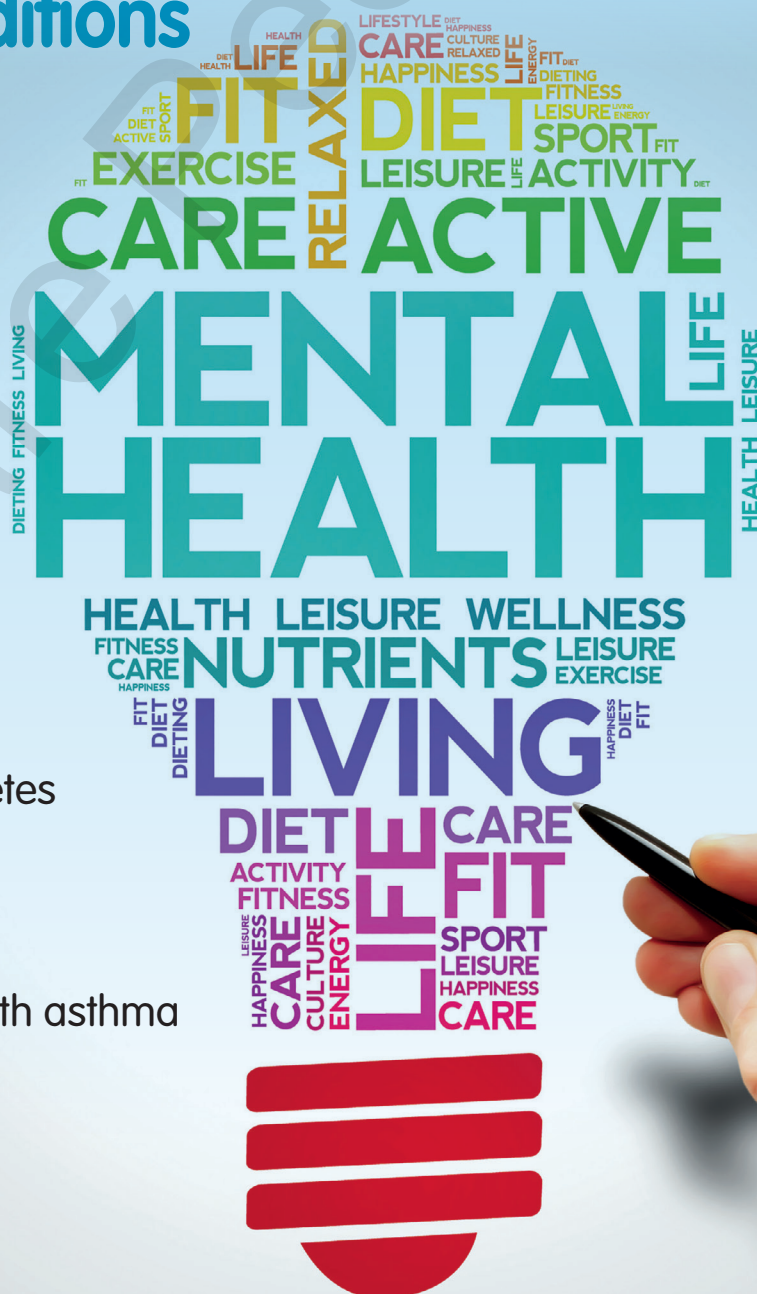


## Managing the effects of mental health and long-term conditions

- Raising gambling awareness
- Impact of cutting NHS ear wax removal services
- Improving outcomes for patients with bowel cancer
- Genitourinary syndrome of the menopause
- Hidradenitis suppurativa
- Malacia conditions
- Impact of stigma within type 1 diabetes
- Pneumonia in babies and children
- Cancer care reviews
- National care bundle for children with asthma
- NICE guidance for type 2 diabetes



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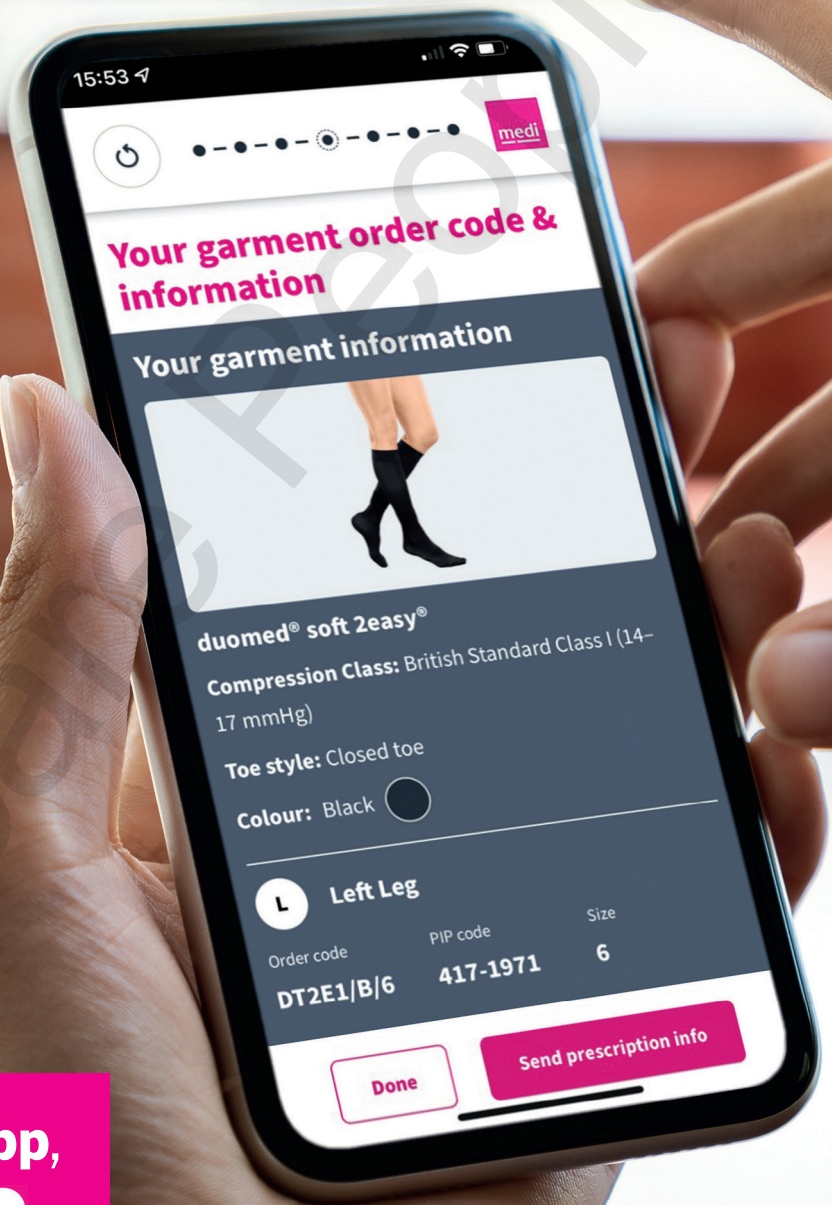
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# Opportunity to gain advanced practice skills



General practice nursing has adapted and evolved many times in the two decades I have been one. I have developed many new skills in this time and I now practice at a level way beyond what I would have imagined when I started my nurse training in 1986. I probably wouldn't have believed you then if you had told me I would be diagnosing, investigating, prescribing, and referring in the same way my medical colleagues do 37 years later. We were not even able to take blood or give paracetamol in 1986. Times have changed and continue to change.

The future of general practice nursing is still full of opportunities. We are experts in chronic disease management, but now need to be able to manage the more complex aspects of this. We also have an important part to play in population health and disease prevention. Enabling people to rehabilitate after illness or with their illness (e.g. pulmonary rehabilitation) and developing further our skills in women's health, contraception, menopause care and sexual health. We manage more results now, work with patients to help them self-manage their illness, and often work with people experiencing multimorbidity, frailty and help people 'wait well' for secondary care interventions.

I was interested to read the 'Practice matters' feature in this issue about mental health — in particular, the impact this can have upon GPNs and their own well-being. While challenge is good, the complexity of our clinics can also be draining. I have a mixture of acute and chronic diseases in my clinics and thought to myself recently 'oh good someone for an asthma review — I can do that easily and catch up' famous last words — I was soon trying to navigate through multiple physical, social and psychological issues with a hugely complex patient who was also angry with the way their hospital specialist appointment had been conducted. I was drowning, but managed slowly to carve out the start of a plan to address the multiple issues facing my patient. It was, however, time-consuming and exhausting using all my skill set to its maximum.

The articles here also reflect our expanding role. They cover the new NICE type 2 diabetes guidelines, stigma and type 1 diabetes, genitourinary syndrome of the menopause, asthma, airway wall diseases which we may see alongside asthma and COPD, how to assess, treat and support those with hidradenitis suppurativa, and improving outcomes for people with bowel cancer to highlight just some. In short, the journal is meeting my needs in my rapidly evolving role.

Please write in with ideas of topics you would like featured. I hope you enjoy reading this issue of the journal as much as I have and that you also take time out to care for yourselves in among the busy yet satisfying and demanding work we deliver.

*Jaqui Walker, editor-in-chief*



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My passion for education has given me such an amazing general practice nursing career. To be invited to become a member of the editorial team for the *Journal of General Practice Nursing* provides the opportunity to contribute to a journal with high standards and vision. This comes at a particularly challenging time for all staff working in primary care; embracing new ways of working in response to the Covid-19 pandemic. Education is what drives good clinical practice; the characteristic adaptability and resilience demonstrated by staff is founded on sound principles. It is a privilege to be part of the editorial board, contributing to the strategic commitment of enabling access to educational material, which is contemporary, relevant and valued.

*Julie Lennon*



I am thrilled to be part of the editorial board. To contribute to the content and review work by inspiring authors is an exciting opportunity. Most of my nursing career has been within primary care. I have worked with many GPN colleagues to assist in providing education, training and service improvement projects within the field of wound care. At present, the challenges that GPNs face are immense and this journal is a fantastic arena to offer support, education and share experiences and best practice.

*Kirsten Mahoney*



I am delighted to have been invited to represent the *Journal of General Practice Nursing* editorial board. It is a privilege to review and contribute to

the work of our incredible colleagues and authors. As a primary care pharmacist, I work closely and collaboratively with experienced general practice nurses (GPNs) and understand and appreciate the dedication, compassion and diverse skill mix GPNs bring to the multidisciplinary team. In these uncertain times, when the challenges and pressures faced in primary care and the health service as a whole are unprecedented, it has never been more imperative for us to keep up to date with current best practice and to be proactive in developing interprofessional relationships to support the delivery of high-quality patient care. I feel the journal is an excellent resource to promote evidence-based, person-centred care across the multidisciplinary team, and I look forward to supporting the up and coming content.

*Caroline McIntyre*



I am thrilled to join the editorial board. I am passionate about improving quality of care across primary care. I enjoy acting as a change agent in general practice to improve patients' experiences and always strive to ensure that high quality, person-centred care is achieved. I am excited to be able to share ideas and discuss topics imperative to our role with like-minded healthcare professionals.

*Cheryl Crawford*





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■ ■ ■ In each issue we investigate a topic affecting you and your practice. Here, we look at...

# Managing the effects of mental health and long-term conditions

Despite the medical advances of the past century, modern healthcare services often seem to treat our bodies as a series of unconnected parts, our ailments divided according to arbitrary physical labels. We may see a urologist for our weak bladder, a cardiologist for a malfunctioning heart, and a psychiatrist for any mental health issues. While it makes sense to apportion separate parts of the body to qualified specialists, these divisions can result in an inability among healthcare staff to see the 'bigger picture' — or to use modern healthcare terminology, to treat the patient 'holistically'.

Nowhere is this more applicable than in the traditional divide between mental health services and physical health, which have historically been viewed as loosely related entities with their own distinct training programmes and staff qualifications, and even separate hospitals. However, it is increasingly being recognised — particularly in general practice nursing — that the physical and mental aspects of health are inextricably linked, particularly when it comes to patients with long-term conditions.

## CHICKEN OR EGG

Back in 2012, the King's Fund, alongside the Centre for Mental Health, carried out some research into the prevalence of people who had both a long-term condition and a mental health issue, as well as the cost, both in human and financial terms. The report found that people with chronic conditions such as diabetes or cardiovascular disease were more likely to experience mental health issues, e.g. depression and anxiety, while £1 in every £8 spent by the NHS on patients with long-term conditions could be linked to poor mental health ('Mental



*This piece really resonated with me. As a GPN in a busy practice, reviewing patients with complex multi-morbidities on a tight time schedule can feel like a mammoth task! Finding the time to properly assess someone's mental health in a complex health review is a real challenge. On the back of lockdowns and the Covid pandemic, with the current cost of living crisis weighing on people, we are seeing an influx in poor mental health and increased levels of anxiety and low mood.*

*Being the GPN reviewing patients regularly, we may often be the one that they feel most comfortable to confide in when they are having a difficult time with their mental health. Also, we are seeing more research and discussion around how complex health conditions can adversely impact mental health, particularly with regards to diabetes and respiratory conditions, which can massively affect quality of life on a long-term basis. So, it is important to consider a person's mental health as part of their regular review, as fast intervention is often key to improving and managing outcomes in the long term.*

*Even on the busiest of days, it is important to take the time to stop and ask, 'how are things at home' — for example, while taking bloods. I have found that this often helps the patient to open up and tell me more about any work/life problems, allowing me to discuss with them whether their mental health is not doing as well and what we can do to help longer term. Having the depression score questionnaires is useful for annual reviews. However, more clinic time is needed with patients, particularly those with multi-comorbidities, to ensure that we are looking at the person as a whole — physically and mentally — to gain a complete picture as to how they are coping with the pressures of life alongside managing a long-term condition.*

**Cheryl Crawford**  
Practice sister, Braehead Medical Practice, Renfrew

health and long-term conditions: the cost of co-morbidity' – [www.kingsfund.org.co.uk](http://www.kingsfund.org.co.uk)).

The National Institute for Mental Health (NIMH) has also stressed the link between chronic conditions



such as cancer, heart disease and dementia, and the likelihood of developing a mental health issue. While it may be common for patients to temporarily experience periods of low mood or to feel discouraged after having a heart attack or receiving a life-changing diagnosis, if these feelings persist the person may be in danger of developing depression ('Chronic illness and mental health: recognizing and treating depression' — [www.nimh.nih.gov](http://www.nimh.nih.gov)).

As well as depression, anxiety is a common feature of many long-term conditions. For patients presented with a diagnosis of cancer or cardiovascular disease for example, anxiety may be a normal and even a positive response. It can prompt them to engage in healthy behaviours such as exercising more regularly, or following a medicines regimen. However, where anxiety about a long-term condition and its treatment or prognosis takes over, it can become detrimental. A recent article in the journal, *Current Psychiatry Reports*, detailed the link between anxiety and cardiovascular disease: 'Anxiety disorders are associated with the onset and progression of cardiac disease, and in many instances have been linked to adverse cardiovascular outcomes, including mortality' ('Anxiety disorders and cardiovascular disease' — <https://link.springer.com>).

Conversely, people with a mental health issue can find themselves at increased risk of developing long-term physical health conditions. People with depression are prone to a range of conditions including heart disease, stroke, diabetes, chronic pain, and Alzheimer's disease. While the reasons for this have not been adequately researched, one theory is that people with depression may not access healthcare services or find it harder to exercise, eat healthily or take medicines.

According to the NIMH, researchers are also looking into whether the physical changes associated with depression, such as raised inflammation, changes in the control of heart rate and blood



*There are a substantial number of long-term physical and mental health conditions. Each disease impacts on the individual differently and when combined can produce a diverse set of needs, which often results in a challenging package of care being required. Although this can stretch practitioners, and managing the care of individuals with both long-term conditions and mental health issues can be complex, it is also rewarding for practitioners and can positively promote the health of the individual if performed in an integrated, person-centred way. Viewing the person as a person who has a diverse set of needs is vital, rather than seeking to address their issues separately. For this to happen, community practitioners need to have an understanding of the complex interaction between the conditions, medications and strategies needed to promote the physical and mental health of individuals who often have a myriad of needs. They and their families need supporting skilfully and with knowledge in the community setting. Practitioners and organisations need to work together with an in-depth understanding of the requirements of the individual.*

*Currently, practitioners often have a focus in one training or skill set, such as mental or physical health, but they need to acquire a fundamental level of knowledge in both branches and areas to enhance the care that they deliver, often working across boundaries in a truly interprofessional way. However, this is continuing to develop due to legislation and the will of practitioners to work together to improve care.*

*Education, both pre- and post-registration for nurses and all practitioners involved in care, needs to be comprehensive and successfully combine both knowledge and skill in the condition itself, in the value of both physical and mental health being equally well supported, in the value of health promotion, as well as having knowledge of the family, carers and community setting. This is undoubtedly a strength of community practitioners.*

*However, there also needs to be a robust support system in place within the community, which may well have resource implications. Community practitioners need to be skilful in promoting and signposting opportunities to their patients and families and to utilise all resources available to support the individuals they care for.*

**Teresa Burdett**  
Principal academic, Bournemouth University

circulation and deregulated stress hormones may have an effect on people's risk of developing long-term conditions ('Chronic illness and mental health: recognising and treating depression' — [www.nimh.nih.gov/health/publications/chronic-illness-mental-health](http://www.nimh.nih.gov/health/publications/chronic-illness-mental-health)).

## FINDING TIME TO CARE

Mental health issues in people with long-term conditions is a particular issue for general practice nurses (GPNs), whose patients are often living with a chronic illness or experiencing long-term symptoms

such as pain. This can mean that patients have limits on their professional and social lives, while they may also be anxious about treatment outcomes and their likely prognosis.

However, for busy GPNs with a long list of patients often with multiple comorbidities, finding time to assess, let alone treat mental health issues, can be a challenge.

