis*. BBC Radio 4, 23 January 2023

Clare H, Oyebode F (2023b) *Is Psychiatry Working? Diagnosis*. BBC Radio 4, 3 February 2023

Clare H, Oyebode F (2023c) *Is Psychiatry Working? Medication*. BBC Radio 4, 10 February 2023

Cooke A, Basset T, Bentall R, Boyle M, Cupitt C, Dillon J (2014) *Understanding Psychosis and Schizophrenia*. British Psychological Society, London

Corrigan PW, Morris SB, Michaels PJ, Rafacz JD, Rüsch N (2012) Challenging the public stigma of mental illness: a meta-analysis of outcome studies. *Psychiatric Services* 63(10): 963–73

Courtois CA, Ford JD, eds (2013) *Treating Complex Traumatic Stress Disorders: An Evidence-Based Guide*. Guilford Press, New York

Davidson L, Bellamy C, Butterworth A, Guy K, Miller R (2016) Peer support among persons with severe mental illnesses: A review of evidence and experience. *World Psychiatry* 15(3): 277–86

Dent R, Blackmore A, Peterson J, Habib R, Kay GP, Gervais A, Taylor V, Wells G (2012) Changes in body weight and psychotropic drugs: a systematic synthesis of the literature. *PlosOne* 7: e36889

Engel GL (1977) The need for a new medical model: a challenge for biomedicine. *Science* 196(4286): 129–36. Cited in: Wade DT, Halligan PW (2017) The biopsychosocial model of illness: a model whose time has come. *Clin Rehabil* 31(8): 995–1004

Fallot RD, Harris M (2009) *Trauma-informed approaches to systems of care*. In: Levin BL, Petrila J, Hennessy K, Peele RA, eds. *Mental Health Services: A Public Health Perspective*. 3rd edn. Oxford University Press, New York: 127–47

General Medical Council (2023) *Prescribing without access to medical records*. Available online: www.gmc-uk.org/ethical-guidance/learning-materials/prescribing-without-access-to-patient-records

Goldberg JF, Ernst CL (2019) *Managing the Side Effects of Psychotropic Medications*. American Psychiatric Publishing, Wasington DC

Goward P, Repper J, Appleton L, Hagan T (2006) Crossing boundaries. Identifying and meeting the mental health needs of Gypsies and Travellers. *J Mental Health* 15(3): 315–27

Greenfields M, Brindley M (2016) *Impact of insecure accommodation and the living environment on Gypsies' and Travellers' health. A report by the Traveller Movement*. Available online: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/

file/490846/NIHB_-_Gypsy_and_Traveller_health_accs.pdf

Harris M, Fallot RD, eds (2001) *Using Trauma Theory to Design Service Systems*. Jossey-Bass, San Francisco, CA

Hart TE, Bird D, Holloway JA (2016) Addressing concordance issues: How motivational interviewing strategies can complement the nurse prescribing consultation. *Nurse Prescribing* 14(10): 510–15

Hearing Voices Network (2013) *Position Statement on DSM 5 & Psychiatric Diagnosis*. Available online: www.hearing-voices.org/about-us/position-statement-on-dsm-5

Johnstone L, Boyle M, Cromby J, Dillon J, Harper D, Kinderman P, et al (2018) *The Power Threat Meaning Framework: Towards the identification of patterns in emotional distress, unusual experiences and troubled or troubling behaviour, as an alternative to functional psychiatric diagnosis*. British Psychological Society, Leicester

Khan A, Kurmi O, Lowrie R, Khanal S, Paudyal V (2022) Medicines prescribing for homeless persons: analysis of prescription data from specialist homelessness general practices. *Int J Clin Pharm* 44(3): 717–24

Keogh B, Brady AM, Downes C, Doyle L, Higgins A, McCann T (2020) Evaluation of a Traveller mental health liaison nurse: service user perspectives. *Issues Ment Health Nurs* 41(9): 799–806

Kirmayer LJ, Narasiah L, Munoz M, et al (2011) Common mental health problems in immigrants and refugees: general approach in primary care. *CMAJ* 183(12): E959–E967

Lin H-Y, Huang C-K, Tai C-M, Lin H-Y, Kao Y-H, Tsai C-C, et al (2013) Psychiatric disorders of patients seeking obesity treatment. *BMC Psychiatry* 13: 1

Middleton H, Moncrieff J (2019) Critical psychiatry: a brief overview. *BJPsych Advances* 25(1): 47–54

Najavits LM (2002) *Seeking Safety: A Treatment Manual for PTSD and Substance Abuse*. Guilford Press, New York

National Development Team for Inclusion (2022) *Oliver McGowan Mandatory Training: Final Report*. Available online: www.ndti.org.uk/assets/files/OMMT-final-report.pdf

NHS England (2019a) *NHS Long Term Plan*. Available online: www.longtermplan.nhs.uk/

NHS England (2019b) *The community mental health framework for adults and older adults*. Available online: www.england.nhs.uk/publication/the-community-mental-health-framework-for-adults-and-older-adults/

NHS England (2021a) *Mental Health of Adults and Older Adults in England*. Available online: www.england.nhs.uk/publication/mental-health-of-adults-and-older-adults-in-england/

NHS England (2021b) *Core20PLUS5 (adults) — an approach to reducing healthcare inequalities*. Available online: www.england.nhs.uk/about/equality/equality-hub/national-healthcare-inequalities-improvement-programme/core20plus5/

NHS England (2022) *Learning from lives and deaths — People with a learning disability and autistic people (LeDeR): Action from learning report 2021/22*. Available online: https://leder.nhs.uk/images/resources/Action-From-Learning-Report-2021-22.pdf

NHS England and NHS Improvement and the National Collaborating Central for Mental Health (2019) *The Community Mental Health Framework for Adults and Older Adults*. Available online: www.england.nhs.uk/wp-content/uploads/2019/09/community-mental-health-framework-for-adults-and-older-adults.pdf

National Institute for Health and Care Excellence (2011) *Psychosis with coexisting substance misuse: assessment and management in adults and young people*. Clinical guideline [CG120]. Available online: www.nice.org.uk/guidance/cg120