One recent study in the *Journal of Clinical Nursing* focused on district nurses' views on detecting mental health issues among older people in the community with multi-comorbidities. Researchers found that most district nurses regarded assessing mental health issues was important, but that they typically focused on more practical healthcare tasks to do with the patient's physical conditions ('District nurses' perspectives on detecting mental health problems and promoting mental health among community-dwelling seniors with multimorbidity' — [onlinelibrary.wiley.com](https://onlinelibrary.wiley.com)).

Evidence also suggests that diagnosing anxiety in patients with cardiovascular disease can be a challenge because of the overlap between anxiety symptoms and many of the symptoms of cardiovascular disease, such as restlessness, poor concentration and disturbed sleep patterns ('Anxiety disorders and cardiovascular disease' — [www.ncbi.nlm.nih.gov/pmc/articles/PMC5149447/](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5149447/)).

In addition, GPNs may also have to take into account the patient's current and past medicines profile when considering the effect of a long-term condition on their mental health and vice versa. For example, research has shown that antidepressants can aggravate a patient's medical condition through drug interactions and the effects of renal, hepatic, or gastrointestinal dysfunction on drug metabolism ('Emotional dimensions of chronic disease' — [www.ncbi.nlm.nih.gov](https://www.ncbi.nlm.nih.gov)).

As well as the challenge of identifying and managing patients



*Although long-term conditions are often thought of as a problem of adulthood, there are many diseases of childhood that fall into this category, asthma and eczema being two of the more common ones, but there are others including diabetes, arthritis and epilepsy.*

*The prevalence of such conditions (one million children in the UK with asthma and one in every five children with eczema) means that it is easy to overlook the negative impact that living with these conditions has on the long-term wellbeing of both the child and their families. Not only is health affected, but relationships within families can deteriorate and school attendance and attainment can suffer. Some studies point to a relationship with chronic childhood illness and low self-esteem, poorer relationships with peers, social anxiety and behavioural problems. Furthermore, frequent hospital visits or illness associated with the long-term condition can lead to poorer cognitive and social learning. Added to this, parents face additional challenges to normal parenting responsibilities in terms of illness-specific demands, such as medication regimens, social and financial constraints with one parent needing to take time off work to attend appointments or manage illness, and maintaining family relationships which may be challenged due to, for example, competing demands with other children or resentment about the amount of focus that the child with the condition requires. The cumulative impact of all these challenges can lead to adverse effects on mental health for the child and family.*

*For parents dealing with a new diagnosis for their child, there can also be a sense of grief and loss of the child they thought they had. Parents will often need support and education about the condition to help them come to terms with it and develop longer term coping strategies to help themselves and the child manage the condition. They will need advice and guidance on recognising and responding to changes in the child's condition, and support with minimising disruption to their lives and building support systems, including the use of educational resources.*

*This will be explored further in an article in the next issue of this journal, which will take a closer look at the emotional effects of living with a child with eczema.*

**Jude Harford**

Paediatric nurse practitioner, Adam Practice, Poole, Dorset

with long-term conditions and mental health issues, it is important to remember the burden this work places on GPNs themselves. Studies have shown that nurses responsible for providing mental

health interventions for patients with long-term conditions experienced a negative effect on their emotional well-being, with a lack of regular supervision worsening the situation ('Feasibility



of training practice nurses to deliver a psychosocial intervention within a collaborative care framework for people with depression and long-term conditions' — [bmcnurs.biomedcentral.com](https://www.bmcnurs.biomedcentral.com)).

Worryingly, there is also evidence that many people who have a long-term condition and a mental health issue receive a lower standard of care than those with a single condition ('Mental health and long-term conditions: the cost of co-morbidity' — [www.kingsfund.org.co.uk](http://www.kingsfund.org.co.uk)). Allied to this is the fact that many people with long-term conditions and mental health issues may live in deprived areas with little access to healthcare resources.

## INTEGRATED CARE

Back in 2012, The King's Fund and Centre for Mental Health report suggested that the care of people with long-term conditions and mental health issues could be improved by:

- Integrating mental health care with primary care and chronic disease management programmes
- Improving liaison psychiatry services in acute hospitals
- Providing all healthcare

professionals with basic mental health training and skills.

While this all sounds positive, there is little here in the way of specifics on exactly how a GPN might approach integrated care for a person with mental health issues and a long-term condition.

More targeted advice can be found in a paper published in the journal, *BMC Nursing*, which studied whether general practice nurses (GPNs) could be trained to deliver a psychosocial intervention for people with depression and long-term conditions. The study used a simple psychological therapy known as behavioural activation, which aims to increase the patient's participation in rewarding activities, such as walking, gardening or simply talking with friends, which they may have stopped due to their condition. This teaches people that their behaviour can positively affect their mood.

The study found that GPNs were ideally placed to deliver behavioural activation due to their extensive contact with patients with long-term conditions. The researchers also detailed the

positive effects for the GPNs themselves, with regards to their confidence in delivering mental health interventions ('Feasibility of training practice nurses to deliver a psychosocial intervention within a collaborative care framework for people with depression and long-term conditions' — [bmcnurs.biomedcentral.com](https://www.bmcnurs.biomedcentral.com)).

Of course, it can be stressful for GPNs to provide emotional and mental health support for patients as well as considering their physical needs. For this reason, it is vital that nursing education programmes include information on the emotional aspects of long-term conditions and their effect on the patient ('Emotional dimensions of chronic disease' — [www.ncbi.nlm.nih.gov](http://www.ncbi.nlm.nih.gov)).

However, while education is vital, perhaps the most important lesson is that whether a patient has a mental health issue, a single long-term condition, or is living with multiple comorbidities, the optimal approach GPNs can take is to view them as a whole person rather than a series of unconnected diagnoses. Or, as a famous Greek person once said — the whole is greater than the sum of its parts. **GPN**



*The NHS faces challenging times, and primary care is particularly compromised. It is important then to consider the opportunities presented with the newly formed integrated care boards (ICBs) to enrich existing services and identify ways of working that lead to improved outcomes and sustainable care. GPN representation needs to be at that table. With regard to managing the effects of mental health and long-term conditions, the true value of GPNs as key providers of holistic management for patients with long-term conditions should be recognised and acknowledged. GPNs are well placed to extend their holistic overview to include mental health, and to facilitate this it is essential to ensure that the right training opportunities are available and resourced.*

*GPNs also play a key role as facilitators, ensuring patients are referred to specialist services where necessary and signposting patients to wider services that support improved health and wellbeing, for example social prescribing. GPNs are rooted in the communities they serve and already have an important role within integrated care teams working collaboratively to support improved outcomes. This can be further enhanced to serve patients compromised by the effects of mental health and long-term conditions.*

**Rhian Last**

GPN facilitation lead, Leeds Community Healthcare NHS Trust; board member, RCGP Yorkshire Faculty; board member, Self Care Forum

Why healthcare professionals need to know gambling disorder is a serious addiction that kills

# Raising gambling awareness



When our son Jack told my husband and I that he was gambling, we had no idea his life was at risk. As parents, we thought we knew all the dangers to warn our children about — drinking, drugs, smoking, road safety, sexual predators.

But there was one predator that no one warned us of, one with bright, flashing lights, a sickening simulation of friendship, pushing products with higher addiction and at-risk rates than that of heroin, marketed as an innocent leisure activity. Jack and his friends were gambling in their dinner hour with their school dinner money. They were told it was just a bit of fun.

Jack was 24 when he took his life because of gambling. He left a suicide note that made it clear it was not because of lost money, debt, or pre-existing mental health problems, but rather the catastrophic effect that high-speed, industrialised forms of electronic gambling had on his mental health. The note said that he thought that he would never be free.

**“ A gambling addiction can have catastrophic effects on a person’s mental and physical health, their relationships, career and overall self-esteem and self-worth for years.**

Since gambling was deregulated in 2005 it has been normalised, just as smoking once was. £1.5 billion is spent each year on advertising and marketing (Parliamentary business, 2020). People are offered inducements such as so-called ‘free bets’ and ‘free spins’, designed to keep people gambling as long as possible and to encourage the development of addiction. These predatory practices have been highlighted by recent multimillion-pound fines levied on gambling operators for breaching their licensing rules (Gambling Commission, 2023).

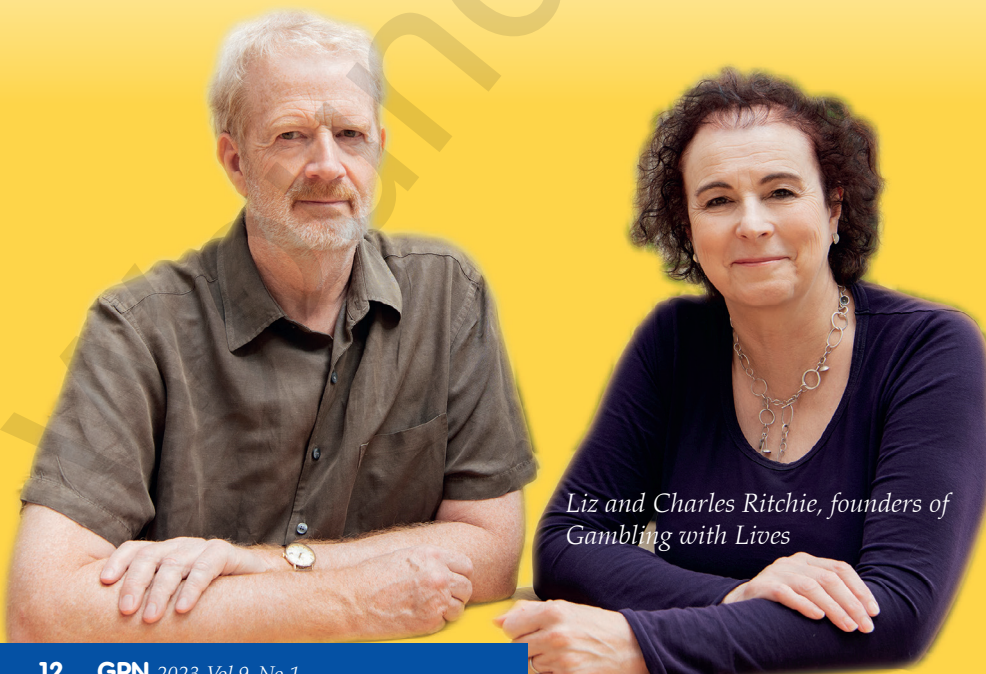
This is an industry which makes over £14 billion gross profit a year

in the UK (Statista, 2023) and where 86% of gross online betting profits come from just 5% of customers (NatCen Social Research, 2021), likely those who are addicted or at risk of addiction. This has created a public health crisis in the UK, with up to 1.4 million people (Gunstone et al, 2021) — including 55,000 children (Parliamentary business, 2020) — addicted to gambling, and many more millions harmed.

Like most industries who have harmful products to sell, the gambling companies try to obscure the link between the products and the harm to health. The best way to do this is to label people who have become addicted to toxic products through predatory practices, as weak, flawed, or vulnerable. This creates a narrative that minimises the risk to the wider public and disguises the reality that it is the products that create this addiction.

High-speed electronic gambling products are designed to target the brain’s reward system and the speed and excitement of the game increases the risk of addiction. Previously thought to be a compulsion disorder, gambling addiction is now identified as a behavioural addiction and a serious diagnosable mental health condition (DSM-5). A gambling addiction can have catastrophic effects on a person’s mental and physical health, their relationships, career and overall self-esteem and self-worth for years. The tool used to assess severity of gambling harm is the Problem Gambling Severity Index (PGSI), but unlike the AUDIT scale for alcohol harms, the PGSI is not well known or used in primary care.

Gambling disorder is highly correlated with suicide. A study from



*Liz and Charles Ritchie, founders of Gambling with Lives*



Sweden found that those addicted to gambling were 15 times more likely to end their lives than those not addicted (Karlsson and Hakansson, 2018). In 2021, a landmark Public Health England (PHE) study estimated that there are more than 400 suicides a year linked to gambling in England alone — more than one every day (PHE, 2021). Bereaved families believe that the normalisation of gambling and the narrative that it is all the individual's fault contributes to suicides. We know it does — we have read the suicide notes.

When Jack began gambling as a schoolboy on fixed-odds betting terminals (FOBTs) during his lunch hour, we had no idea about any of this, and nor did he. Jack had an early 'big win' — a common precursor to addiction — but he never lost huge, life-changing sums of money. He frequently abstained from gambling for long periods of time. He was the definition of what the gambling industry would call a 'responsible gambler'. He eventually began gambling online, where the most dangerous gambling products are available 24/7 in a completely unsupervised environment.

He actively sought help to stop gambling: he came to us, went to see his GP, and self-referred to psychological services, but no one had the information that could help him. If Jack had said he was taking heroin, we would have known the



Jack Ritchie.



Gambling with Lives at the Labour Party conference.

**“ Screening in primary care, clear referral pathways, training about products, and how to talk to those at risk, and widespread knowledge about the link between gambling harms and the increased risk of suicide must become common practice.**

risks. We would have known how to help him, services would have known how to help him, but this was not the case with gambling.

Jack was ultimately misdiagnosed with an anxiety disorder, when really the symptoms he was presenting with — insomnia, anxiety, depression — were caused by an untreated gambling disorder. His GP did not know the severity and risks of gambling addiction and the impact it has on a person's health and wellbeing. Instead, Jack was seen as using gambling to cope with these symptoms. Consequently, the right treatment was not provided, and the risk of suicide not seen.

To be clear, we do not blame the healthcare professionals for misdiagnosing Jack — they had also been kept in the dark and did not have the necessary information or training to help patients like Jack.

Last year at the inquest into Jack's death, the coroner confirmed what we already knew when he ruled that the 'warnings, information and treatment available to Jack were woefully inadequate' and ultimately contributed to his death.

During the inquest, the coroner heard how it was well known across government departments and the Gambling Commission (the body responsible for regulating the industry) that gambling carries a high suicide risk, but that not enough was done to warn the public. The coroner issued a prevention of future deaths report (Courts and Tribunals Judiciary, 2022) to government departments and highlighted the urgent need for more training for GPs, nurses, and all healthcare professionals about how to diagnose and treat gambling disorder.

Things have improved since Jack died. There are now a growing number of specialist NHS gambling clinics that offer patients evidence-based treatments like cognitive behavioural therapy (CBT), but in the words of the coroner at Jack's inquest, 'significantly more' needs to be done.

Screening in primary care, clear referral pathways, training about products, and how to talk to those at risk, and widespread knowledge about the link between gambling harms



and the increased risk of suicide must become common practice.

Identifying, supporting, and signposting someone to engage with specialist NHS treatment organisations and industry-free support services (see *Treatment and support* box) could change someone's life, and the people close to them.

After Jack died, my husband Charles and I started Gambling with Lives, a charity that supports those who have lost loved ones to gambling-related suicide. We offer emotional support, peer support, arrangement of memorial events, help with legal proceedings, debt and probate, and the opportunity to campaign for changes that will save others lives.

Gambling with Lives is one of many organisations campaigning for life-saving amendments to the 2005 Gambling Act, which is currently under review, with the white paper due. One of the most important things we have been pushing for is an independently administered statutory levy on the gambling industry's profits to pay for independent treatment, education, and research. We must end the industry-funded commercial disruption of health care that stops treatment from being impartial and effective — the statutory levy is key to this.

GPs, nurses, and mental health professionals need to know gambling disorder is a serious addiction that kills. Those on the frontline of care should understand that some products are far more dangerous than others, and that the shame, stigma, and misinformation that surrounds gambling will prevent patients seeking support.

Effective evidence-based treatment options and established pathways within the NHS are needed, as well as proper public health messaging, information, and education. Gambling disorder should be placed in the same territory as other addictions and primary care has a key role to play in the identification, assessment, and support of these harmed and maligned individuals. **GPN**

## Treatment and support

### For gamblers

Blocking tools — treatment for gambling disorder is essential, but the first step to stopping gambling often involves using blocking tools, such as Gamban and GAMSTOP. Once set up and registered, these tools will automatically self-exclude you from all UK-licensed online bookmakers.

- Gamban: [www.gamban.com](http://www.gamban.com)
- GAMSTOP: [www.gamstop.co.uk](http://www.gamstop.co.uk)

Many banks also give you the option to block all gambling transactions, including Lloyds, Halifax, HSBC, Starling and Monzo.

Self-excluding from land-based venues:

- MOSES (multi-operator self-exclusion scheme).
- [www.self-exclusion.co.uk](http://www.self-exclusion.co.uk)

### Treatment providers

- NHS Northern Gambling Service — NHS clinic offering specialist addiction therapy, covering the whole of the north of England; Tel: 0300 300 1490; Email: [referral.ngs@nhs.net](mailto:referral.ngs@nhs.net)
- NHS National Problem Gambling Clinic — NHS clinic offering specialist addiction therapy based in London; Tel: 020 7381 7722; Email: [gambling.cnwl@nhs.net](mailto:gambling.cnwl@nhs.net)
- The Southern Gambling Service — [www.southernhealth.nhs.uk/our-services/a-z-list-of-services/gambling-service](http://www.southernhealth.nhs.uk/our-services/a-z-list-of-services/gambling-service) Tel: 02382310786
- The West Midlands Gambling Harms Clinic — [www.inclusion.org/our-services/addiction-services/west-midlands-gambling-harms-clinic/](http://www.inclusion.org/our-services/addiction-services/west-midlands-gambling-harms-clinic/)

### Peer support

- Gamblers Anonymous — organising meetings of people struggling with gambling addiction across the country: [www.gamblersanonymous.org.uk](http://www.gamblersanonymous.org.uk)
- GamLearn — support for people harmed by gambling by aiding their professional development: [www.gamlearn.org.uk](http://www.gamlearn.org.uk)

### For family and friends

- GamFam — help for families to recognise and deal with gambling addiction: [www.gamfam.org.uk](http://www.gamfam.org.uk)
- GamAnon — local meetings for families of gamblers: [www.gamanon.org.uk](http://www.gamanon.org.uk)

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Equitable ear wax removal services for all

# Impact of cutting NHS ear wax removal services

National charity, RNID, is concerned that many people are risking their hearing by trying to remove problematic ear wax themselves, as they are unable to access wax services on the NHS. The charity is calling for fully funded ear wax removal services to be brought back into primary and community care settings, in line with National Institute for Health and Care Excellence (NICE) guidelines, and for the NHS to clarify how people can safely manage ear wax build-up themselves at home.

Ear wax is a normal substance that helps protect the outer ear. For most people, ear wax moves out of the ear naturally over time, however for some it builds up, eventually requiring professional removal. It is thought that around 2.3 million people require professional ear wax removal every year (NICE, 2018).

If troublesome ear wax is not removed, it can lead to temporary hearing loss, tinnitus, earache, and even dizziness. Fortunately, these symptoms do not usually continue after wax has been removed.

Significant ear wax build up can also delay or prevent essential hearing care in audiology.

Previously, most people who needed ear wax removal could access it at their GP surgery, where the procedure was carried out by the general practice nurse (GPN). Recently however, more people are finding that their GP practice no longer offers this service and are instead being advised to seek private removal or attempt to manage ear wax themselves. This is primarily due to changes to the General Medical Services (GMS) Contract, where wax removal is no longer funded as a core service, and NICE guidance stating the traditional 'syringing' method is unsafe. Safe removal methods such as electronic irrigation and microsuction are recommended, but it is unclear how widely these are used.

Following a significant number of enquiries from the public about difficulties accessing NHS ear wax removal services, especially since the onset of the Covid-19 pandemic, RNID surveyed more than 1,400 adults who have experienced ear wax build up to find out what advice they were given, the action they took, and the impact this had on them.

## SURVEY FINDINGS

Key findings from the survey included:

- 66% of respondents had been told ear wax removal was no longer available on the NHS

- 26% of respondents could not afford to get their ear wax removed privately, which can cost between £50 and £100
- 71% of respondents resorted to attempting to remove ear wax themselves, although two-thirds did not feel confident doing this
- Many of the methods people described to remove ear wax were dangerous. These included hair clips, paper clips, toothpicks, cotton buds and Hopi ear candles.

After trying to remove ear wax themselves, only 20% of respondents said their problems went away, while 55% of people noticed no change in their condition. One in 10 said that their symptoms got worse, or they caused themselves injury which required medical attention.

## BARRIERS TO TREATMENT

As said, 66% of people surveyed said that they had tried to get wax removed on the NHS, but were told the service was no longer available.

Some respondents considered private ear wax removal (often through high street providers), but more than a quarter (26%) stated that they could not afford to pay for it. Ear wax build-up is often recurrent, with some people needing removal three or four times a year, making private services even more out of reach. This was found to be especially problematic for hearing aid wearers, who are more likely to experience wax build-up.

Many people cited long waiting times, both for NHS hospital wax removal, and in some cases, for private removal.

Paul Clarke, 51, lost his hearing through meningitis when he was a child. He used to get ear wax



Franki Oliver, audiology manager, RNID



professionally removed at Belfast Royal Victoria Hospital, but the service was stopped during the pandemic. He said:

*I lost my balance and fell. I contacted the GP who checked my ears, he gave me two options — either to go private or go on a waiting list with the health trust. I thought about going privately but it was too costly. I experienced a lot of discomfort, and it had a severe effect on my communication with others. Eventually I got an appointment, but it took over a year.*

It is worth mentioning that RNID does not believe hospital-based ear wax removal provided by ENT is an appropriate solution for most patients, nor is it cost-effective for the NHS. The tariff price for an outpatient ENT appointment is significantly more than what it would cost to deliver in primary or community care.

## EFFECT ON PATIENTS

73% of respondents experienced hearing loss due to ear wax build up, and 37% experienced tinnitus. 48% of respondents experienced earache or discomfort, and 23% experienced dizziness.

Many people said that their symptoms caused distress or impacted their wellbeing and mental health. Respondents described feeling socially isolated, depressed, anxious, and frustrated. Some said they feared losing their independence or felt worried about leaving the house due to being unable to hear hazards. Respondents also reported having more difficulty communicating with others.

## HEARING AIDS AND AUDIOLOGY APPOINTMENTS

Hearing aid wearers made up 36% of survey respondents, and many reported not being able to wear their hearing aids due to excessive ear wax.

As ear wax removal has not traditionally been offered in NHS audiology, those that attend

appointments with significant ear wax are usually turned away, wasting the patient's time and NHS resources. 22% of hearing aid wearers stated that they were unable to have an essential audiology procedure, such as a hearing test or ear mould impression due to too much ear wax.

For hearing aid wearers, having working aids and timely access to audiology services is essential. From previous research, RNID knows that being unable to access audiology services can have a serious impact on an individual's quality of life and mental health.

## SELF-MANAGEMENT

Many patients are being advised self-management as the first line treatment for ear wax build-up. A quarter of the survey respondents said a healthcare professional had instructed them to manage their ear wax themselves.

The NHS advises using two to three drops of 'medical grade olive oil', three to four times a day for three to five days (NHS, 2021). Encouragingly, the majority of respondents (85%) were advised to use ear drops, however half reported not being given sufficient advice on how to use them. Concerningly, around 10% were told to use a bulb syringe, a device that is not recommended by NICE due to a lack of evidence suggesting it is safe or effective (NICE, 2018).

Of those that attempted self-removal, only 20% found their symptoms resolved, while 55% noticed no difference. Worryingly, some people reported their symptoms got worse (7%) or they caused themselves injury that required medical attention (3%). This included a perforated ear drum, bleeding, ear infections, and a foreign body stuck in the ear.

Of those that attempted to manage wax themselves, a third (33%) sought professional treatment at a healthcare provider afterwards. Of these, only one in five managed to get their wax removed

professionally, while 38% were, again, advised to seek treatment elsewhere.

## DANGEROUS REMOVAL METHODS

NICE advises never inserting objects into the ear to remove wax, as it risks causing injury to the delicate structures in the ear. Worryingly, many of the methods people used to remove their own ear wax were classed as dangerous (e.g. hair grips, paper clips, toothpicks, cotton buds, and Hopi ear candles).

## CONCLUSION

The withdrawal of NHS ear wax removal services in primary care has had a far-reaching impact. If people are unable to access NHS wax removal services, they can experience bothersome and distressing symptoms, be denied essential audiological care, or experience poor mental health. People are also more likely to try to manage wax themselves, but a lack of appropriate advice could result in no improvement, or injury.

Action is required to ensure ear wax removal services are funded and provided in line with NICE guidelines, that innovative solutions to the wax removal pathway are explored by both national and local bodies, and that clear advice on self-management of wax is made available to all. **GPN**

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 **More information...**

... about RNID, please visit:  
[www.rnid.org.uk](http://www.rnid.org.uk)

■ ■ ■ GPNs have a responsibility to know how to access the plethora of specialised veteran services in the UK

# Identifying and supporting veteran patients

Veterans and the armed forces community should be high on our agendas as healthcare professionals. In 2021, for the first time, Census data aimed to capture the true number of veterans living in the UK. Data revealed that 1,853,112 people in England and Wales reported that they had previously served in the UK armed forces; to put that into perspective, that is 3.8% of total residents aged 16 years and over, a significant proportion of the population. Despite this, research suggests that many GP surgeries do not know how many veteran patients they have, or indeed how to address their specific health needs, which may differ from those of the general population for various reasons (Simpson et al, 2015).

The military lifestyle often requires frequent travel and therefore can reduce contact and make it harder for veterans to build trusting relationships with healthcare services. The transition to civilian life itself should also not be overlooked, as this has long

**“ ... research suggests that many GP surgeries do not know how many veteran patients they have, or indeed how to address their specific health needs, which may differ from those of the general population for various reasons.**

been identified as being potentially problematic, and can be a major life stressor for both the veteran and their family. A study found that in a sample of 800 veterans, 70% felt that the general community misunderstood their experience, and many felt disconnected from civilian life due to profound differences between civilian and military life (Oster et al, 2017). This is why it is critical as healthcare professionals to understand these challenges, so that we can help to identify early issues and signpost to specialised support when needed.

Some sources suggest that 52% of veterans have a long-term illness or disability, compared to 36% of the general population (Royal British Legion, 2006). Similarly,

Hall et al (2022) found that a higher prevalence of cardiovascular disease and high blood pressure was observed in male veterans compared with the general population. Research from King's College, London estimated the rate of post-traumatic stress disorder (PTSD) among UK veterans to be 7.4% (the PTSD rate among the general public is 4%), and this figure is estimated to be even higher for veterans who served in Iraq or Afghanistan (9%), with 30% of this group predicted to develop a mental health condition (King's College, 2021). It is important to note too that these are the cases we know about — underreported PTSD is sadly common, with veterans and their families trying to deal with symptoms themselves rather than seeking support.

There is also the issue of substance misuse. Prevalence of alcohol-related harm and alcohol dependence within the UK armed forces community has been shown to be greater than in the UK general population (Murphy et al, 2016). Thus, veterans are likely to need support and healthcare professionals, such as general practice nurses (GPNs), have a responsibility to know how to access the plethora of specialised veteran services in the UK.

GP surgeries are often the first point of contact for veterans, whether the contact is related to their service or not. Simply asking the question, 'Have you ever served?' helps to identify this population, meaning that if they present with needs which may be related to their service, they can be appropriately signposted. The greatest challenge is knowing exactly what help is out there, as this in itself can feel overwhelming.



*Jordana Wright, advanced nurse practitioner, Derbyshire Community Health Services NHS Foundation Trust*

To address this, the Royal College of General Practitioners' (RCGP) veteran friendly GP practice accreditation scheme is an initiative which aims to provide GP surgeries with the knowledge and resources they require to best support their veteran patients. The scheme is free, and all it takes is for the practice to nominate a veterans' clinical lead, ask patients if they have ever served in the armed forces, and code them as 'military veteran'. In return, the clinical lead and wider team receive easy-to-access training and information on how to identify, support and, if necessary, refer veteran patients to services like Op Courage or the Veterans Trauma Network. Once they have received this training and information, they can take the lead on championing veterans' care in their practice.

In many cases, the scheme is driven forward by GPNs, who can take on the role of clinical lead for their practice and have the responsibility for sharing the latest information they receive from the RCGP with the wider practice team. Veteran friendly accreditation has been found to be effective at enhancing practice care for veterans and is universally recommended, with 99% of accredited practices recommending the scheme (Finnegan et al, 2022). **GPN**

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## More information...

To find out more about the RCGP's veteran friendly scheme, visit: <https://elearning.rcgp.org.uk/mod/book/view.php?id=12533&chapterid=285>


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 You can't pour from an empty cup...

# New free digital wellbeing resource for nurses

Last November I was proud and privileged to be joined by over a thousand nurses, speakers and leaders across the country for the live launch of the new nursing version of our ShinyMind mental health and wellbeing app — available now, free of charge to all NHS nurses, midwives, nursing associates, and healthcare support workers in England.

ShinyMind is the only app co-created, developed and tested in partnership with NHS employees across all levels, and the new nursing version provides over 150 resources, tools and exercises to help support nurses' wellbeing, created in collaboration with nurses and nursing organisations from across the country, including the Florence Nightingale Foundation, Foundation of Nursing Studies, The Cavell Trust and NHS England and Improvement.

The ShinyMind nursing app includes tailored resources, co-designed with nurses, such as reflective supervision exercises, regular 'ShinyMind Live!' webinars and 'LifePacks', such as self-care, mental wellness and coping with

anxiety, providing both daily support and help with professional needs such as continuing professional development (CPD). The ShinyMind app is evidence-based and also provides other personalised psychotherapeutic masterclasses (including stress, sleep, self-compassion and resilience and 12 more, with others planned), responsive daily mental health support and health nudges.

Additional resources will continue to be added and co-designed with the nursing community, led by Karen Storey, NHS England and Improvement nursing retention and liaison lead, who is in her second year seconded into ShinyMind to support the ongoing development of the app for nurses, and to help engage nurses in co-designing all resources.

For almost 20 years, the majority of our work has involved supporting the NHS and its people. It is currently more important than ever that support is available, as the stark reality is that huge pressures exist in the system, built up over many years even before the additional hammer blow of Covid. We all repeatedly hear of burnout, of truly committed and talented people leaving due to stress and anxiety and, in coaching nurses across the country, I have heard first-hand sad and harrowing stories of anxiety, struggle and helplessness.

But, I also hear many more stories of strength, courage, positivity and passion for their profession from nurses. We never know when loved ones will need their support, but we trust that they will be there in our time of need, always doing their best for us.

*Rebecca Howard, CEO and founder of ShinyMind and a psychotherapist*

At ShinyMind we felt that it was important to give nurses support in return. We want to instil confidence that they can trust in a resource to support them at their time of need, to enhance their wellbeing and mental health, enabling them to have a positive mindset to continue in the job they love, and on which we all depend.

And because it's important, we wanted to make sure the app worked. Over five years of evidence gathering, live sessions with over 3,000 NHS employees, independent research and testing, and vital collaboration with the nursing professions it's created for, ShinyMind can and does help. Our latest research shows that 94% of a nursing group felt better after using it, 77% felt better at managing their own mental health, and 100% would recommend it to other nurses.

We are privileged to be supported by a nursing advisory board of senior leaders, including Professor Steve Hams MBE, chief nursing officer at North Bristol NHS Trust, who has been helped personally by ShinyMind and spoke at the nursing version launch:

*I've been fairly open about my mental health. I've had two experiences of poor mental health and more recently anxiety and depression coming out of the pandemic. I genuinely believe that ShinyMind has helped my recovery this time round and I think that it's truly special, as things like the 'Inspire Me' messages I get at the most impromptu times during the day are really comforting and make me smile. The 'Daily Shine' helps me reflect on what's gone well, and what could've been better, and the Masterclasses really set this app way above the others —*



*sleep, self-compassion and coping with anxiety are those I've used most frequently.*

*ShinyMind is in my kitbag now. My mental health is my superpower and defines me, and ShinyMind is a fab app!*

Professor Gemma Stacey, deputy chief executive officer and director of policy unit at the Florence Nightingale Foundation, believes it is vital that nurses look after their own emotional needs so that they can best support the needs of their patients. Professor Stacey has more than 20 years' experience as a mental health nurse and helped to develop the restorative clinical supervision aspect of ShinyMind:

*ShinyMind has so many different kinds of resources within it. It's like an education tool as well as something that you can use practically on a day-to-day basis and to support wellbeing.*

Marsha Jones, deputy chief nurse at Epsom and St Helier University Hospitals NHS Trust, is also an advocate for Black, Asian and Minority Ethnic (BAME) employee wellbeing, and believes ShinyMind could help to reduce stigma surrounding mental health within minority ethnic communities. She said:

*They're exhausted, they get some of the most awful shifts to work or some have the hardest tasks to complete. Sometimes people don't get a break. They're juggling family life, they're depleted, and that is often sometimes not comparable with the experiences of their white counterparts. So, that's why it is vitally important that we manage the stigma within mental health, especially for cohorts or communities who don't normally feel comfortable to talk about these things.*

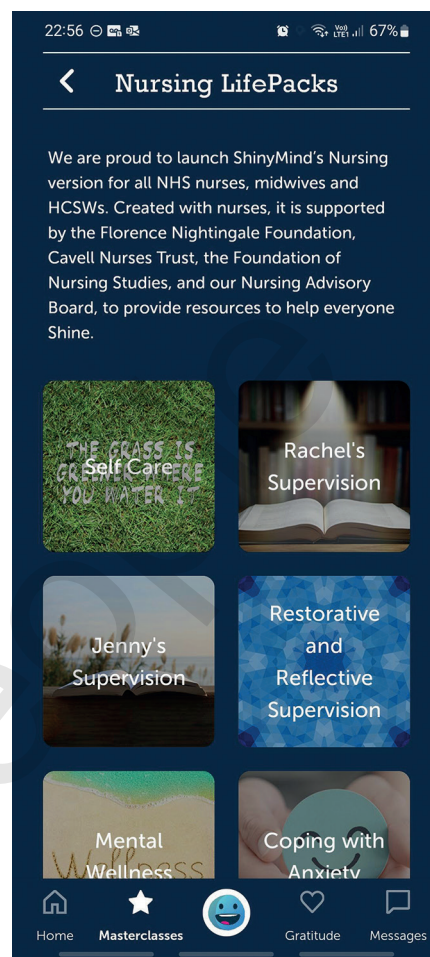
In addition, ShinyMind and primary care staff have co-designed a prescribing portal and NHS systems are now prescribing ShinyMind as a 'wellbeing prescription' for patients with stress

and anxiety or suffering from long-term conditions. Initial feedback has been positive, with 83% of patients stating that they would recommend it to others, 60% said that they were feeling better, and 28% reported an improvement in life satisfaction and a 17% improvement in GAD scores within six weeks.

While it is early days, we are also encouraged by 12-month longitudinal research which is showing that the same patients have 3.5 less GP contacts per year, so reducing pressure on services and staff. This has the potential to create a 'virtuous circle' with our Shine Programme already providing training to GP practice employees, including their own ShinyMind community to support their mental wellness. There are also many other settings where ShinyMind can help, such as in the heart of communities, and we are in discussions with nurse leaders about its potential in community nursing.

The NHS Fuller Stocktake report commissioned by NHS England in May 2022 recognises that 'there are real signs of genuine and growing discontent with primary care — both from the public who use it and the professionals who work within it.' It notes an ever-increasing pressure on primary care services, with teams stretched beyond capacity and staff morale at a record low — the same factors prevalent across the nursing community.

The launch is called 'You can't pour from an empty cup' and that's the reality. We all have different levels at different times, but Steve Hams is by no means alone in terming the situation around nursing burnout as 'endemic', and many of those working within the professional nursing community may have cups about to run dry, if they have not already. The nursing version of ShinyMind aims to help nurses to re-fill their cups, increase understanding of self, be kinder to themselves and help build a positive growth mindset. It also provides resources for professional practical needs such as CPD and reflective supervision.