National Institute for Health and Care Excellence (2018) *Post-traumatic stress disorder*. Clinical guideline [CG26]. Available online: www.nice.org.uk/guidance/cg26

Nursing and Midwifery Council (2018) *The Code: professional standards of practice and behaviour for nurses, midwives and nursing associates*. Available online: www.nmc.org.uk/standards/code/

Nursing and Midwifery Council (2020) *Being inclusive and challenging discrimination*. Available online: https://www.nmc.org.uk/standards/code/code-in-action/inclusivity/

Office for Health Improvement and Disparities (2022) *Health disparities and health inequalities: applying All Our Health*. Available online: www.gov.uk/government/publications/health-disparities-and-health-inequalities-applying-all-our-health/health-disparities-and-health-inequalities-applying-all-our-health

Oluyase AO, Raistrick D, Hughes E, Lloyd C (2019) The appropriateness of psychotropic medicines: an interview study of service users attending a substance misuse service in England. *Int J Clin Pharm* 41(4): 972–80

Perkins A, Ridler J, Browes D, Peryer G, Notley C, Hackmann C (2018) Experiencing mental health diagnosis: a systematic review of service user, clinician, and carer perspectives across clinical settings. *Lancet Psychiatry* 5(9): 747–64

Pilling S, Whittington C, Taylor C, Kendrick T (2011) Identification and care pathways for common mental health disorders: summary of NICE guidance. *BMJ* 342: d2868–d2868

Public Health England (2016) *Making Every Contact Count (MECC): Consensus Statement*. Available online: www.england.nhs.uk/wp-content/uploads/2016/04/making-every-contact-count.pdf

Royal Pharmaceutical Society (2021) *Competency Framework for All Prescribers*. Available online: www.rpharms.com/resources/frameworks/prescribing-competency-framework/competency-framework

Sewell H (2013) *The Equality Act 2010 in Mental Health: A Guide to Implementation and Issues for Practice*. Jessica Kingsley, London

Substance Abuse and Mental Health Services Administration (2014) *SAMHSA's Concept of Trauma and Guidance for a Trauma-Informed Approach*. Available online: https://store.samhsa.gov/sites/default/files/d7/priv/sma14-4884.pdf

Sue S, Cheng JKY, Saad CS, Chu JP (2009) Asian American mental health: A call to action. *Am Psychologist* 64(3): 220–31

Treasure J, Schmidt U, Furth E (2003) *The Essential Handbook of Eating Disorders*. John Wiley & Sons, Chichester

Van Cleemput P (2018) Health needs of Gypsy Travellers. *InnovAiT* 11(12): 681–8

Wade DT, Halligan PW (2004) Do biomedical models of illness make for good healthcare systems? *BMJ* 329: 1398

World Health Organization (2019) *International Statistical Classification of Diseases and Related Health Problems (ICD-11, 11th edition)*. WHO, Geneva

Quality of life in dementia: role of community nurses

Madeleine Walpert, Amy Pepper

Dementia is a progressive neurodegenerative condition and poses significant challenges to an individual's quality of life (QoL). As the global prevalence of dementia continues to rise, understanding and enhancing QoL for people living with dementia becomes even more important. This article explores the concept of QoL in the context of dementia, its application in community nursing practice, and the pivotal role nurses can play in improving QoL. An overview of the challenges, considerations, and evidence-based strategies to improve QoL are explored. Through person-centred care, education and advocacy, community nurses can make a significant difference in supporting the wellbeing and dignity of people living with dementia.

KEYWORDS:
Dementia ■ Quality of life ■ Person-centred care
Community nursing ■ Wellbeing

Dementia is characterised by progressive cognitive impairment, which impacts multiple facets of a person's life including their memory, communication, behaviour, and the ability to perform daily activities. The World Health Organization (WHO) estimates that the global prevalence of dementia will reach 78 million by 2030 (WHO, 2022), and in the UK, it is projected that 1.6 million people will be living with dementia by 2040 (Alzheimer's Society, 2022). Dementia profoundly impacts an individual's overall wellbeing, cognitive function, emotional state, social interactions, relationships and independence — all factors which collectively contribute to their quality of life (QoL) (Jing et al, 2016).

QUALITY OF LIFE IN DEMENTIA

Quality of life is a multidimensional concept. It has been defined as the individual's perception of their life in relation to their cultural beliefs, values, goals, expectations, standards and concerns, and incorporates physical, psychological, social, and spiritual wellbeing (Klapwijk et al, 2016). For people living with dementia, QoL often refers to an individual's ability to maintain autonomy, engage in meaningful activities, experience joy and connection, and preserve their sense of identity (Beerens et al, 2018).

Lawton's model of quality of life in dementia recognises a framework with four domains of importance (*Figure 1*). The four domains should be assessed both independently and collectively to evaluate a person's QoL (Bökberg et al, 2017).

It is important to note that while dementia is a progressive disease, QoL does not have to diminish as functional abilities are lost due to dementia. Research into QoL in dementia highlights that good QoL can still be achieved even in the later stages of dementia. Things like mood and the quality of relationships seem to be a bigger predictor of QoL than cognition or functional ability (Hoe et al, 2009).

QUALITY OF LIFE ASSESSMENTS

Measuring QoL in individuals with dementia presents challenges in research and clinical practice. One of the primary difficulties lies in the subjective nature of QoL, which is further compounded by the cognitive impairments and communication limitations of dementia. Assessment tools that are reliant on self-reports can be difficult to obtain, whereas alternative methods such as proxy reports from caregivers can introduce additional biases. Moreover, the progressive nature of dementia means that QoL assessments must be dynamic, reflecting the evolving needs and experiences of individuals over time. Cultural and personal values further complicate matters, highlighting the need for nuanced, context-specific approaches to capturing and understanding QoL. Although there is no gold standard or consensus measurement, several standardised instruments have been developed to assess QoL (Burks et al, 2021), including those shown in *Table 1*.