At the live launch of the nursing version, Janet Thornley, strategic primary care nurse lead at Bedford, Luton and Milton Keynes Integrated Care System likened sharing the app with colleagues and patients to giving a gift you know the recipient is going to like, and 'a job well done.' ShinyMind is free and we believe it can help, so my hope is that as many of the nursing community as possible give it a try.

Given the wonderful support received from the nursing profession, the launch aims to be just the beginning of a journey with every member of the wider nursing community, to collaborate in creating exciting new resources to help and support nurses' mental health and wellbeing in the most trusted, highly regarded profession. **GPN**





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Providing expert information and support for everyone affected by bowel cancer



# Improving outcomes for patients with bowel cancer

Bowel Cancer UK is the UK's leading bowel cancer charity, determined to save lives and improve the quality of life of everyone affected by bowel cancer. Its vision is a future where nobody dies of the disease.

Bowel cancer is the fourth most common cancer in the UK and the second biggest cancer killer (Bowel Cancer UK, 2022a). Nearly 43,000 people are diagnosed with bowel cancer every year in the UK (Bowel Cancer, 2022b).

The symptoms of bowel cancer can include:

- Rectal bleeding/blood in stools
- A persistent and unexplained change in bowel habit
- Unexplained weight loss
- Extreme fatigue
- A pain or lump in the abdomen.

## WHAT ARE THE RISK FACTORS OF BOWEL CANCER?

Those with one or more of the following risk factors are at greater risk of getting bowel cancer:

- Aged over 50
- Strong family history of bowel cancer
- A history of non-cancerous growths (polyps) in your bowel



- Longstanding inflammatory bowel disease, such as Crohn's disease or ulcerative colitis
- Type 2 diabetes
- An unhealthy lifestyle.

## HOW COMMON IS BOWEL CANCER?

Around 268,000 people living in the UK today have been diagnosed with bowel cancer (Bowel Cancer, 2022b).

More than nine out of 10 new cases (94%) are diagnosed in people over the age of 50, and nearly six out of 10 cases (59%) are diagnosed in people aged 70 or over. But, bowel cancer can affect anyone of any age. More than 2,600 new cases are diagnosed each year in people under the age of 50 (Bowel Cancer, 2022b).

One in 15 men and one in 18 women will be diagnosed with bowel cancer during their lifetime (Bowel Cancer, 2022b).

## HOW MANY PEOPLE SURVIVE BOWEL CANCER?

Bowel cancer is treatable and curable, especially if diagnosed early. Indeed, nearly everyone survives bowel cancer if diagnosed at the earliest stage (Bowel Cancer, 2022b). However, this drops significantly as the disease develops. Early diagnosis really does save lives.

More than 16,500 people die from bowel cancer in the UK every year. It is the second biggest cancer killer in the UK. But the number of people dying of bowel cancer has been falling since

the 1970s. This may be due to earlier diagnosis and better treatment.

## EARLIER DIAGNOSIS

Improving earlier diagnosis is a key priority for Bowel Cancer UK. An estimated nine in 10 people will survive bowel cancer if diagnosed at the earliest stage (Bowel Cancer UK, 2022a).

Bowel Cancer UK are supporting primary care health professionals to increase the number of patients diagnosed at an earlier stage by providing education opportunities, and raising awareness of the symptoms and the work of the charity.

## SUPPORTING YOUR PATIENTS

Bowel Cancer UK provides expert information and support for everyone affected by bowel cancer. It is also leading change for younger patients with bowel cancer, campaigning to improve survival and quality of life for those with advanced bowel cancer and working to improve early diagnosis by ensuring people are getting the right test at the right time. **GPN**

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**> To join...**

... Bowel Cancer UK's professional network, please visit: [www.bowelcanceruk.org.uk/professionalsnetwork/](http://www.bowelcanceruk.org.uk/professionalsnetwork/)

*Beth Jones, health professional education and engagement manager, Bowel Cancer UK*



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 Understanding GSM and treating appropriately

# Genitourinary syndrome of the menopause (GSM)

This clinical skills series — Think menopause — looks at menopause-related issues to help general practice nurses (GPNs) identify, assess and manage women whose day-to-day lives may be detrimentally affected by this stage in their life. Here, Sue Thomas, advanced nurse practitioner (ANP) based in Leamington Spa, discusses the complications that can arise with genitourinary syndrome of the menopause (GSM).

## SYMPTOMS OF GSM

Genitourinary syndrome of the menopause (GSM) is an umbrella term to more accurately describe a range of vulvovaginal and lower urinary tract symptoms related predominately to low oestrogen levels. Signs of GSM include atrophic changes of the external and internal female genitalia with regression and thinning of the labia minora, retraction of the introitus, and prominence of the urethral meatus (Nappi et al, 2013). Symptoms may include genital dryness, painful intercourse, post-coital bleeding, burning, soreness, irritation and itching of the vulva or vagina, including urinary frequency and urgency (Portman and Gass, 2014). Some of these symptoms can lead to repeated oral antibiotic courses for suspected urinary tract infections (UTIs) and can have a significantly negative impact for women in terms of intimate relationships, sexual function and quality of life (Phillips et al, 2022).

Up to 80% of postmenopausal women report troublesome GSM symptoms and despite this, only 25% of women seek help and less than 10% start any treatment. (Nappi and Kokot-Kierepa, 2012). There are long-held beliefs and attitudes among women (including healthcare professionals) that GSM symptoms are a natural and unavoidable part of the ageing process (Sturdee and Panay, 2010). Embarrassment, anxiety and confusion continue to exist in both women and their healthcare providers leading to patients not presenting in the first place and clinician reluctance to prescribe.

Indeed, in a survey of healthcare professionals, 70% admitted that they never, or rarely asked about troublesome symptoms relating to vaginal dryness (Nappi and Kokot-Kierepa, 2012). Given the significant impact on women's quality of life and evidence that only a minority of these symptomatic ladies present, it should be seen as an ideal opportunity to screen all menopausal women regardless of what they present with in primary care (Pitkin and British Menopause Society [BMS], 2018; Newson et al, 2021). It should also be noted that those with atypical presentations, such as irritability and behaviour changes, and those who may not be able to articulate symptoms, such as those with learning disabilities or dementia, may also go undetected (Martin et al, 2003; Newson et al, 2021).

## TREATMENTS FOR GSM

Around 10–25% of women on systemic hormone replacement therapy (HRT) will also need local oestrogen, particularly for those with recurrent UTIs (Newson et al, 2021). Hormone treatment using low-dose vaginal oestrogen is still considered the gold standard and is safe and well tolerated (Pitsouni et al, 2018). However, many women remain reluctant to use them because of historical misguided concerns regarding long-term safety issues with hormone exposure, including breast cancer risks and potential side-effects. These apprehensions are further compounded by alarmist, inaccurate and outdated boxed warnings in oestrogen products (Pitsouni et al, 2018).

Local oestrogen can be started in the presence of a good clinical history and examination is not always necessary or possible during remote consultations. However, examination should be completed if there are any worrying symptoms, such as lumps or abnormal vaginal bleeding, to suggest underlying pathology, or when there is no response to treatment or symptoms worsen after starting treatment (Newson et al, 2021). If speculum examination can be performed, a cervical smear can also be offered to those who are eligible to save a further appointment. If, however, speculum insertion is uncomfortable or painful, the woman should be advised to return for screening a few months after gaining informed consent to start local oestrogen treatment.

Depending on the vaginal product, initial treatment generally requires daily vaginal insertion or application for two to three weeks, then twice weekly for as long as needed. Treatment should be started promptly as the response can take time and will depend on the degree of atrophy at the time of presentation (Stuenkel et al, 2015). Vaginal epithelial absorption is greatest during the initial loading of local oestrogen when the tissue is most atrophic. Once the tissue quality has improved, absorption decreases and so smaller doses can be used indefinitely to maintain rigour in most preparations (Stuenkel et al, 2015).

Generally speaking, improvements are normally seen within three to four months, but the most severely affected women may take longer to respond. Treatment should be provided indefinitely with



ongoing annual review (Newson et al, 2021). The only longer acting local oestrogen which does not require an initial loading schedule is the ESTRING vaginal ring (Pfizer), which is inserted high into the vagina and worn continually for three months (Table 1). Women should know that symptoms will likely recur on stopping treatment and that long-term use is safe.

Systemic absorption of vaginal estradiol has been found to be below the reference range in postmenopausal women (Santen et al, 2019). To further illustrate this point, using a vaginal oestrodial pessary twice weekly for one year

equates to taking one dose of a 1mg oestrodial oral tablet (Hirschberg et al, 2021). There is therefore no need to protect the endometrium with progestogens (Hillard et al, 2017). Although local oestradiol preparations could cause minor problems, such as vaginal irritation and discharge, there is no evidence of an increased risk of cardiovascular disease, thromboembolism, colorectal cancer, endometrial cancer and primary or recurrent breast cancer (American College of Obstetricians and Gynecologists [ACOG], 2016; Laing et al, 2022).

Discouraging the use of soap or perfumed products is advisable and

women can use simple emollients to both wash and moisturise with. Other local non-hormonal treatments, including vaginal lubricants and moisturisers (some of which are available on an NHS prescription), can be used on their own, or alongside, hormonal treatments (e.g. YES® and Sylk products).

Pelvic floor exercises and referral to physiotherapists who have specialised techniques to strengthen the pelvic floor and retrain the bladder can also be helpful (Women's Health Concern, 2022). Other alternative treatments include vaginal dehydroepiandrosterone (DHEA), an oral selective oestrogen receptor

**Table 1:** Summary of localised hormonal treatments

Formulation	Administration	Frequency of administration	Advantages	Disadvantages
Pessaries containing oestradiol: Vagifem® (10mcg) and Vagirux® (10mcg) (oestradiol)	Inserted into the vagina using an applicator	Daily for first two weeks and then twice weekly. Can be used more frequently as dose is so low	When used at night-time, can stay in place for several hours. Vagirux more environmentally friendly as box contains one reusable applicator	Vagifem less environmentally friendly. Low dose, so often needs to be used more frequently
Vaginal tablet containing oestradiol: Gina (10mcg)	Inserted into the vagina using an applicator	One tablet daily for first two weeks, then twice a week. Can be used more frequently as dose is so low	Can be purchased over the counter	Licence is only for postmenopausal women aged 50 years and older who have not had a period for at least one year and who suffer from vaginal symptoms due to oestrogen deficiency. Less environmentally friendly as single-use applicator
Pessary containing oestriol: Imvaggis® (30mcg) (oestriol)	Inserted into the vagina using fingers	Daily for first three weeks, then twice a week. Can be used more frequently as dose is ultra low	No applicator	Can result in a waxy discharge. Can damage latex condoms
Pessary containing DHEA: Intrarosa** (active ingredient Prasterone, 6.5mg, converts intracellularly to androgens and oestrogens) *Please refer to DHEA section	Inserted into the vagina with or without an applicator	One pessary daily	Easy to use	Can damage latex in barrier contraceptives
Creams: Ovestin (500mcg) (oestriol)	Inserted into the vagina with an applicator. Can also be applied to external genitalia	Daily for two weeks then twice weekly. Can be used more frequently as dose is so low	Useful for vulval itching or soreness	Can be messy
0.01% oestriol (500mcg)	Inserted into the vagina with an applicator	Daily until symptoms improve and twice weekly thereafter	Some women find it less irritating than Ovestin	More diluted so large volume needed. Contains peanut oil, avoid if allergy
Gel: Blissel® (50mcg) (oestriol)	Inserted into the vagina with an applicator	Daily for first three weeks and twice a week thereafter	Lower dose option	
Ring: ESTRING (7.5mcg/24 hours) (oestradiol), a soft flexible silicone ring	Inserted into the vagina by woman or healthcare professional if preferred	Needs replacing every 90 days	Does not require daily application and no discharge (as sometimes with pessaries or creams). Slightly stronger than Vagifem® pessary. Can be removed for sex if preferred	

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## Practice points

- Be prepared to ask questions about GSM symptoms
- Vaginal oestrogen is safe, cost-effective and can be used long term
- Women can be given systemic HRT and local oestrogen together
- Vaginal lubricants and moisturisers can be prescribed and used alongside HRT.

modulator (ospemifene) and laser treatment. However, the evidence for these is less convincing and longer term data is lacking (Kearley-Shiers et al, 2022).

## IMPACT ON SEXUALITY

GSM can also affect sexual desire, responsiveness and pleasure and can be associated with hypoactive sexual desire disorder (HSDD). Testosterone replacement has demonstrated improvements with these troublesome symptoms (Davis et al, 2019) and should be considered for menopausal women with low sexual desire if HRT alone is not effective (National Institute for Health and Care Excellence [NICE] 2015). Testosterone may also have beneficial effects on urinary tract function, as a survey found that women with low circulating serum testosterone were much more likely to have urinary incontinence (Kim and Kreydin, 2018).

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## Useful resources

- Balance menopause library and free menopause support app at: [www.balance-menopause.com](http://www.balance-menopause.com)
- <https://balance-menopause.com/uploads/2021/10/GSM-BSSM-2023.pdf>
- <https://patient.info/womens-health/menopause/vaginal-dryness-atrophic-vaginitis>
- [www.nhs.uk/conditions/vaginal-dryness/](http://www.nhs.uk/conditions/vaginal-dryness/)



# Assessing, treating and supporting patients with hidradenitis suppurativa

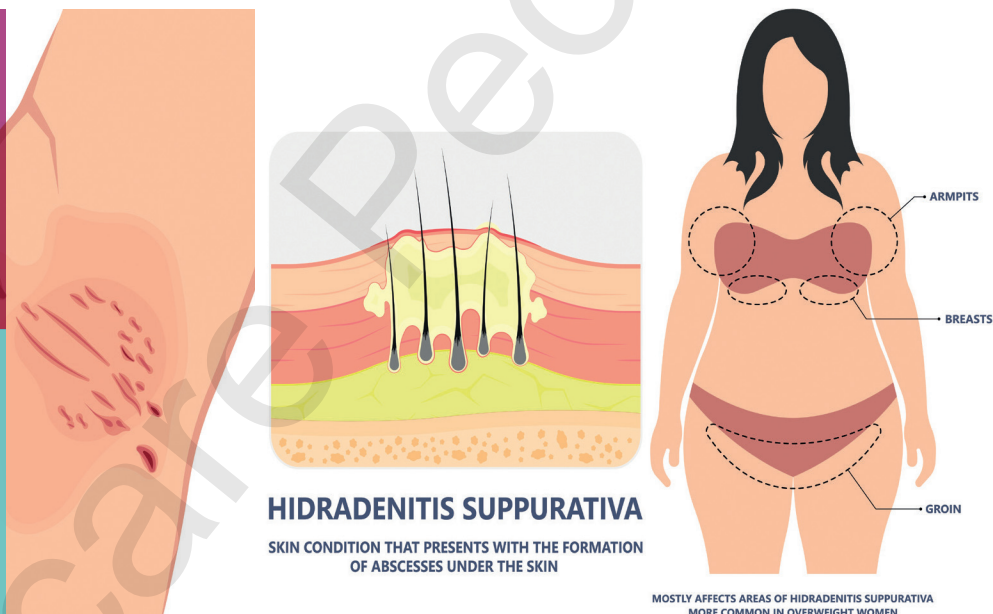
Hidradenitis suppurativa (HS) is a chronic long-term condition that occurs mostly in intertriginous areas of the skin. Unfortunately, HS is often not recognised and is poorly managed in clinical practice. Early detection and referral to an appropriate service such as dermatology is essential to reduce the long-term impact of the disease. Treatment is multifactorial and includes management of associated comorbidities and lifestyle factors, such as obesity and smoking, medication, surgical intervention and managing depression and anxiety. This article explores the assessment and management options for general practice nurses (GPNs) to consider when presented with a patient with HS.

## KEY WORDS:

- Hidradenitis suppurativa
- Apocrine glands
- Inflammatory skin condition
- Assessment
- Management

## Kirsty Mahoney

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Hidradenitis suppurativa (HS) is a chronic and often debilitating inflammatory skin condition that occurs in otherwise healthy adults and adolescents (World Union of Wound Healing Societies [WUWHS], 2016; Ferris and Harding, 2019). The condition is sometimes referred to as acne inversa, Verneuil's disease, *pyoderma fistulans significa* (PFS) and apocrinitis (WUWHS, 2016; Ferris and Harding, 2019).

Patients with HS often present to a variety of healthcare settings, including general practice (Ferris and Harding, 2019). As this condition is often not recognised and subject to misdiagnosis (Ferris and Harding, 2019), general practice nurses (GPNs) should be aware of the signs and symptoms

As this condition is often not recognised and subject to misdiagnosis, general practice nurses (GPNs) should be aware of the signs and symptoms of HS so that early diagnosis and appropriate interventions can be instigated.

of HS so that early diagnosis and appropriate interventions can be instigated. A multidisciplinary approach is usually required to manage the condition long term and may include dermatology, tissue viability, and surgical intervention. This list is not exhaustive and many

other disciplines may be needed depending on availability and patient symptoms (Casserino, 2022).

The prevalence of HS in the UK has been estimated to be around 0.77% (Ingram et al, 2018). However, it is thought that this figure may be much higher due to poor recognition of the disease and delays in accurate diagnosis (Saunte et al, 2015; Ingram et al, 2018). HS is more common in females (Ingram, 2018) and can occur in all races, however, there is some evidence that occurrence is more prevalent in the African and afro Caribbean population (Vaidya et al, 2017; Garg et al 2018).

As with any wound, GPNs should have the knowledge and skills to undertake a full and accurate

holistic assessment (Wounds UK, 2018; 2022). This assists in reaching a diagnosis, guiding decision-making, and preventing delays in referral and appropriate management (Wounds UK, 2018).

This article discusses the causes of HS, how to identify it using assessment skills, and treatment and management options utilising the CASE (cause, assess, select, evaluation) assessment framework (Scott-Thomas et al, 2017).

## CAUSE

The aetiology of HS is not fully understood (Isoherranen et al, 2019) and may have several contributing factors, including genetics, environmental, lifestyle and hormones, as highlighted in *Table 1* (Cassarino, 2022).

HS originates in the hair follicles with secondary involvement of the apocrine glands, which become inflamed as the disease progresses (Cassarino, 2022). The apocrine sweat glands are found in areas such as the armpits, breast, groin, abdominal folds and buttocks and thus these are the most common areas for HS to develop (British Association of Dermatologists [BAD], 2021). Hair follicles become

**Table 1: Risk factors and associated comorbidities for HS (adapted from WUWHs, 2016; Ingram et al, 2018; Dermatological Nursing, 2022)**

▪ Family history of HS
▪ Obesity
▪ Smoking
▪ Female
▪ Type 2 diabetes
▪ Crohn's disease
▪ Hyperlidaemia
▪ Down's syndrome
▪ Acne
▪ Depression
▪ Presence of other inflammatory conditions and syndromes, e.g. acne, arthritis, <i>Pyoderma gangrenosum</i> — PASH (PG, acne and suppurative hidradenitis) PA-PASH (pyogenic arthritis, acne, PG and suppurative hidradenitis) (Isoherranen et al, 2019)

occluded with keratin debris preventing drainage and leading to inflammation, rupture and sinus development in adjacent apocrine glands (Ferris and Harding, 2019; Cassarino, 2022). There is increased levels of white cells (neutrophils, monocytes and macrophages) and cytokine activity, which leads to a prolonged and recurrent cycle of inflammation within the area (Ferris and Harding, 2019).

HS often presents around puberty and is considered a long-term condition with episodes of recurrence which are characterised by inflamed nodules or abscesses, that may leak or discharge pus, often accompanied by significant pain in the affected area (Isoherranen et al, 2019). The long-term effects of HS for individuals may result in scarring, dermal contractures, restricted mobility, lymphoedema, chronic pain and have a significant impact on quality of life (WUWHs, 2016).

## ASSESSMENT

There is no laboratory test available to confirm the diagnosis of HS (Ferris and Harding, 2019). Diagnosis is therefore made based on holistic patient assessment, which includes:

- Identifying associated risk factors and comorbidities (*Table 1*)
- Gaining previous history of recurring lesions
- Observing the position and presentation of current lesions (WUWHs, 2016).

Other relevant patient history to note are flare ups in women before a period, or a patient may have had previous treatment for acne vulgaris (Cassarino, 2022). Many patients may have been previously treated with antibiotics with little effect (Cassarino, 2022).

Typically, a patient will present with painful recurrent nodules (more than two in six months) in areas where the apocrine glands are situated, mostly intertriginous areas, e.g. axilla, groin, abdominal, gluteal (*Figure 1*) and perianal areas ( Ferris and Harding, 2019). Sinus tracts, dermal contractures, rope-like scars



**FIGURE 1.**  
*Extensive HS to the gluteal region.*



**FIGURE 2.**  
*HS to groin with comedones to surrounding skin.*

and comedones (*Figure 2*) (clogged skin pore that may appear as a raised bump or blackhead) may be present to the surrounding skin. HS may start on one side of the body, but as the disease progresses can become bilateral (Cassarino, 2022). Asking the patient if they have had any previous episodes in other areas of the body is therefore a key question.

To assess the severity of the disease, the Hurley classification system (*Table 2*) is often used in clinical practice, which is based on presentation of the lesions and extent of scarring (Cassarino, 2022). This is also useful in determining treatment options.

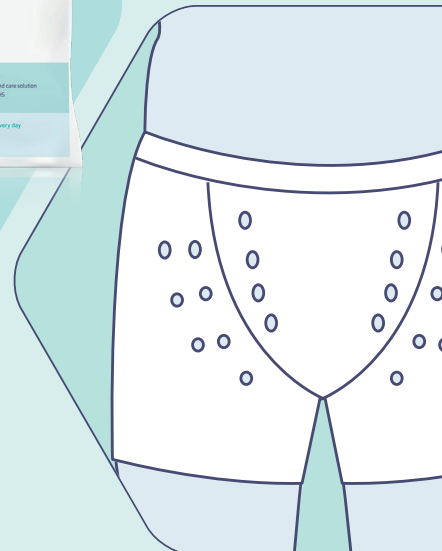
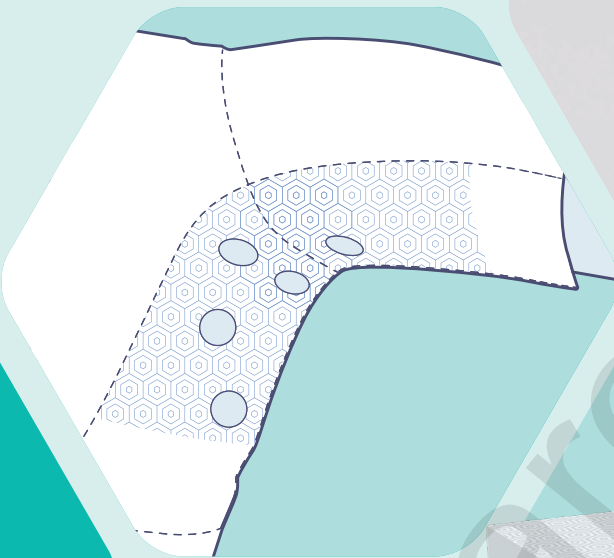
Assessment of the wound bed and surrounding skin should follow the principles of TIMES (tissue, infection/inflammation, moisture balance, edge, surrounding skin)





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**Table 2: Hurley classification system for HS (adapted from WUWHs, 2016; Casserino, 2021)**

Stage 1 (mild)	■ Isolated inflamed lesions without sinus tracts or scars
Stage 2 (moderate)	■ One or more recurrent abscesses, inflammatory lesions within scarring — these are separated by areas of healthy skin
Stage 3 (severe)	■ Interconnected tracts and multiple abscesses over an extended area (Figure 3)

**Table 3: Points for consideration when assessing HS wounds using the TIMES framework**

Tissue	The wound bed may be difficult to view as the wounds may present as multiple abscesses, sinus tracts, or even inflamed nodules rather than open wounds (Ferris and Harding, 2019)
Infection/inflammation	Patients may present with both inflammation and infection to the wound and surrounding skin. Observing for signs and symptoms of infection, e.g. erythema, pain, heat, purulent exudate, wound breakdown, malodour (International Wound Infection Institute [IWII], 2022) should form part of assessment. Wound swabs are of little benefit and usually reveal normal skin microflora such as coagulase-negative staphylococci (WUWHs, 2016; Ferris and Harding, 2019)
Moisture balance	High exudate is often associated with HS wounds and can cause leakage if the dressings are not managing exudate effectively. Excess exudate can also cause moisture-associated skin damage (MASD) (Dermatological Nursing, 2022)
Edge	Wound edge may be static and rolled, but may be difficult to assess depending on presentation of lesions
Surrounding skin	There may be rope-like scarring or comedones present to surrounding skin. Due to high exudate, surrounding skin may be vulnerable to both MASD and also MARS (medical adhesive-related skin injury). This is due to the possible frequent removal and application of dressings, or adhesives to keep dressings in place (Dermatological Nursing, 2022)



**FIGURE 3.** Hurley stage 3 to axilla with rope-like scarring.

assessment tool that has been used in HS patients is the Dermatol. This can help in determining how a patient is coping with the effects of the disease and what is important to them. From this, the patient can be supported in establishing appropriate coping strategies and referred to services such as counselling or cognitive behavioural therapy (CBT) if required (Dermatological Nursing, 2022).

### SELECT

As with any long-term condition, treatment options should always have the patient at the centre of decision-making, ensuring that they are well informed about their condition and understand the treatment options available.

Management of HS is multifactorial and requires a multidisciplinary approach (Cassarino, 2022). As said, the Hurley classification system can be used to assess severity of disease and guide the decision-making process (WUWHs, 2016). Treatment objectives should focus on:

- Effectively managing associated comorbidities and risk factors (Table 1)
- Managing contributing lifestyle factors if appropriate, e.g. smoking and obesity
- Reducing formation of new lesions and scarring
- Addressing local symptoms, such as pain, infection and exudate (Cassarino, 2022).

Patients with HS often suffer from embarrassment, low self-esteem, with the condition impacting on personal

(Wounds UK, 2016), as, in the author’s clinical experience, this will assist in establishing treatment objectives and selecting the most appropriate dressing regimen to manage the local wound environment. Table 3 outlines some points for consideration when assessing HS wounds.

Other important aspects of assessment that should be considered are pain and quality of life (QoL). Patients with HS often experience high levels of pain (Moloney et al, 2022). Assessment of pain should be conducted at each dressing change using an appropriate pain assessment tool e.g. visual analogue scale (VAS) (Scott-Thomas et al, 2017). This will help in selecting appropriate pain-relieving strategies, such as analgesia or atraumatic dressing selection (Dermatological Nursing, 2022).

The impact of having HS on a person’s wellbeing cannot be underestimated. A recent study

**Patients with HS often suffer from embarrassment, low self-esteem, with the condition impacting on personal relationships. Emotional support and having an understanding of how the disease affects the individual is an important aspect of any patient care.**

of 908 patients indicated that HS affected many aspects of life, including:

- Relationships and sex life
- Social life and hobbies
- Mental health
- Day-to-day activities
- General wellbeing

(Moloney et al, 2022).

Assessing and monitoring patient QoL should be an important part of the assessment process. One





**FIGURE 4.** Healing wound following wide excision of area.

relationships (Moloney et al, 2022). Emotional support and having an understanding of how the disease affects the individual is an important aspect of any patient care (Ferris and Harding, 2019). Patients can be signposted to information and support websites, such as Hidradenitis Suppurativa online (hsonline.ae) and NHS choices (www.nhs.uk/conditions/hidradenitis-suppurativa).

For patients who are experiencing depression and anxiety, it may be necessary to refer for counselling, CBT or treatment with medication.

### Medical and surgical management of HS

There are several medical and surgical options for the treatment of HS (Table 4). However, these will possibly require management by a specialist service, such as dermatology, and often the disease will reoccur (Ferris and Harding, 2019).

### Dressing selection

Dressing selection for patients can be challenging, often due to the awkward position of the wound, high exudate and pain (Dermatological Nursing, 2022). The surrounding skin is also at risk of moisture-associated skin damage (MASD) if exudate is not appropriately controlled. A skin

barrier preparation product should be considered in patients who are at risk (Fletcher et al, 2020).

Dressing selection should be based on the requirements of the wound environment identified within the TIMES assessment (Wounds UK, 2016). Due to excess exudate, patients may need to change their dressings several times a day so dressing choice needs to consider ease of application, suitable size and shape to fit area, as well as being able to manage exudate appropriately, such as superabsorbent and foam dressings (Dermatological Nursing, 2022). However, careful consideration is required if adhesive dressings or surgical tapes are used to fix dressings in place, as there is a high risk of medical adhesive-related skin injury (MARSIs) (Downie and Collier, 2021). Adhesive removers can be used to reduce this risk at dressing changes.

More recently, there has been a wearable retention garment that has been developed specifically for HS patients to keep dressings in place without the need for tapes or adhesives (Hidrawear®). However, in the author's opinion, these products could be cost prohibitive.

### EVALUATION

Evaluation of interventions is essential to monitor the progress of the condition and to determine if treatment modification is required. This may be important if the patient is experiencing challenging issues, such as pain, dressing leakage, or anxiety or depression (Dermatological Nursing, 2022).

### CONCLUSION

HS is a long-term condition that can have a significant impact on an individual's quality of life. It is often misdiagnosed and mismanaged.

**Table 4: Medical and surgical treatments (adapted from WUWHS, 2016; Ferris and Harding, 2019; Cassarino et al, 2022)**

Medical intervention	Comments
Appropriate pain	Analgesia should be based on pain assessment and World Health Organization (WHO, 2022) recommendations
Antimicrobial wash	Antimicrobial wash may be helpful to reduce bacterial load to area, e.g. chlorhexidine
Antibiotics	Topical antibiotics such as clindamycin 0.1% or metronidazole in mild HS Oral tetracyclines for mild-to-moderate disease can assist in reducing pain and inflammation (12 weeks of therapy area required to be effective). A combination of antibiotic therapy may be used, e.g. clindamycin and rifampicin. Sulphones, e.g. dapsone can be considered second line in patients who fail to respond
Steroids	Oral corticosteroids may assist in reducing pain and inflammation
Retinoids	
Monoclonal and immunosuppressive therapies	These therapies (e.g. cyclosporine, infliximab) are thought to switch off the inflammatory cascade that may cause damage to the tissue. Considered for Hurley stage 2 or 3 in patients who have been unresponsive to antibiotic therapy
Carbon dioxide laser therapy	Nodules and abscesses are vapourised down to subcutaneous tissue and left to heal by secondary intention
Surgical intervention	Comments
Deroofing	The sinus tract is opened to allow removal of debris and drainage of abscesses and healing by secondary intention. This can be undertaken under local anaesthetic. Preserves surrounding skin with minimal scarring. Recurrence rates are usually high
Wide excision	Wide surgical excision (Figure 4) removes affected tissue. Surrounding skin and apocrine glands can be left to heal by secondary intention or flap or graft technique can be used for closure. Recurrence rates are low. NB: Contractures can occur, especially in the axillary area — gentle mobilisation exercises post operatively should be encouraged to avoid this

GPNs should have the skills and knowledge to assess and manage HS in clinical practice and ensure that early referral to other members of the multidisciplinary team is undertaken to prevent disease progression and reduce the overall impact on the individual. **GPN**

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## Key points

- Hidradenitis suppurativa (HS) is a chronic and often debilitating inflammatory skin condition that occurs in otherwise healthy adults and adolescents.
- Unfortunately, HS is often not recognised and is poorly managed in clinical practice.
- A multidisciplinary approach is usually required to manage the condition long term and may include dermatology, tissue viability, and surgical intervention.
- To assess the severity of the disease, the Hurley classification system is often used in clinical practice, which is based on presentation of the lesions and extent of scarring.
- Assessing and monitoring patient QoL should be an important part of the assessment process.
- GPNs should have the skills and knowledge to assess and manage HS in clinical practice and ensure that early referral to other members of the multidisciplinary team is undertaken.

### Revalidation Alert

Having read this article, reflect on:

- Why it is important to identify and diagnose HS as soon as possible
- Your knowledge of the Hurley staging system
- Why HS is a serious condition
- Dressings you would consider using for patients with HS
- The impact and burden that HS can have on patients .

Then, upload the article to the free GPN revalidation e-portfolio as evidence of your continued learning: [www.gpnnursing.com/revalidation](http://www.gpnnursing.com/revalidation)

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# Join our Professional Networks



The QNI has a number of national networks for nurses working in the community and primary care.

All of our networks were created to connect community nurses in their specific fields of work and to build a strong support network where they are free to share best practice and innovations to improve patient care. The networks are free to join and offer free online events.

They range from the Homeless and Inclusion Health Network created in 2007 to the QNI's newest network, the Integrated Care Board (ICB) Chief Nurse Network, launched in 2023.

## Our networks:

- ✚ Care Home Nurse Network
- ✚ Community Children's Nurse Network
- ✚ Community Nurse Executive Network\*
- ✚ Community Nursing Research Forum
- ✚ Homeless and Inclusion Health Network
- ✚ ICB Chief Nurse Network\*
- ✚ Infection Prevention and Control (IPC) Champions Network
- ✚ Long Covid Nurse Group
- ✚ Queen's Nurse Network\*

*\*these networks require an application process to join*

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# Tracheomalacia, bronchomalacia and laryngomalacia

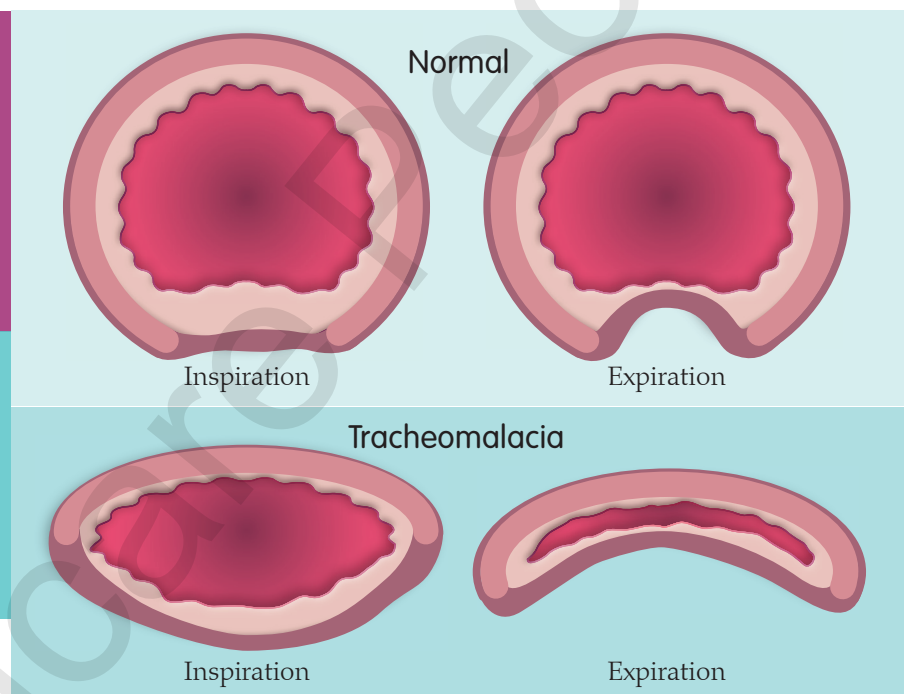
Tracheomalacia, bronchomalacia and laryngomalacia are conditions where there is a deficiency in the functioning of the cartilage in the airway walls, which causes them to be weaker or even absent in places. This leads to an exaggerated luminal narrowing within the affected airway during expiration. The malacia may be localised or generalised. There is limited literature and published research in this area. These three conditions are seen in both children and adults. However, because of the size of the airways in small children and the more marked clinical response to any narrowing of the airway, these malacias are usually diagnosed at an earlier stage than when the conditions occur in adults. In the fully mature airway, the symptoms may be less obvious, leading to the conditions being under-recognised and under-diagnosed in adults. It is also important to understand that in the adult population malacia may coexist with more common conditions such as asthma or chronic obstructive pulmonary disease (COPD), where breathlessness, cough, dyspnoea and other symptoms may be misattributed to these more common diseases. This article raises awareness of these three malacia conditions.