Practice point

- What strategies could you use to try to gain the perspective of the person with dementia themselves as much as possible when considering their QoL?
- What practical steps could you take to better understand and incorporate a patient's values, preferences and life history into their care plan?

Madeleine Walpert, research fellow; Amy Pepper, Admiral Nurse research assistant, both at Dementia UK

These instruments measure various domains, such as physical health, cognitive function, social interactions and environmental factors, across a range of items. *Box 1* shows the question topics included in the Quality of Life in Alzheimer's Disease (QOL-AD) measure, with each question being rated as either poor, fair, good or excellent, and demonstrates the range of factors that can impact QoL. While community nurses may not be carrying out formal QoL assessments, it is helpful to have an idea of the different domains that can impact QoL, to help think holistically about the person with dementia.

Two of the tools in *Table 1*, QOL-AD and Dementia Quality of Life (DEMQOL), were designed to accommodate both self and proxy reporting. In the authors' clinical experience, assessments that integrate both self-report and proxy assessments foster a more comprehensive understanding and ensure the inclusion of the person living with dementia in measures that will inform their care, even if they cannot take part in the assessment themselves. Logsdon et al (1999) found that individuals with dementia can self-report their QoL, even with higher levels of cognitive impairment. However, they were found to rate their QoL higher than the proxy reports. Despite this, a systematic review by Burks et al (2021) showed that the majority of studies rely heavily on proxy reports for assessing QoL.

ROLE OF COMMUNITY NURSES

Community nurses play a crucial role in influencing the QoL for individuals with dementia by providing essential care, support, and advocacy within the community setting. As frontline healthcare professionals, they are uniquely positioned to assess the holistic needs of people living with dementia and their families. They play a pivotal role in implementing person-centred care plans that address not only the medical aspects of dementia, but also the array of other factors that impact QoL, such as facilitating social engagement, supporting independence and functional abilities, and creating a supportive physical environment. Community nurses facilitate early detection and diagnosis of dementia, offer ongoing monitoring of symptoms and progression, and provide education and guidance to families and caregivers (Pepper and Harrison Dening, 2024). Through care packages that prioritise and understand the person's preferences and values, while promoting independence, dignity, and wellbeing, community nurses significantly contribute to enhancing the overall QoL for individuals living with dementia in their communities.

Person-centred care is a fundamental principle in enhancing QoL for people living with dementia (Chenoweth et al, 2019). This approach emphasises treating individuals with respect, dignity, and empathy, while actively involving them and their families in decisions about their health and care (Kitwood, 1997). By understanding a person's life history, values, preferences, and current strengths and abilities, nurses can tailor care plans and interventions that promote meaningful engagement, maintain independence, preserve identity, and uphold personhood. Person-centred care empowers individuals with dementia to have a voice in their care, fosters trusting relationships with providers, and ensures that care aligns with their unique needs, values and goals (Kitwood, 1997).

Table 1: Quality of life assessment tools

Measurement tools	Reference
Quality of Life in Alzheimer's Disease Scale (QOL-AD)	Logsdon et al, 1999
Alzheimer's Disease-Related Quality of Life Scale (ADRQL)	Rabins et al, 1999
Dementia Quality of Life (DEMQOL)	Smith et al, 2005
Quality of Life in Late-Stage Dementia (QUALID)	Weiner et al, 2000
Dementia-Specific Quality of Life (QUALIDEM)	Ettema et al, 2007

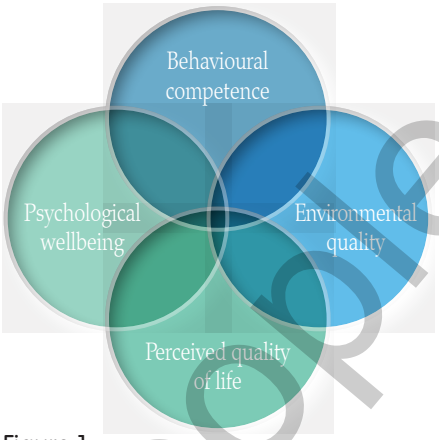

Figure 1.
Dimensions of quality of life in people with dementia according to Lawton's model (Bökberg et al, 2017).

CHALLENGES IN ENHANCING QUALITY OF LIFE

Enhancing QoL for individuals with dementia presents considerable challenges. One significant difficulty is the management of complex behavioural and psychological symptoms associated with dementia, such as agitation, aggression, and sundowning (Tible et al, 2017). These symptoms can severely disrupt routines, social interactions, and the ability to engage in activities, further diminishing QoL.

People with dementia also often live with multiple coexisting health conditions, particularly age-related ailments (Bunn et al, 2014), which can increase cognitive decline and functional impairments, reducing independence and increasing reliance on others. Addressing multiple conditions concurrently demands integrated and holistic care strategies.

The progressive nature of dementia necessitates ongoing adjustments to care plans and support strategies as cognitive and functional abilities change and decline. Strategies that may have worked effectively before may need modifications to remain effective in improving QoL.

Balancing autonomy, independence, and dignity while ensuring safety is another critical

Hassan has a diagnosis of Alzheimer's disease and lives alone in a rural setting. He has a carer once a day to support him with his morning routine, but is otherwise quite isolated, as he has had to give up driving. He is referred to the community nursing team as his carers are worried that he may have developed a urinary tract infection (UTI). During the visit, you are able to rule out a UTI, however, do note concerns about Hassan's mood and living situation. He has family but they live some distance away and cannot visit easily, and he has become increasingly isolated due to his rural location, lack of a car, and dementia impacting on his ability to make and keep social plans.

Patient story

challenge in dementia care. Without proper care management, individuals with dementia may inadvertently pose risks to themselves or others through medication mismanagement, wandering, falls, and injuries (Aldridge and Harrison Dening, 2024). Nurses play a crucial role in assessing risks, providing education, and implementing supportive interventions with a neutral and non-judgemental approach (Harrison Dening et al, 2016).

Insufficient training in communication skills specific to dementia care can create communication barriers between professionals and people with dementia (Eggenberger et al, 2013), resulting in misunderstanding and frustration which can further lead to lower QoL. Effective communication is fundamental to understanding the needs and preferences of individuals with dementia, and a lack thereof can hinder the provision of person-centred care (Pepper and Harrison Dening, 2023a).