## KEY WORDS:

- Malacial conditions
- Symptoms
- Diagnosis
- Management

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Firm C-shaped cartilage supports and helps maintain the basic architecture of the airways, as the trachea and the bronchi expand with inhalation and contract on exhalation.

'Malacia' is a word or suffix from the Greek 'malakia', meaning softening or weakening, and describes softening or underdevelopment of tissue. It can refer to bone or cartilage. Airway malacia can occur at a number of sections in the airway and is named according to which area of the airways is affected.

Bronchomalacia is a condition where the cartilage in the bronchi is either absent or weakened. As a consequence, the calibre of the airway is not maintained on expiration (*Figure above*). If the

malacia affects the trachea and one or both bronchi are involved, the term tracheobronchomalacia (TBM) is used (which this article focuses on). It can sometimes also be referred to as excessive dynamic airway collapse (EDAC) or large airway collapse (LAC) (Leong, 2013). If the proximal or distal trachea is affected, without involvement of the bronchia, this is referred to as tracheomalacia. If malacia occurs at the level of the larynx, it is known as laryngomalacia. Knowledge of these conditions is limited with no universal classification of severity or management (Wallis et al, 2019). Indeed, the number of people living with these conditions is unclear.

## TRACHEOBRONCHOMALACIA

Although there is no official classification, TBM can be divided into primary or secondary TBM.

### Primary TBM

Primary TBM occurs in infancy or early childhood. At this stage of life, the cartilage is already soft and therefore can be affected more easily. TBM may be present from birth and can resolve by the age of six months as the lungs grow and mature (Wallis et al, 2019). TBM can also result from genetic or congenital abnormality (*Table 1*). It may also develop as a result of chest deformity due to disease, such as poorly controlled



**Table 1: Congenital causes affecting the trachea (Wallis et al, 2019)**

Trachea	Oesophagus
<ul style="list-style-type: none"> <li>■ Laryngotracheal clefts</li> </ul>	<ul style="list-style-type: none"> <li>■ Oesophageal atresia</li> </ul>
<ul style="list-style-type: none"> <li>■ Tracheal stenosis</li> </ul>	<ul style="list-style-type: none"> <li>■ Tracheoesophageal fistula</li> </ul>
<ul style="list-style-type: none"> <li>■ Malformation of heart and large vessels in chest causing external pressure on trachea and bronchi</li> </ul>	

- Fatigue with activity
- Harsh cough, often described as ‘seal-like’
- Difficulty clearing phlegm which predisposes to chest infections or even pneumonia (Ramakrishnan et al, 2022).

As stated earlier, it should be noted that cyanosis may be the presenting symptom in infants.

## DIAGNOSIS OF TBM

Diagnosis can be difficult and may be attributed to other conditions such as asthma, as the main presenting symptoms are wheeze — typical symptoms of both asthma and TBM. A study by Dal Negro et al (2013) reported a prevalence of around 41% of patients with asthma undergoing bronchoscopy had a diagnosis of TBM, which was also identified as being related to age, female sex and asthma severity. Although it seems to be unclear from this study whether the TBM coexisted with asthma, or that asthma was an incorrect diagnosis.

A study published in 1977 of 2150 patients undergoing bronchoscopy identified that 5% had varying degrees of malacia, with 53% having a concurrent diagnosis of chronic bronchitis (Jokinen et al, 1977). More recently, Joosten et al (2012), using computer tomography (CT) imaging, suggested that almost a third of patients with a diagnosis of COPD may have a degree of TBM. Boisselle et al (2013) reported that the risks of EDAC were increased when two or more conditions coexist, for example, COPD and morbid obesity. Although Ramakrishnan et al (2022) found that a 50% collapse of the airways was not uncommon in healthy

asthma when Harrison’s sulcus (i.e. permanent indentation of the chest wall along the coastal margins where the diaphragm inserts) may develop, or as a result of cardiac or vascular malformations, which increase the pressure on the trachea and bronchi causing further collapse of the already soft cartilage (Wallis, 2019). It should be noted that cyanosis may be one of the presenting symptoms in infants.

## Secondary TBM

Secondary TBM is usually acquired in adulthood as a result of other conditions (Table 2) causing compression of the airways, or secondary to trauma. Compression of the airways as a consequence of trauma or surgical interventions, such as endotracheal intubation or tracheostomy, have the potential to weaken the tracheal wall causing tracheomalacia. The cause may not be identified/unknown, but is thought to be associated with chronic inflammation. Chronic unmanaged cough and/or long-term irritation of the airways can result in TBM. In addition, chronic respiratory conditions, such as poorly controlled asthma or chronic obstructive pulmonary disease (COPD), may lead to weakening of the airway walls affecting the architecture of the airways and resulting in loss of tone and airway collapse (Jokinen et al, 1977; Wallis, 2019).

## LARYNGOMALACIA AND INDUCIBLE LARYNGEAL OBSTRUCTION

Laryngomalacia is an abnormality of the larynx cartilage causing an inward collapse of the airway on inspiration. The age group usually affected are from birth with gradual improvement and spontaneous resolution before the age of two. Symptoms include inspiratory stridor, difficulty in

**6** **Diagnosis can be difficult and may be attributed to other conditions such as asthma, as the main presenting symptoms are wheeze — typical symptoms of both asthma and TBM.**

feeding and is often associated with gastroesophageal reflux disease (Boardman, 2022). This differs from inducible laryngeal obstruction (ILO) or vocal cord dysfunction (VCD), which are terms used where there is inducible, intermittent upper airway obstruction. Symptoms include exertional breathlessness with an inspiratory wheeze due to closure of the glottis or supraglottis (Rendo, 2019). ILO or VCD can affect all age ranges, with the diagnoses being confirmed usually following referral to ear, nose and throat specialists. For ILO or VCD, management is usually provided by speech and language therapists (Christenson et al, 2015).

## SYMPTOMS OF TBM

These are similar to those seen in many respiratory conditions, i.e:

- Wheeze more notable on expiration
- Shortness of breath with activity

**Table 2: Acquired causes of tracheobronchomalacia (Wallis et al, 2019)**

Trauma/injury	Chronic compression	Infection, as a result of	Inflammation
Tracheostomy	Malignancy	Cystic fibrosis	Severe emphysema
Endotracheal intubation	Benign mediastinal goitre	Chronic bronchitis/ COPD	Smoking
Chest trauma	Vascular compression	Bronchiectasis	Significant inhalation of noxious substances
Chest surgery	Benign lesions/cysts		Uncontrolled gastroesophageal reflux disease

individuals with undiagnosed TBM. The latter study, in the author's opinion, may suggest that EDAC may be relatively common and not always cause symptoms.

Diagnosis of TBM is usually made on a clinical interpretation of the symptoms. Investigations that can conclusively confirm the diagnosis are most commonly nasopharyngolaryngoscopy or bronchoscopy (Leong et al, 2013). Dynamic imaging by CT scan of the central airways is being increasingly used as an effective, non-invasive aid to diagnosis (Leong et al, 2013). Pulmonary function tests can also provide supportive evidence, but are not diagnostic and may be normal (Murgu and Colt, 2006). Two studies in healthy volunteers with normal pulmonary function tests demonstrated that 20% of the subjects had EDAC identified on CT scan, with 17% having abnormal flow volume pattern (Boiselle et al, 2009).

## MANAGEMENT

Studies suggest that EDAC/TBM with no symptoms may be common and no interventions are required (Boiselle et al, 2009; Litmanovich et al, 2010; Mitropoulos et al, 2021). There are limited treatment options and few published research papers suggesting management pathways for mild/moderate symptomatic TBM, and so, in the author's clinical opinion, the focus should be on managing symptoms and their impact. There are currently no physiotherapy guidelines for the management of TBM and no direct evidence for effective interventions (Grillo et al, 2022).



### Practice point

As a result of 'airway collapse', exertion/physical activity will increase symptoms associated with TBM and so the person may reduce their physical activity. In addition, the potential for difficult sputum clearance may cause embarrassment and alter lifestyle (Grillo, 2022).

Referral to a respiratory physiotherapist to teach techniques to help manage sputum clearance may reduce the risk of recurrent chest infections, which have the potential to lead to further respiratory conditions, such as bronchiectasis — the Coles hypothesis (Cole, 1991). The

**There is no evidence that either bronchodilator inhalers or inhaled corticosteroids are of benefit, as TBM is caused by collapse of the weakened or absent cartilage, not by bronchospasm or airway inflammation.**

respiratory physiotherapist may also teach breathing exercises/techniques, such as those which avoid forced expiration — such expiration can lead to airway collapse due to the malacia. Airway collapse will increase symptoms and may deter the person with TBM from undertaking activity/exercise. Stopping smoking should also be encouraged as, apart from the well-known risks associated with smoking, smoking increases the volume of sputum (Grillo, 2022).

There is some evidence of increased prevalence of gastroesophageal reflux (GORD) in patients with TBM (Nataraj et al, 2009). Management of GORD should be optimised by healthy eating, weight reduction, and stopping smoking (National Institute for Health and Care Excellence [NICE], 2019). Use of antacids may also be of benefit, although the population with TBM may require more continuous treatment with, for example, proton pump inhibitor (PPI) therapy (NICE, 2019).

Continuous positive airway pressure (CPAP) and non-invasive positive pressure ventilation (NIV) as a means of managing severe TBM have limited research to

support their use, although two studies published in the '80s and '90s as case reports demonstrate positive outcomes for a short period of time before surgery (Kanter et al, 1982; Ferguson and Benoist, 1993). More recently, centres are assessing patients with TBM by introducing CPAP while undergoing bronchoscopy to assess the response to CPAP as a management option and the level of TBM/EDAC, and to identify if surgical intervention may be successful (Murgu et al, 2010; Wallis et al, 2019; McGinn et al, 2020).

Surgery, such as tracheo-bronchoplasty, is usually only indicated in severe or life-threatening cases (Gangadharan et al, 2011). The use of 3D-printed airway stents to help manage severe life-threatening TBM in critically ill children is emerging as a possible treatment (Sood et al, 2021).

There is no evidence that either bronchodilator inhalers or inhaled corticosteroids are of benefit, as TBM is caused by collapse of the weakened or absent cartilage, not by bronchospasm or airway inflammation (Baraldi et al, 2010; Shah et al, 2020). An awareness of TBM will aid with differential diagnosis, particularly where a patient has commenced anti-asthma inhaler treatment, with good adherence and inhaler technique, but has failed to respond to what seemed to be appropriate medications. At this point, in the author's clinical experience, TBM should be considered as a differential diagnosis.

As discussed, there are limited options for managing EDAC/TBM, with non-surgical management being the mainstay of symptom management. However, as stated, there is little published research in this area. Implications of living with EDAC/TBM include constant symptoms and their potential negative impact on the person's lifestyle. The risks associated with general anaesthesia or ventilation (reducing oxygen levels and the potential to increase the risk of extubation), should these be required,



may present a challenge because of the risk of airway collapse.

## CONCLUSION

This article raises awareness of these malacia conditions to help general practice nurses (GPNs) avoid misdiagnosing and introducing inappropriate treatment, as adding in medications such as inhaled therapy in patients with TBM is likely to be of no benefit. In the author's opinion, respiratory physiotherapy to manage expectoration and provide instruction in breathing techniques for less severe symptoms, appear the best options until further research in this under-diagnosed field of medicine is published. **GPN**

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## Key points

- Airway malacia can occur at a number of sections in the airway and is named according to which area of the airways is affected.
- Knowledge of these conditions is limited with no universal classification of severity or management.
- The focus should be on managing symptoms and their impact.
- This article raises awareness of these malacia conditions to help GPNs avoid misdiagnosing and introducing inappropriate treatment, as adding in medications such as inhaled therapy in patients with TBM is likely to be of no benefit.

# Impact of stigma within type 1 diabetes mellitus

Type 1 diabetes mellitus (T1DM) can affect individuals at any age, yet often develops in the younger population, accounting for approximately 8% of diabetes diagnoses in the UK. Although there has been extensive research into the physiology of diabetes, less work has addressed the psychosocial demands and consequent effects on management and quality of life. This article is a critical synthesis of the literature, adopting the Health Stigma and Discrimination Framework (Stangl et al, 2019) as a theoretical lens through which the multifactorial impact of stigma for individuals living with T1DM is unpacked. Having this understanding can help general practice nurses (GPNs) recognise how stigma within T1DM can permeate throughout the five layers of society: individual, interpersonal, community, organisational, and policy. A case study is provided to highlight how nurses working within primary and community care are well positioned to help understand the causes of stigma for individuals living with T1DM.

## KEY WORDS:

- Type 1 diabetes mellitus
- Stigma
- Mental health
- Health inequalities
- Social determinants of health

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# Diabetes

Diabetes is one of the most common long-term conditions, affecting more than 4.6 million people in the UK (Diabetes UK, 2019a). Globally, the number of people with diabetes rose from 108 million in 1980 to 422 million in 2014 (World Health Organization [WHO], 2020). What has been described as the 'global burden' of diabetes has been largely attributed to type 2 diabetes mellitus (T2DM), estimated to account for 90% of all diabetes cases in the UK (Public Health England [PHE], 2018b). It is commonly associated with obesity, physical inactivity, raised blood pressure and disturbed blood lipid levels (National Institute for Health and Care Excellence [NICE], 2015a). An important policy focus has therefore been on prevention of diabetes (NHS England, 2019a).

However, while prevention is imperative, it is also important to consider the needs of those already living with diabetes. Type 1 diabetes

mellitus (T1DM) is an autoimmune disease whereby the body is unable to produce insulin (NICE, 2023). Although only 8% of people have T1DM, it often affects the younger population. It is therefore associated with a higher lifetime burden and accounts for a higher degree of life-changing macrovascular and microvascular complications (Diabetes UK, 2019b). Everyday self-care involves complex activities that are often intrusive, i.e.:

- Monitoring blood glucose levels
- Managing hyperglycaemic and hypoglycaemic symptoms
- Assessing carbohydrate intake
- Meal-to-meal adjustment of insulin dose depending on diet and physical activity.

How well young people cope with this, while at the same time negotiating the transition into adulthood, has important implications for long-term physical and mental health, quality of life and life expectancy (Clarke et al, 2018).

Research suggests that 70% of people with T1DM fail to achieve the conservative target of a haemoglobin A1c (HbA1c) of 58 and the treatment targets of blood pressure and cholesterol control (NICE, 2015b). Less research has addressed the disease's psychosocial demands and their consequent effects on management and quality of life (Liu et al, 2017; Askew and Solomon, 2019). Thus, there is a recognised gap that a greater understanding of the multifactorial importance of stigma within T1DM is needed (Diabetes UK, 2019c). The issues are multifaceted, linked to a range of psychosocial problems such as psychiatric disorders, eating disorders, depression, and anxiety (Kakleas et al, 2009; Bernstein et al, 2013; McManus et al, 2016).

While there is recognition that this vulnerable group is at risk of worsening health outcomes, landmark studies revealing that T2DM can be prevented and policies



centred on preventing T2DM and ‘tackling the obesity epidemic’ have neglected public discussions on improving health outcomes for individuals with T1DM (Department of Health and Social Care, 2020).

Stigma is a universal phenomenon, which has received substantial research attention in medical conditions such as human immunodeficiency virus (HIV), epilepsy and obesity (Brown et al, 2003; Agerstrom and Rooth, 2011). It is widely accepted that stigma adversely affects health (Nyblade et al, 2019). Health-related stigma can be defined as:

*A social process or related personal experience characterized by exclusion, rejection, blame, or devaluation that results from experience or reasonable anticipation of an adverse social judgment about a person or group identified with a particular health problem.*

(Weiss and Ramakrishna, 2006)

However, much of the literature focuses on the consequences of one form of stigma in isolation. The need to recognise an individual’s membership in multiple stigmatised groups has been a relatively recent consideration in the literature (Hatzenbuehler et al, 2013; Turan et al, 2019). Stigma is relatively under-investigated in the context of T1DM and there is growing recognition that more research is needed to understand the extent and severity of diabetes stigma, its causes and consequences (Browne et al, 2017).

## HEALTH STIGMA AND DISCRIMINATION FRAMEWORK

Using the Health Stigma and Discrimination Framework (HSDf) (Stangl et al, 2019) as a theoretical lens through which to unpack the multifactorial impact of stigma enables nurses to think holistically about how they can help meaningfully in promoting self-care behaviours for individuals living with T1DM (Turan et al, 2019).

The HSDf is a layered model where one’s experience passes through and filters several mediators

Joseph Ricci is a 32-year-old who presented to the general practice nurse (GPN) for his diabetes review. He had not been seen for a number of years as he had avoided his review appointments. However, he has noticed another ulcer developing on his foot, and the burning pain in his feet is getting worse. He has recently missed a hospital appointment regarding this.

### Mr Ricci’s story

He was diagnosed with T1DM at the age of nine. As a child he was supported to manage his condition by his mother, but as an adolescent he became disengaged with services. He avoided taking his insulin in public spaces, which stemmed from comments his peers made at school. He has had multiple admissions to the emergency department with diabetic ketoacidosis (DKA), his last being in 2021.

He began smoking at the age of 15 and binge drinking at weekends. From his records, the GPN can see that he has had multiple diabetes-related complications in the past, including Charcot’s foot, retinopathy, and proteinuria. He is under ophthalmology, vascular and orthopaedics for these, as well as endocrinology, but has not been attending appointments and recent letters to the GP state that, as a result, he has now been discharged from these services.