Addressing these challenges requires ongoing education, support, and the development of specialised skills among community nurses to optimise their ability to enhance the quality of life of people living with dementia in the community setting (Pepper and Harrison Dening, 2023b).

INNOVATIONS AND AWARENESS TO SUPPORT QUALITY OF LIFE

Innovative technologies have the potential to improve care for individuals with dementia. Assistive devices, such as smart home sensors, GPS tracking systems, and medication management tools empower individuals to maintain independence and safety while reducing caregiver burden (Lauriks et al, 2007). Telemedicine and virtual care platforms support remote monitoring, offering convenient healthcare access for those living in rural areas or with mobility challenges. Virtual social engagement interventions enable individuals to stay connected with their friends and family more easily. Integrating these technologies into care approaches not only enhances autonomy and social participation, but also provides peace of mind to families and caregivers. Creating dementia-friendly environments involves incorporating features like clear signage, adequate lighting, and noise reduction to promote safety and ease of navigation (Harrison Dening et al, 2017; Parry, 2019). Indeed, making small adaptations to a person's home could also help to enhance their sense of wellbeing, reduce anxiety, and increase their independence.

PATIENT STORY — HASSAN

Considering Hassan's situation in the context of the domains of the QOL-AD assessment tool (*Box 1*), a number of areas where his QoL may be rated as poor can be seen, in particular his mood, living situation, family and friends. As a community nurse, you may not be involved in meeting all of Hassan's needs in this area, but this contact with him provides the opportunity for a comprehensive assessment which takes account of not just Hassan's physical health, but also his psychosocial needs. In Hassan's case (and with his consent) it may also be important to involve his family in the assessment process, perhaps over the phone, and this may provide an opportunity to explore if they could offer more support to counteract some of Hassan's isolation.

There is also the opportunity to explore referral for a social care assessment for Hassan, to look at any extra support that could be offered to help him access his local community, perhaps a carer visiting for a longer period to take him out, or a day centre. If there was a social prescribing service locally, this would also be worth exploring. It is important to remember that social support does not always have to be in the form of professional-led services, as there may also be opportunities to help Hassan connect with informal clubs and groups, or with faith groups.

Where there are concerns around mood, it is important to refer back to the GP, who may consider antidepressant medication, referral to talking therapies, or mental health services for support.

CONCLUSION

Research has shown that QoL is not necessarily linked to the stage of dementia or the level of functional

Box 1 Domains of the QOL-AD

- Physical health
- Energy
- Mood
- Living situation
- Memory
- Family
- Marriage
- Friends
- Self as a whole
- Ability to do chores around the house
- Ability to do things for fun
- Money
- Life as a whole.

(adapted from Logsdon et al, 1999)

Practice point

- Thinking about Hassan's situation, what other community resources or services could potentially help address his isolation and low mood?
- If you encountered a patient like Hassan, what collaborative approaches could you take to address their holistic needs?

and cognitive ability, thereby allowing good QoL to be achieved, even in the later stages of dementia. Community nurses are in a unique position to address concerns about QoL in the people they work with. It is important to have an understanding of the different domains that can impact QoL for people with dementia, and that these are considered as part of holistic assessment. JCN

REFERENCES

Alzheimer's Society (2022) Dementia UK: Update. https://kclpure.kcl.ac.uk/portal/en/publications/dementia-uk-update

Aldridge Z, Harrison Dening K (2024) Risk management and decision-making in dementia care. *Nurs Older People* 36(1): e1460 [online ahead of print]

Beerens HC, Zwingerman C, Struckmann V, Deeg DJH, de Deyn PP, de Boer, B, et al (2018) Quality of life in community-dwelling people with dementia: A quantitative analysis of factors associated with cognitive, functional and psychosocial decline. J Alzheimer's Dis 66(3): 1193–1206

Bökberg C, Ahlström G, Karlsson S (2017) Significance of quality of care for quality of life in persons with dementia at risk of nursing home admission: A cross-sectional study. *BMC Nurs* 16(1): 39

Bunn F, Burn AM, Goodman C, et al (2014) Comorbidity and dementia: A scoping review of the literature. *BMC Med* 12: 192

Burks HB, des Bordes JK, Chadha R, Holmes HM, Rianon NJ (2021) Quality of life assessment in older adults with dementia: a systematic review. *Dement Geriatr Cogn Disord* 50(2): 103–10

Chenoweth L, Stein-Parbury J, Lapkin S, Wang A, Liu Z, Williams A (2019) Effects of person-centered care at the organisational-level for people with dementia. A systematic review. *PloS One* 14(2): e0212686

Eggenberger E, Heimerl K, Bennett MI (2013) Communication skills training in dementia care: A systematic review of effectiveness, training content, and didactic methods in different care settings. *Int Psychogeriatrics* 25(3): 345–58

Ettema TP, Droes R-M, de Lange J, Mellenbergh GJ, Ribbe MW (2007) QUALIDEM: development and evaluation of a dementia specific quality of life instrument. Scalability, reliability and internal structure. *Int J Geriatr Psychiatry* 22(6): 549–56

Harrison Dening K, King M, Jones L, Sampson EL, Blanchard MR (2016) Advance care planning for people with dementia: Towards the GOLD standard. *Rev Clin Gerontol* 26(1): 86–95

Harrison Dening K, Aldridge Z, Pepper A, Hodgkison C (2017) Admiral Nursing: case management for families affected by dementia. *Nurs Standard* 31(24): 42–50

Hoe J, Hancock G, Livingston G, Woods B, Challis D, Orrell M (2009) Changes in the quality of life of people with dementia living in care homes. *Alzheimer Dis Assoc Disord* 23(3): 285–90

Jing W, Willis R, Feng Z (2016) Factors influencing quality of life of elderly people with dementia and care implications: A systematic review. *Arch Gerontol Geriatr* 66: 23–41

Kitwood TM (1997) *Dementia reconsidered: the person comes first*. Open University Press, Buckingham

Klapwijk MS, Caljouw MA, Pieper MJ, van der Steen JT, Achterberg WP (2016) Characteristics associated with quality of life in long-term care residents with dementia: A cross-sectional study. *Dement Geriatr Cogn Disord* 42(3–4): 186–97

Lauriks S, Reinersmann A, Van der Roest HG, Meiland FJM, Davies RJ, Moelaert F, et al (2007) Review of ICT-based services for identified unmet needs in people with dementia. *Ageing Res Rev* 6(3): 223–46.

Logsdon RG, Gibbons LE, McCurry SM, Teri L (1999) Quality of life in Alzheimer's disease: Patient and caregiver reports. *J Ment Health Aging* 5: 21–32

Parry L (2019) Can patient and carers' experiences shape services? *BMJ Supportive Palliat Care* 9(3): 287–90

Pepper A, Harrison Dening K (2023a) Person-centred communication with people with dementia. *Nurs Older People* 35(2): 28–33

Pepper A, Harrison Dening K (2023b) Dementia and communication. *Br J Community Nurs* 28(12): 592–7

Pepper A, Harrison Dening KH (2024) Community support for families affected by dementia. *Br J Community Nurs* 29(5): 218–23

Rabins PV, Kasckow J, Kleinman L, Black BS (1999) Concepts and methods in the development of the ADRQL: An instrument for assessing health-related quality of life in persons with Alzheimer's disease. *J Ment Health Aging* 5: 33–48

Smith SC, Lamping DL, Banerjee S, Harwood RH, Foley B, Smith P, et al (2005) Measurement of health-related quality of life for people with dementia: Development of a new instrument (DEMQOL) and an evaluation of current methodology. *Health Technol Assess* 9(10): 1–93

Tible OP, Riese F, Savaskan E, von Gunten A (2017) Best practice in the management of behavioural and psychological symptoms of dementia. *Ther Adv Neurol Disord* 10(8): 297–309

Weiner MF, Martin-Cook K, Svetlik DA, Saine K, Foster B, Fontaine CS (2000) The quality of life in late-stage dementia (QUALID) scale. *J Am Med Dir Assoc* 1(3): 114–6

World Health Organization (2022) *Dementia*. WHO, Geneva. Available online: www.who.int/news-room/fact-sheets/detail/dementia

KEY POINTS

- For people living with dementia, QoL often refers to an individual's ability to maintain autonomy, engage in meaningful activities, experience joy and connection, and preserve their sense of identity.
- The progressive nature of dementia means that QoL assessments must be dynamic, reflecting the evolving needs and experiences of individuals over time.
- Community nurses play a crucial role in influencing the QoL for individuals with dementia by providing essential care, support, and advocacy within the community setting.

Constipation in children

Constipation is not much talked about, but it affects one in three children and will not go away by itself. ERIC, The Children's Bowel and Bladder Charity, is the only UK-wide charity dedicated to children's continence services. It provides online resources on all things wee and poo, webinars for healthcare professionals and parents/carers, and a free Helpline — on which the most common call is about constipation. Here, Sunni Liston, ERIC nurse, discusses constipation and how to help treat it.

Constipation is a problem for one in three children (https://eric.org.uk). It commonly starts around the potty-learning stage, but it can also affect babies.

Constipation can seriously impact a family's life and it will not go away by itself. It is a medical problem that needs treating properly to prevent it getting worse (www.eric.org.uk).

When there is a history of less than four weeks, constipation is considered 'acute'. If it persists beyond this point, it is considered 'chronic'.

Acute constipation needs proactive, ongoing, preventative treatment so that it does not become chronic, due to the pain on bowel opening resulting in fear and withholding (NHS England, 2023). Symptoms become chronic in more than one-third of patients and constipation is a common reason for referral to secondary care (National Institute for Health and Care Excellence [NICE], 2017).

Unfortunately, children and young people, and their families, are often given conflicting advice and practice is inconsistent, making treatment potentially less effective and frustrating for all concerned. Early identification of constipation and effective treatment can improve outcomes for children and young people (NICE, 2017).

CAUSES OF CONSTIPATION

There are many different causes of constipation in children. It can be difficult to find just one obvious reason.

'Unfortunately, children and young people, and their families, are often given conflicting advice and practice is inconsistent, making treatment potentially less effective and frustrating for all concerned.'

Occasionally, an underlying organic problem with the bowel such as Hirschsprung's disease or spina bifida cause symptoms of constipation. This is usually picked up before or soon after birth, but not always. It is important for every child to have a physical examination to ensure that there is no underlying cause (NICE, 2017).

Most children have what is known as functional constipation. This means that there is no underlying physical cause. Their bowel should work properly, but for some reason they have become constipated.

Risk factors for constipation include:

- Insufficient fluid intake
- Lack of a well-balanced diet
- An illness such as a stomach bug which causes dehydration
- Some medications can cause constipation as a side-effect
- Children with additional needs may be more prone to idiopathic constipation
- Changes in routine, such as starting potty-learning, starting school, or feeling worried about something — when children feel anxious it can be hard for them to relax on the potty or toilet

(ERIC, 2022).

COMMON SYMPTOMS

Many people do not recognise the signs and symptoms of constipation, which can result in delays seeking help, causing further problems.

Common constipation symptoms in children include:

- Doing fewer than four poos in a week. Ideally, children should pass some soft poo every day, or at least every other day
- Pooing more than three times a day. This can show that their bowel is full, and poo is leaking out a bit at a time (soiling). It might be hard bits of poo, soft or even liquid poo called overflow
- Poo that looks like little pellets or rabbit droppings
- Big poos, or lots of poo all at once
- Pain when they poo and needing to strain. There may even be some bleeding when they poo or afterwards. Hard, large poos can cause an 'anal fissure' or small tear in the bottom
- Having a swollen, painful tummy. They might not feel like eating, have a reduced appetite, or even feel sick
- Smelly poo, wind, and bad breath
- Bladder problems, such as doing lots of small wees, needing to wee urgently, wee accidents, bedwetting and urinary tract infections (UTIs)
- Difficulty with potty training, including children who refuse to poo unless they are wearing a nappy. They may withhold or strain to prevent themselves from passing large painful stools
- Irritable or unhappy mood, which may or may not be accompanied by reduced energy levels

(ERIC, 2022).