He works as a mechanic but has been out of work for over a year due to his previous foot complications, which has affected both his routine and mental wellbeing. He has a strained relationship with his mother, who is also registered at the surgery, and he has been staying with a friend short term.

before becoming fully formed. It moves away from previous silo attempts at reducing stigma within different diseases. Instead, the concept of filtration considers the broader social, cultural, political, and economic forces that structure stigma (Parker and Aggleton, 2003; Stangl et al, 2019), embodying how complex stigma is. A focus on stigma can then be considered as a step towards addressing the wider social determinants of health. This is fundamental in addressing health inequalities. Closing the gap in health inequalities is rhetoric echoed throughout UK and global policy, compounded with the Marmot Review in 2010. However, ten years later, we are still no closer to closing the gap, with evidence revealing that that it is, in fact, widening (Marmot et al, 2020).

When care provision for stigmatised conditions is deprioritised, stigma can deter care seeking behaviour and undermine

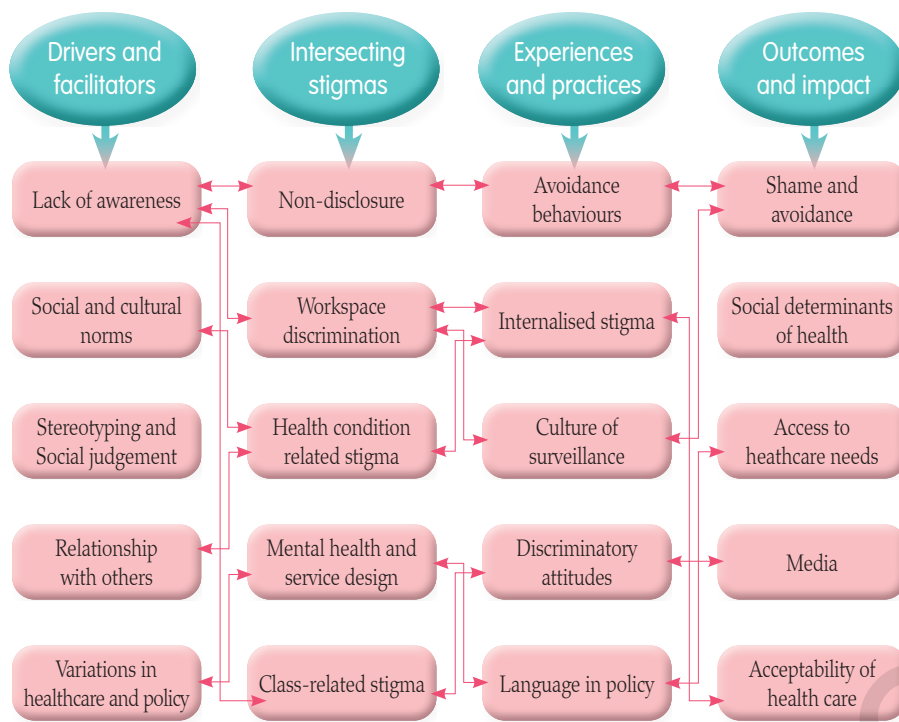
investments in health. While there have been calls to reduce stigma within certain conditions such as HIV, stigma within T1DM has been overlooked (Schabert et al, 2013).

## THE FINDINGS

The first author undertook a critical synthesis of the literature, looking at the research through the lens of the HSDf. The intersecting threads experienced by individuals living with T1DM filtered throughout the socioecological spectrum: individual, interpersonal, organisational, community and policy. The first author subsequently created a table demonstrating how these threads are interlinking (Figure 1).

## DRIVERS AND FACILITATORS

Figure 1 shows some of the drivers and facilitators of stigma that Mr Ricci might have experienced. For example, at a crucial transition period Mr Ricci may have felt social



**FIGURE 1.**  
*The findings.*

judgement from his peers. This fear of judgement relates to findings in the literature. For example, fear of social judgement can lead to resistance and avoidance behaviours, such as not administering insulin in public (Souris et al, 2016; Anderson et al, 2017; Capistrant et al, 2019). Social judgement and stereotyping with regards to insulin were also an important theme in Browne et al (2014). Participants in this qualitative study spoke of being compared to 'being drunk' or 'illicit drug users'. It is interesting that when participants felt discriminated, they in turn used discriminating language. This also extended when describing individuals with T2DM as 'lazy' and associations with being overweight. This fits with Major and O'Brien's (2005) social psychological model of stigma-induced identity threat. In this model, individuals face identity threat when they feel the demands of a stigma-related stressor imposed on them, for example, insulin taking in public. Indeed, stigma could have induced a threat to Mr Ricci's identity, contributing to his avoidance behaviours.

Several studies have identified the concept of feeling different and how managing the daily intrusiveness of monitoring blood sugars imposed a sense of difference (Brown et al,

2014; Souris et al, 2016; Crespo-Ramos et al 2018 ;Varni et al, 2018; Ferrier et al, 2021). Blixen et al (2016) looked at barriers to self-management, one being the 'cycle of despair' which embodied the stress of diabetes — particularly at crucial time points, such as navigating through adolescence, adjusting to diagnosis, and processing the feelings that come with this.

### INTERSECTING STIGMAS OR 'MARKINGS'

One of the key intersecting stigmas in the literature was the design of mental health services. In Crespo-Ramos et al (2016), there was a strong association of stigma within T1DM and depression. In Stahl-Pehe et al (2014), individuals with T1DM and mental health problems experienced an impaired quality of life.

Holmes-Truscott et al (2020) found that there were significant positive associations between diabetes stigma and depression and anxiety; measured using GAD7 and PHQ9 (P=0.001). However, they did not find a significant association between this and engaging with self-care behaviours, but they only explored some limited self-care ones. For example, they did not include glucose monitoring or medication

taking as key variables. Furthermore, the self-care assessment tools used were not sensitive to any context-specific changes in behaviours.

Liu et al (2017) on the other hand, revealed that a disturbingly high percentage of people with diabetes experience stigma which can affect health outcomes, particularly those with T1DM (76% of respondents). The experience of stigma by participants disproportionately affected those with a higher body mass index (BMI), high Hba1c, and poorer self-reported blood glucose control. This suggests that those who need the most support are also the most affected by stigma.

One paper evaluated the lived experience by reflecting on the Diabetes Optimal Health Program (MIND OHP), an eight-week psychoeducational self-empowerment intervention. Participants were invited to take part in semi-structured interviews or focus groups (Ferrier et al, 2021). A key theme identified was the need to bridge the gap between mental and physical health to improve health outcomes. This is in keeping with the UK's drive to achieve parity of esteem — a core concept of UK policy, 'no health without mental health' (Department of Health and Social Care, 2011).

Perhaps a barrier to achieving this parity is the lack of communication between physical and mental health care providers (Blixen et al, 2016). In Stahl-Pehe et al (2014), adolescents with T1DM and mental health problems reported poorer quality of life compared to adolescents without diabetes. They called for early intervention and prevention in transition care. While this has been highlighted as essential, there is not a standardised transitional care model within the UK, due to the devolution of services locally (Association of British Clinical Diabetologists [ABCD], 2017). Supporting individuals with mental health problems is recognised within current UK guidelines on T1DM diagnosis and management (NICE 2015b). However, individuals may experience complex needs that cannot be categorised as depression

or anxiety, particularly during the crucial transition period (Diabetes UK, 2018). And, although validated screening tools such as GAD7 and PHQ7 are important, they may not be wholly sensitive. For example, scoring high for tiredness may be a symptom of diabetes as opposed to depression (Diabetes UK, 2017). Furthermore, increased recognition rates from these tools does not necessarily lead to increased treatment initiation and improved patient outcomes (Stoop et al, 2015). In the authors' clinical opinion, general practice nurses are well placed to be able to translate these assessment tools into meaningful interventions for individuals living with diabetes by finding out what their motivation and drive are.

It can be seen from the patient story how Mr Ricci's mental wellbeing perpetuates his health outcome. He has been out of work due to previous foot complications, which is affecting his wellbeing. Workplace discrimination can lead to stigma 'markings' across organisations. In Leung et al (2021) for example, a reluctance to tell work meant withholding self-care activities. In Browne et al (2014), disclosing diabetes led to exclusions from work and promotions. Through exploring the impact of unemployment with Mr Ricci, the nurse can facilitate and signpost areas for support and could also provide a fit note with new training which has come into place for GPNs, thereby supporting Mr Ricci with personal independence payment (PIP) (Department for Work and Pensions, 2022).

## EXPERIENCES AND PRACTICES

How different communities perceive diabetes, as discussed above, means that individuals can experience discrimination, internalised or perceived stigma. Stigma practices across communities may involve stereotyping and discriminatory attitudes. Furthermore, social stigma may increase within large families or households. For example, caregivers may blame individuals for not reaching self-care goals (Crespo-Ramos, 2018). However, strong community networks can

contribute to positive mental health and wellbeing. In Crespo-Ramos et al (2018), this stemmed from a sense of belonging, which may make individuals with T1DM more eager to take care of themselves and others. This is in keeping with the wider literature on the benefits of communities on wellbeing (Hackworth et al, 2013)

## OUTCOMES AND IMPACTS

Studies show that having support from family and communities leads to a greater sense of self-worth (Beran, 2014; Souris et al, 2016; Anderson et al, 2017; Hansen et al, 2020). Yet, access to health care has the potential to undermine this support. This was apparent not only in studies from deprived countries (Anderson et al, 2017; Crespo-Ramos et al, 2018; Capistrant et al, 2019; De-Graft et al, 2019), but also in Akhter et al's (2016) UK-based study, where housing problems were a common theme. One participant spoke of being unable to afford housing and having ongoing problems with the council, which meant that managing their diabetes and blood glucose control was a low priority. Mr Ricci's case shows how housing and the wider social determinants of health impact on his health outcomes. This fits Beran's (2014) hierarchy of needs framework for individuals living with T1DM (Figure 2), which encapsulates the core requirements that can lead to living positively with diabetes, and therefore limiting stigma. This is crucial during critical time points in life, such as the transition to adulthood (Le Roux et al, 2017).

## ROLE OF THE NURSE

With an ageing population, there is understandably a policy focus on the role of prevention to improve modifiable lifestyle factors. While all nursing staff have an important role in the treatment, management and prevention of diabetes, T1DM cannot be prevented. As we can see from Mr Ricci's presentation, supporting people living with T1DM can be complex. In the authors' clinical opinion, nurses working in the community and primary care settings are well placed to provide this care,

and having an understanding of the layers of stigma involved can help unpack what support might be required to improve an individual's health outcomes.

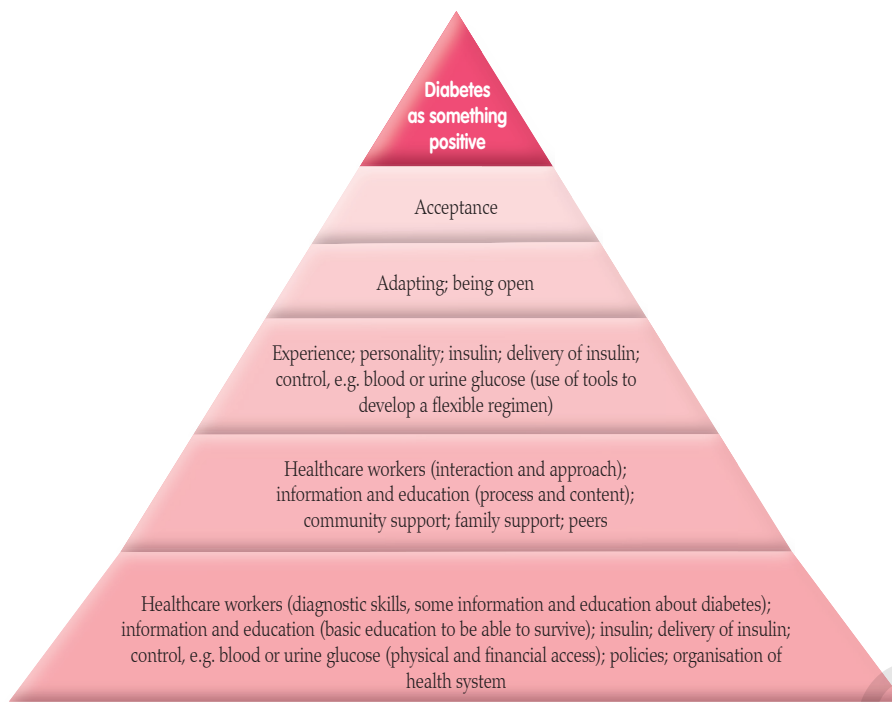
Mr Rikki's case shows how complex the interplay is between physical and mental health, highlighting how stigma can negatively affect health outcomes. While his physical health is paramount in preventing life-threatening complications (such as risk of amputation), the nurse working with him needs to incorporate an understanding of how stigma has affected him. Without addressing this, he is not going to be in a place of acceptance (Beran, 2014).

## RECOMMENDATIONS FOR PRACTICE

Key areas of future service level development include the integration of mental wellbeing for individuals with T1DM, and for this to hold just as much emphasis as physical health aspects. Without this, parity of esteem will not be achieved. Indeed, reducing the long-term complications of T1DM cannot be done without equal weight placed on mental and physical health needs. While it has been highlighted that a new integrated approach to commissioning is needed to recognise and treat psychological needs, the specifics are being left to care providers leading to variations in practice (Kozłowska, 2017; NHS England, 2019b). It is encouraging that mental health practitioners and other extended roles are moving into primary care. However, if the targets for the Quality Outcomes Framework do not change (British Medical Association 2021), in the authors' opinion there is no incentive for local providers to really explore stigma and the mental health impact of diabetes.

One suggestion from the literature was the creation of a 'welfare officer' in the clinic to talk about psychosocial issues informally, which could lessen this emotional burden (Akhter et al, 2016). This is reflected in some areas, with housing officers working in some deprived London boroughs to support individuals with housing problems (London Clinical





**FIGURE 2.**  
*Hierarchy of needs for type 1 diabetes (Beran, 2014).*

Networks, 2015). The wider social determinants of health are central to the development and progression of diabetes; housing, access to nutritious food, education, income, all influence how people manage their diabetes (Beran, 2014). In addition, nurses who manage people with diabetes should be trained not only to screen and identify common and increasing more complex mental health problems, but also to provide interventions and support.

There is also a need to improve education awareness for people without diabetes, as this is a step in reducing intersecting stigmas for T1DM. One study highlighted key areas to focus anti-stigma and found that stigma within diabetes was rooted in a lack of information (Irani et al, 2014). There is a need to develop context-specific information campaigns aimed at increasing public awareness of diabetes and correcting myths and misconceptions, taking into account the culture and context of country-specific education. These were also mentioned as the goals by the International Diabetes Federation (IDF) in 2010, yet arguably over 10 years later we are no closer to achieving this globally (IDF, 2010).

Peer support networks were also invaluable in providing a sense of

community for individuals with T1DM throughout the literature. Having a supportive network can enhance social cohesion and health outcomes (Fone et al, 2014). What is evident through the findings, is that reducing stigma requires a systemically multilayered approach. The HSDF provides an opportunity to recognise how stigma can permeate throughout all levels of society. Utilising knowledge, skills and best practice from multiple agents and disciplines across provider boundaries — health, social care, voluntary — while having sound leadership from the individual living with T1DM's secondary care team, can help deliver tailored care based on collective understanding of individual needs (Ali et al, 2021).

## STRENGTHS AND LIMITATIONS

This article is based on the first author's critical synthesis, an approach that is theoretical, open and explorative through the lens of a framework (Ritchie et al, 1993). Conventional systematic review techniques have limitations when the aim of a review is to construct a critical analysis of a complex body of literature. Stigma within T1DM is nuanced and so this article offers an attempt to conduct an interpretive review of the literature (Dixon-Woods et al, 2006).

The studies included came from a variety of countries, and were often small, qualitative, semi-structured interviews. Thus, although they may not be transferable to other healthcare settings, they offer an insight into how diabetes is regarded globally. One of the limitations of this may be that not all articles might be included in the same way as a systematic review would, and thus it may not hold the same rigor (Snyder, 2019).

## CONCLUSION

Through the adoption of an intersectional approach to explore how stigma within T1DM can permeate throughout the layers of society, the authors found that certain drivers and facilitators of stigma spiral to impact how individuals with T1DM behave with consequential effects on health outcomes. These drivers and facilitators included a lack of awareness of T1DM, different social and cultural norms, stereotyping and social judgement, relationships with others, and variations in health care and policy. In turn, these elements influence various intersecting stigmas such as class stigma, non-disclosure of diabetes and mental health service design, which can lead to avoidance practices, thus leading to poorer health outcomes.

The drivers and facilitators of stigma stem from the influences of the wider social determinants of health and lead to contention between the felt need to distinguish T1DM from the narrative that diabetes is preventative. Another key theme was the inextricable link between diabetes, stigma, and mental health. As the UK government has rightly identified, there is 'no health, without mental health'. Yet, achieving parity of esteem between mental and physical health against a background of stigma requires the adoption of a systemically multilayered approach with multiagency input across service boundaries (Akhter et al, 2016).

GPNs are well placed to be upskilled not only in screening for mental health issues, but also providing interventions to break down the stigma experienced by individuals living with T1DM. **GPN**

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# Pneumonia in babies and children: what GPNs should know

Pneumonia continues to cause mortality around the world, despite advances in treatment and prevention. The disease can affect any age and can present with variable degrees of severity ranging from mild to severe, with the worst cases resulting in admission to hospital. While vaccination in the UK has impacted on the severity and death rate of this potentially devastating disease, the condition continues to be the largest cause of mortality in children with the highest death rates seen in under developed countries. This article gives an overview of treatment, management and prevention, as well as a brief insight into the possible long-term effects following recovery from pneumonia in babies and children.