TREATMENT

The best way to get rid of constipation is to treat it as early as possible. The longer it is left, the harder it will be to treat. Constipation is not a problem that can be helped by a change in diet only or waiting for the child to 'grow out of it'.

If there is indication that a child may be constipated, the parent/carer should be advised to keep a poo diary for the child, and to keep track of their bowel habits for a few days. They should record the frequency, the amount and the consistency, using a poo diary (the poo checker can be helpful; *Figure 1;* https://eric.org.uk/poo-checker/).

If constipation is suspected, ensure that the child has been seen and examined by a GP to rule out any underlying condition which may be the cause of the constipation. There are certain 'red flags' that should be eliminated through an assessment, carried out by a relevant healthcare professional (usually the GP). If red flags are identified, children should be referred to a paediatrician for further investigation. Assessment should include history-taking and a physical examination, which includes checking for any signs of faecal impaction, e.g. overflow soiling and/or faecal mass (https://eric.org.uk/childrens-continence-pathway/flowchart-constipation/).

NICE guidelines set out clear guidance for the treatment of constipation in children (NICE, 2017). The guidelines recommend that laxatives should be first-line treatment of idiopathic constipation in children.

A child who presents with suspected faecal impaction should follow a disimpaction regimen. Indications of faecal impaction include a history of more than one week without a bowel movement, as this is suggestive of a sufficient backlog of poo. A disimpaction is where laxatives are given in sufficiently large quantities to clear out the poo. An oral paediatric macrogol laxative is used in increasing doses until watery stool is passed (NICE, 2017).

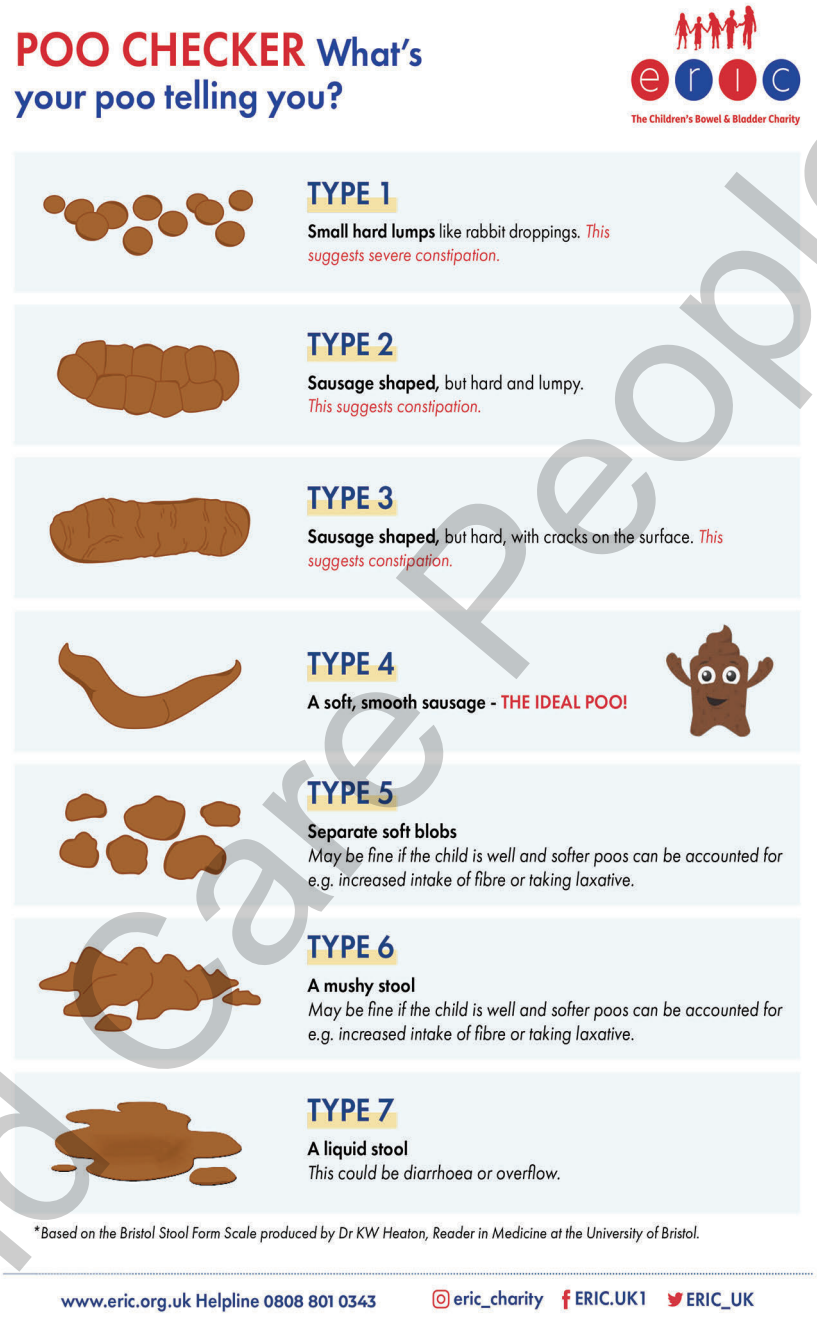

Figure 1.
Poo checker.

'The best way to get rid of constipation is to treat it as early as possible. The longer it is left, the harder it will be to treat.'

Children over 12 years should be treated with the adult preparation — the macrogol is exactly the same but there is twice as much in the sachet.

The dose needs to be increased until all the backlog of poo is cleared. Although the dosing regimen is written out over seven days, that does NOT mean that disimpaction will only take one week. It will take as long as it takes to clear all the accumulated poo — and that depends how much there is, which in turn depends on how long the child has been constipated.

The only way to be sure disimpaction has been achieved is to continue until the child is passing watery poo, i.e. brown water with bits in (https://eric.org.uk/childrens-bowels/parents-guide-to-disimpaction/). Macrogol laxatives are not absorbed into the bloodstream, but simply 'bind with' the water and deliver it to the large bowel, where it

will soften and lubricate the poo and stimulate a bowel action. Therefore, as long as the guidance is followed, the child will not come to any harm from taking such large doses of medication.

NICE guidelines recommend adding a stimulant if disimpaction is not achieved after two weeks on macrogols. Stimulant laxatives (e.g. senna, sodium picosulphate or bisacodyl) increase the muscular squeezing of the bowel, speeding up evacuation. However, due to the way that they work, stimulant laxatives can cause abdominal cramps (https://eric.org.uk/childrens-bowels/parents-guide-to-disimpaction/).

MAINTENANCE THERAPY

If a child presents with a very short history of constipation, indicating that faecal impaction is unlikely, or if the child has completed disimpaction, maintenance dose laxatives should be started.

First-line maintenance treatment consists of macrogol therapy, the dose of which should be adjusted according to symptoms and response. For children and young people who have completed disimpaction, the suggested starting maintenance dose depends on the maximum dose required, and the time taken to achieve complete clear out. NICE guidelines (2017) suggest maintenance dose might be half the disimpaction dose.

If macrogol therapy is not sufficient on its own, a stimulant laxative should be added. This may also be substituted if the child does not tolerate macrogol therapy.

Children should be reassessed frequently during maintenance therapy to ensure that they do not become re-impacted, and to assess any issues which may be affecting maintaining treatment, e.g. toileting.

Maintenance doses of laxatives for chronic constipation should be continued for at least three to six months after symptoms resolve and toilet training is established, unless loose stools develop. Even then, caution needs to be taken to ensure that the loose stools are not overflow and suggestive of re-impaction. They should be slowly and cautiously titrated down as the child tolerates. The aim is to prevent relapse. Many children need to stay on laxatives longer term and this is not a cause for concern (NICE, 2017).

'For children with additional needs, there should always be a combined approach of medication and behavioural strategies, as well as regular support and follow-up... .'

CHILDREN WITH ADDITIONAL NEEDS

Children with additional needs can be more prone to constipation for a variety of reasons. Restricted diets, insufficient fluid intake, medications, and reduced mobility can all increase the likelihood of constipation. Additional considerations, such as sensory preferences, communication difficulties and challenges with adapting to change, can also play a part and must be taken into account when assessing and treating the child or young person for constipation (https://eric.org.uk/treating-constipation-in-children-with-additional-needs/).

For children with additional needs, there should always be a combined approach of medication and behavioural strategies, as well as regular support and follow-up.

In the author's clinical experience, an individual toileting programme tailored to the specific needs of the child can be helpful. When developing the toileting programme, it is important to think about the physical factors affecting the child as well as the individual behaviours, so that both these aspects can be included. Using the ERIC bowel and bladder assessment chart to record the child's bowel and bladder activity for a few days can be helpful in developing a toileting programme based around the habits of the child (https://eric.org.uk/children-with-additional-needs/toileting-support-for-autistic-children/).

Red Flags **For immediate onward referral**

- Symptoms that commence from birth or in the first few weeks
- Failure or delay (>first 48 hours at term) in passing meconium
- Ribbon stools, leg weakness or locomotor delay
- Abdominal distension with vomiting
- Abnormal examination findings, including:
  - Abnormal appearance of anus
  - Gross abdominal distension
  - Abnormal gluteal muscles, scoliosis, sacral agenesis, discoloured skin, naevi or sinus, hairy patch, or central pit
  - Lower limb deformity including talipes
  - Abnormal lower limb reflexes or neuromuscular signs unexplained by existing conditions
  - Other symptoms that cause concern

(NHS England, 2023).

As well as bladder/bowel function and development, it is often useful to consider how sensations affect a child's response to using the toilet. Toileting, like eating, is an extremely sensory experience. Many children find that bathrooms and toilets are upsetting or scary. They may have difficulties in understanding the sensations experienced by their own body and knowing how to react to them. Some children may be especially sensitive to the sensations they feel and find them upsetting. Others may have reduced sensation and actively try to seek sensory input. It is useful to look at the different sensory experiences a child has and try to analyse and understand which aspects are causing difficulty. This helps in appreciating a child's perception and difficulties, and to create an environment where the child feels more relaxed, secure and comfortable (https://eric.org.uk/sensory-needs-and-toileting/).

Charlotte's story

Our daughter, Charlotte*, started solid foods at around six months old and issues with constipation began. This led to her passing hard, difficult stools. She became reluctant to do a poo and started withholding her stools.

We thought potty training would help but, when Charlotte was around two, she did a poo on the potty that petrified her. She developed a real fear surrounding poo. When she did a poo, she would scream for us to get it off her and take it away. She started to withhold even more, which led to more difficult bowel movements, resulting in more fear It was a vicious cycle.

I felt like a failure — like we had done everything wrong. Despite ensuring Charlotte had a good diet and drank plenty, we just couldn't seem to eliminate the constipation completely. Even when we treated it with medication, Charlotte was left with lingering fear of pooing (or 'toilet anxiety').

When she was three and a half years old and still not potty trained, I really started to panic. It began to take over my life. I read books, listened to podcasts, spoke to anyone I could to find 'the answer'. Charlotte was starting school in the September and I was concerned about her being 'the only child in nappies'.

Her fear of pooing outside a nappy began to extend to weeing outside a nappy. She refused to potty train, fearful.

Charlotte not being toilet trained wasn't what bothered me. If it were just a case that she was being lazy with it, I wouldn't have minded. What bothered me was how worried and distressed she was whenever we even mentioned potty training to her. I needed help to help her.

I heard about ERIC through a Facebook group for mums. Through email and the Helpline, I spoke to an advisor who reassured me that I wasn't alone and that none of this was my fault. They made me feel as though there was an answer and that we would get there. The advisor broke potty training down into manageable steps and advised on how to make her less scared of poo by looking at the poo in her nappy and talking about it positively.

We took Charlotte out of nappies and told her to ask for a pull-up when she needed to poo or wee. She took this well, with no accidents.

We started encouraging Charlotte to poo upstairs, then in the bathroom standing near the toilet, then on the toilet wearing a pull-up nappy. It took a while but she did really well. We then started undoing the sides of the pull-up, then putting the pull-up across the seat for her to wee/poo onto and we eventually moved the pull-up further down the toilet bowl.

One day, Charlotte just jumped onto the toilet and did a poo without even asking for the nappy. Once she conquered her fear, she flew through toilet training. All in all, it took about two months.

Charlotte started school in pants, using the same process as at home, where she asked for a pull-up to wee and poo in. School were amazing at supporting us with this.

Now, Charlotte is almost four years old and she's toilet trained day and night.

Since toilet training, Charlotte has not needed any more treatment for constipation. It has been such a weight off our minds, and we couldn't be more relieved. ERIC's support was invaluable. Having someone to speak to who understood what we were going through was such a relief.

As told to ERIC, The Children's Bowel and Bladder Charity by Amy*. This story has been edited for length and clarity.
*Charlotte and Amy's names have been changed.

STOOL WITHHOLDING

Stool withholding is when children avoid passing a poo by using their bottom muscles to stop themselves from having a bowel movement when they feel the urge to go. It often follows on from a period of constipation. Passing just one painful or uncomfortable poo, even as a baby, can scare a child and trigger a physical reaction.

Other common triggers for stool withholding include:

- An illness, such as a virus, with a high temperature and sickness that can lead to dehydration. Dry poo is harder to push out and will hurt more
- Passing a bigger than normal poo can make a small tear in a child's bottom called an anal fissure. This can make pooing painful and something they want to avoid doing again
- It is common for children to start holding on to their poo when they begin potty-learning
- A change in routine and using a different toilet away from home at nursery or school
- Lots of children prefer not to poo at school and then become constipated as a result (https://eric.org.uk).

Children often exhibit certain behaviours when they are withholding. They may refuse to sit on the toilet/potty, hide, strain, deny, ask for a nappy, poo at night, and have poo accidents. Sometimes these mannerisms can be mistaken for straining and therefore require careful explanation to parents and carers.

Stool withholding can result in a vicious cycle. The more the child holds on to their poo, the harder and drier it will become, resulting in poos that are painful to pass. This increases the child's anxiety, making it harder to relax and causing them to avoid going more. This cycle of holding poo can quickly mean a child becomes constipated.

Breaking the cycle of withholding focuses around treating constipation, reassurance, and confidence building, and can take time and patience (*Figure 2*; https://eric.org.uk/childrens-bowels/stool-withholding/).

SOILING AND CONSTIPATION

Soiling is uncontrolled leakage of poo, often into the underwear. Occasionally, soiling has an underlying cause so any child presenting with soiling should have an assessment carried out by a healthcare professional. However, it is normally associated with chronic constipation and is usually totally out of the child's control.

Chronic constipation means that the rectum is persistently full of stool, and therefore persistently stretched. Awareness of the need to defaecate usually arises from the action of the stretch of the rectum (as it is formed of smooth muscle containing stretch receptors) (https://eric.org.uk/childrens-bowels/soiling/).

ERIC resources

ERIC, The Children's Bowel & Bladder Charity, is the UK's leading charity supporting all children and teenagers with a bowel or bladder problem. ERIC's vision is for all children and young people to live a healthy and happy life regardless of any bladder or bowel issue they may face. ERIC has a wide variety of resources on constipation for children, families and professionals. These include:

- Advice sheet for children with constipation: https://eric.org.uk/advice-for-children-with-constipation/
- How to use macrogol laxatives: https://eric.org.uk/how-to-use-macrogol-laxatives/
- Poo diary: https://eric.org.uk/poo-diary/
- Poo checker: https://eric.org.uk/poo-checker/
- Parents guide to disimpaction: https://eric.org.uk/childrens-bowels/parents-guide-to-disimpaction/

ERIC also delivers webinar training for healthcare professionals at: https://eric.org.uk/professionals/health-professionals-training/

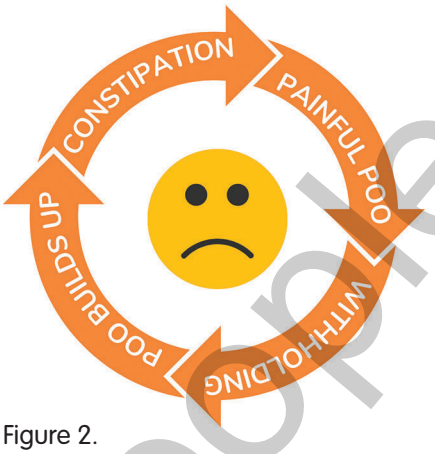

Figure 2.
Vicious circle of withholding.

Treatment is usually with laxatives, which may initially make the problem worse as the backlog of poo is cleared out. Often children with soiling require a disimpaction to start off with to empty the bowel fully. These laxatives may be required for several months, but the bowel can recover and the child will be able to poo normally again with the correct treatment and management (https://eric.org.uk/childrens-bowels/soiling/).

CONCLUSION

Constipation affects more children than many realise and can have a serious impact on their health, wellbeing and family life. Early diagnosis and timely, effective treatment and management, can improve patient outcomes and ensure that children live a healthy, happy life free of constipation. JCN

REFERENCES

ERIC (2022) *Constipation in children: symptoms, causes and relief*. Available online: https://eric.org.uk/childrens-bowels/constipation-in-children/

NHS England (2023) *National clinical constipation pathway for primary care for children*. Available online: www.england.nhs.uk/long-read/national-clinical-constipation-pathway-for-primary-care-for-children/

National Institute for Health and Care Excellence (2017) *Constipation in children and young people: diagnosis and management*. Clinical guideline [CG99]. Available online: www.nice.org.uk/Guidance/CG99

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1 UTI risk factors defined by Kennelly M., et al. (2019), 10.1155/2019/2757862
2 Luja has close to no flow stops and complete bladder emptying is defined as <10 mL (NCT05485922, N=42) . Individual results may vary.

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