## KEY WORDS:

- Pneumonia
- Treatment
- Management
- Prevention

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Pneumonia is defined as an acute infectious disease affecting the lungs (World Health Organization [WHO], 2021). The condition can affect all ages and severity of symptoms varies from mild to severe. The disease remains a leading cause of mortality around the globe, and is the single largest cause of death in children worldwide, with the highest death rates occurring in South Asia and sub-Saharan Africa (WHO, 2021). This article looks at the causes, treatment, management and prevention and hopes to give nurses and non-medical prescribers a greater understanding of this potentially devastating illness.

## PREVALENCE RATES

Pneumonia has been the leading cause of death in children younger than five years for many years, and although there have been substantial decreases in overall child mortality and in pneumonia-specific mortality, the disease remains the major single cause of death in children outside the



neonatal period (Roux and Zar, 2017). According to statistics from WHO, pneumonia killed 740,180 children under the age of five in 2019, accounting for 14% of all deaths of children in this age range, and 22% of all deaths in children aged one to five (WHO, 2021). Over the last 20 years, there has been a substantial decrease in the incidence of childhood pneumonia and pneumonia-associated mortality, largely due to improvements in treatment and vaccination preventative strategies.

## PNEUMONIA TYPES

Pneumonia can be viral, bacterial or fungal, and there are several organisms that could be the cause. It can be difficult in babies and young children to determine the specific organism, but the patient's age may be helpful in determining the most likely causative agent (Ostapchuk et al, 2004; Table 1).

## RISK FACTORS

The majority of healthy children will be able to ward off many infections with the body's natural defence mechanisms, however there are several issues which place babies and children at greater risk. In some parts of the world where malnutrition is still a problem, normal defence mechanisms and the immune system may not function as well, placing children at a greater risk of contracting disease.

Other recognised risk factors include (Sutriani et al, 2021; WHO, 2021):

- Crowded living conditions
- Indoor pollution, including parental smoking
- Pre-existing illnesses, such as human immunodeficiency virus (HIV) or measles
- Low birth weight
- Incomplete vaccinations
- Babies not exclusively breastfed,

### Red Flags

- Pneumonia can be caused by viruses, bacteria or fungi
- Presentation in babies and children often differs from that seen in adults and is often related to age
- Diagnosis in primary care is usually made on clinical assessment
- Investigations are not usually needed unless diagnosis is uncertain or admission to hospital is needed.

particularly in the first six months of life.

### PATHOPHYSIOLOGY

The process by which pneumonia develops is highly complex and involves a number of stages and processes. A simplified explanation will be given here. The invading pathogen needs to reach the alveoli and overwhelm the host's defence mechanisms. The origin of causative microorganisms may arise from nasal carriers, sinusitis, oropharynx, gastric, or tracheal colonisation, or be carried by the blood (Alcon et al, 2005). The pathophysiology of pneumonia is characterised by four stages, namely (Morris, 2004):

- First stage: this occurs within 24 hours of acquiring the infection and is distinguished by infiltration of neutrophils and the causative organism leading to congestion and alveolar oedema
- Second stage: this is referred to as 'red hepatization', so called because the lungs take on a structure similar to the consistency of the liver, with the presence of many neutrophils, erythrocytes, epithelial cells and fibrin within the alveoli
- Third stage: this is described as 'grey hepatization' in which the lung becomes brown to yellow because of fibrin purulent exudate, disintegration of red cells and haemosiderin (an iron storage complex)
- Fourth stage: this is the final stage, called resolution, and is characterised by the breakdown of

substances causing inflammation. During this phase, white blood cells actively fight off any invading microorganisms and any remains are expelled by coughing. The normal pulmonary architecture is restored during this phase.

### MODE OF TRANSMISSION

In some cases, the lungs become infected when inhalation of the viruses and bacteria that are commonly found in nasal passages or throat occurs, leading to infection. Alternatively, spread may occur when air-borne droplets are inhaled from a cough or sneeze from an infected person. Pneumonia can also be spread from the mother during birth of the baby (WHO, 2021).

### SIGNS AND SYMPTOMS

Signs and symptoms vary widely and are often related to the age of the infant or child. New-born babies with pneumonia often present with irritability or feeding concerns, as well as rapid breathing (tachypnoea). In infants, the commonest symptom is cough with tachypnoea, congestion, fever, reduced feeding and irritability. Among older children and adolescents, symptoms are similar to those of younger children, but they may also experience headaches, chest pains and non-specific abdominal pains (Waseem, 2020).

### DIAGNOSIS

Diagnosis is usually made on clinical assessment and findings — observing a child's respiratory rate is considered an important first step in making the diagnosis (Waseem, 2020). Investigations such as chest X-ray, sputum analysis and blood tests (full blood count [FBC], C-reactive protein [CRP]) are often not requested but may be necessary in the presence of severe symptoms, or in those who are hospitalised (Ostapchuk et al, 2004). Abnormalities on auscultation are less frequently found in young children with pneumonia than in adults, a high fever, tachycardia and increased respiratory rate and effort may be the only signs (Best Practice Journal [BPJ], 2012).

### ASSESSING THE NEED FOR HOSPITAL ADMISSION

The decision to admit a child to hospital can be a difficult one to make because despite guidelines to aid decision-making there are no validated severity criteria for assessing children, and definitions for mild, moderate, and severe pneumonia vary across the literature, making the decision-making process even more complicated (Dean and Florin, 2018).

The following factors are considered important when assessing an ill child (Harris et al, 2011; BPJ, 2012):

- Repeated visits with persistent fever, or parents concerned about a persistent fever should raise concern of possible community-acquired pneumonia (CAP)
- Children being treated in the community for CAP with persistent symptoms or poor response to treatment should be reassessed
- Absent breath sounds and dull percussion note on examination may suggest pneumonia complicated by effusion, and should raise alarm bells that referral to hospital is needed
- Severe tachypnoea and/or increased respiratory effort
- Children with low oxygen saturation levels (below 92%) should be assessed in hospital.

### TREATMENT AND MANAGEMENT

For children who can be treated in the community, both pharmacological and non-pharmacological measures

### Red Flags

- Repeat GP consultations for persistent fever raise suspicion of pneumonia
- Decision to admit is based on findings at assessment
- Poor response to treatment will need further assessment
- No validated tools are available to help differentiate between mild, moderate or severe pneumonia.

**Table 1: Likely causative organisms by age (Ostapchuk et al, 2004)**

Likely age group	Causative organism
Babies younger than three weeks of age	Often caused by an infection obtained from the mother at birth
Babies aged three weeks to three months	Streptococcal pneumoniae and viruses are the most common causes in this age group
Pre-school age children	Viruses are the most frequent cause of pneumonia in pre-school-aged children, or, if bacterial, Streptococcus pneumoniae is the most common pathogen
Children aged five or older and adolescents	Mycoplasma pneumoniae (MP) and Chlamydia pneumoniae (CP) are often the causative organism in these age groups

are usually beneficial. Non-pharmacological treatments are shown in *Table 2*.

### Pharmacological treatment

When antibiotics are needed, there are several choices available (National Institute for Health and Care Excellence [NICE], 2021):

- Babies below two years of age may not need antibiotics but should be reviewed if symptoms persist. A history of having had pneumococcal vaccination will be useful in guiding this decision
- Amoxicillin is first-line choice of antibiotic
- Alternatives include co-amoxiclav or cefaclor (if the child has pneumonia associated with influenza, co-amoxiclav is the recommended choice of antibiotic)
- Erythromycin, clarithromycin and azithromycin are alternatives

**Table 2: Non-pharmacological treatments (NICE, 2021)**

■ Regular intake of fluids should be encouraged
■ Infants who are breastfed, mother should be advised to continue this
■ Parents who smoke should be advised not to do so
■ Paracetamol and ibuprofen should be given for feverish babies and children, but should only be continued for as long as the child is distressed
■ Paracetamol and ibuprofen should not be given together but can be given alternately if distress persists or recurs before the next dose of either agent is due
■ Tepid sponging/and or removing clothing should not be used to reduce fevers

and may be given if the child is allergic to penicillin. Drugs from this group can also be added to children of any age if response to initial treatment is poor

- Duration of antibiotics may be seven or 14 days depending on response to treatment prescribed.

Further information on dosing can be found in NICE guidelines (2021).

### Treatment failure

Failure to respond may indicate that the causative organism is not sensitive to the antibiotics prescribed and they have therefore been ineffective. In cases of severe pneumonia, treatment with monotherapy may be inadequate and dual therapy may be required. Treatment failure may also be due to one of the following (Paraby and Balfour-Lynn, 2013):

- Antibiotic resistance
- Atypical organisms such as Mycobacterium tuberculosis being only partially sensitive to antibiotics
- Or because the disease is the first presentation of an underlying condition, such as cystic fibrosis, immunodeficiency or congenital thoracic malformation (CTM).

### COMPLICATIONS

There are many complications of pneumonia, some of which are extremely rare. The most well known will be discussed here. Rarer and less well-known complications are shown in *Table 3*.

### Sepsis

Sepsis occurs as a result of the

body's overwhelming and life-threatening response to infection that can lead to tissue damage, organ failure, and death (Sepsis Alliance, 2022). The incidence of this is not known but is thought to be very low, even in children who present with empyema (accumulation of pus between the lungs and chest wall; see below) (Pabary and Balfour Lynn, 2013).

### Lung abscesses

Lung abscesses usually occur as a consequence of a localised lung infection by particularly virulent, pyogenic bacteria. Although they can develop when treatment has been sufficient, they more frequently occur when treatment is delayed or has been inadequate (Mani, 2017). Antibiotics are usually needed for at least two weeks or in some cases four. Eighty to ninety per cent of lung abscesses resolve with antibiotic therapy alone, provided that there is no associated bronchial obstruction or underlying lung disease such as cystic fibrosis, but occasionally, drainage is required (Mani, 2017).

### Pleural effusion/empyema

Injury to the lung parenchyma due to infection can lead to increased capillary permeability and accumulation of fluid in the pleural space (pleural effusion) (Pabary and Balfour-Lynn, 2013).

This process generally occurs in three stages — exudative, fibrinopurulent and organising stage (Shebl and Paul, 2021).

### Exudative stage

In this stage, there is an accumulation of fluid in the pleural space due to increased capillary permeability that results from proinflammatory cytokines, such as interleukin 8 (IL-8) and tumour necrosis factor-alpha (TNF-a). The pleural fluid is usually clear exudative fluid containing many neutrophils. The pleural fluid at this stage is regarded as a simple parapneumonic effusion, which usually resolves with adequate antibiotic treatment of pneumonia without the need for drainage and generally occurs two to five days after disease onset.



**Table 3: Rare complications of pneumonia (Pabary and Balfour Lynn, 2013)**

Complication	Additional information
Acute respiratory distress syndrome	This is an extremely rare complication caused by fluid in the lungs which leads to defective lung expansion and low oxygen levels (hypoxaemia)
Syndrome of inappropriate antidiuretic hormone secretion	Characterised by excessive release of antidiuretic hormone from the posterior pituitary gland leading to hyponatraemia, which cause confusion or seizures. Fluid restriction is needed
Secondary thrombocytosis	In adult's secondary thrombocytosis, (previously considered a normal inflammatory response to infections), is now associated with respiratory complications (pleural effusion and empyema) and poorer outcomes. Platelet counts may therefore be of prognostic value in paediatric CAP although antiplatelet treatment is not currently recommended
Haemolytic uraemic syndrome	Haemolytic uraemic syndrome (HUS) is one of the main causes of acute renal failure in the paediatric population and has been described following invasive streptococcal pneumonia infection. Mortality rates are higher than in cases caused by other organisms. Should be suspected in children with anaemia, thrombocytopenia and renal dysfunction (anuria) as 75% of these cases are likely to require dialysis
Pericardial effusion	There is an accumulation of fluid between the heart and the pericardial sac. Extremely rare in children and in most cases improves with treatment of the underlying infection
Atelectasis	Acute atelectasis is defined as collapse of part or all of one lung and it is now thought to be due to accumulation of alveolar fluid. Flexible bronchoscopy, both as a diagnostic and therapeutic intervention, has been shown to be beneficial for atelectasis in children associated with infection

an increased risk of adult asthma, non-smoking related chronic obstructive pulmonary disease (COPD), and bronchiectasis (Grimwood and Chang, 2015).

## PREVENTION

Before the introduction of childhood pneumococcal vaccination, approximately one child in every 200 in the UK was admitted to hospital for pneumococcal pneumonia during the first five years of life (Prendergast, 2018). In 2006, the pneumococcal conjugate vaccine (PCV) was introduced into the UK schedule and estimates suggest that in the first 11 years of the PCV programme nearly 40,000 cases of invasive pneumococcal disease and about 2,000 deaths have been prevented (Prendergast, 2018). With updates and improvements to the vaccine, which now covers 13 pneumococcal bacteria types, disease in babies and young children has become far less common. As a result, pneumococcal vaccination is offered routinely as part of the immunisation schedule. The scheduled dates at which vaccination is recommended was updated in 2020, with vaccination currently offered to all babies born on or after 1/1/2020 to be given at 12 weeks and

### Fibrinopurulent stage

This can develop if adequate treatment is not provided. In this phase there is a deposition of fibrin clots and fibrin membranes in the pleural cavity, leading to fluid loculations and empyema. This stage takes about five to 10 days after pneumonia onset.

### Organising stage

Fibrin membranes are transformed by fibroblast into a thick non-elastic membrane, leading to reduced lung expansion and restrictive respiratory dysfunction. This stage may take about two to three weeks to develop.

### Necrotising pneumonia

In children, necrotising pneumonia (NP) is an uncommon, severe complication of pneumonia, characterised by destruction of the underlying lung parenchyma resulting in multiple small, thin-walled cavities, often accompanied by empyema and bronchopleural fistulae (Masters et al, 2017). Long-term intravenous (IV) antibiotics are usually needed (Masters et al, 2017).

## LONG-TERM EFFECTS OF PNEUMONIA

During normal foetal development and the first three to four years of rapid postnatal growth, the developing lungs are most vulnerable to injury by infectious and non-infectious insults, and it is during this early postnatal period, when new alveoli are still forming and lung growth is most rapid, that the developing lungs are susceptible to the long-term effects of pneumonia (Grimwood and Chang, 2015). Infectious insults to the rapidly growing, developing lungs in the first one to three years of life is reported to be associated with an increased risk of impaired lung function in adulthood (Grimwood and Chang, 2015). Edmond et al (2012) suggested an overall risk of long-term major respiratory sequelae from childhood pneumonia in non-hospitalised children of 5.5%, but was found to be three times higher in hospitalised children. Conditions associated with early childhood pneumonia include restrictive or obstructive lung function deficits,

## Vaccine types

- Pneumonia conjugate vaccine (PCV): Prevnar is the brand name of the vaccination used in children below the age of two years of age.
- Pneumococcal polysaccharide vaccine (PPV) is given to children over the age of two who are at greater risk of pneumonia. This includes children who are immunocompromised, have asplenia, splenic dysfunction or complement disorder (a malfunctioning or immunodeficiency causing recurrent infections, immune diseases or glomerulonephritis). This vaccine is ineffective in babies below the age of two.

(NHS, 2019)

one year of age (GOV.UK, 2022). Babies born before this will continue to be offered three doses at eight and 16 weeks, and a booster at one year (NHS, 2019). Parents should be advised that the vaccine cannot give the child pneumonia as it is not a live vaccine.

## CONCLUSION

Despite improvements in treatment and prevention, pneumonia continues to kill babies and children around the world, although deaths are higher in underdeveloped countries compared to those occurring in wealthier nations. The introduction of vaccination into the routine immunisation programme has improved things enormously and pneumonia in babies and children is now far less frequently seen. General practice nurses (GPNs) and nurse practitioners play an important role in encouraging parents to take up the offer of vaccination to hopefully prevent a decline in the improving trend seen in recent years. This article

gives an insight into the disease, its impact as well as treatment management and prevention, to give nurses confidence in advising parents about this potentially devastating disease. **GPN**

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### Revalidation Alert

Having read this article, reflect on:

- Risk factors for developing pneumonia in babies and young children
- What to look out for when assessing an ill child
- The different pharmacological and non-pharmacological treatments available
- Your knowledge of complications which can occur with pneumonia.

Then, upload the article to the free GPN revalidation e-portfolio as evidence of your continued learning: [www.gpnrnursing.com/revalidation](http://www.gpnrnursing.com/revalidation)

# Cancer care reviews: a solution to delivering personalised care

Increasing cancer survival rates and evolving models of care require primary care teams to adapt their practice to meet the needs of people after a cancer diagnosis and completion of treatment. The needs of people after a cancer diagnosis are often complex and require a person-centred, holistic model of care. The 'NHS Long Term Plan' sets out the ethos of personalised care for those living with long-term conditions (LTCs), including cancer. Interventions to support personalised care include cancer care reviews (CCR) in primary care. Recent Quality Outcome Framework guidance for CCR has aimed to personalise the intervention to improve patient experience. General practice nurses (GPNs) are well placed to deliver CCR but need access to education to feel confident and develop competence in this area. There are several resources that have been developed to support CCR as a personalised care intervention. These interventions need further evaluation to assess their impact on patient experience and outcomes.

## KEY WORDS:

- Personalised care
- Cancer care review
- Patient experience
- General practice nurses
- 'NHS Long Term Plan'

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The provision of cancer services in the United Kingdom (UK) has changed. The life-time risk of a cancer diagnosis has risen to one in two people for those born after 1960 (Ahmad et al, 2015). Survival for people diagnosed with cancer in the UK and other developed countries has improved dramatically: half of people diagnosed with cancer today are predicted to survive their disease for at least ten years (Cancer Research UK, 2022). Due to increased incidence and survival, the population of those living with cancer in the UK is growing; thus, developing models of care to meet the needs of people living with and beyond cancer within primary care is becoming increasingly important.

**“ ... the population of those living with cancer in the UK is growing; thus, developing models of care to meet the needs of people living with and beyond cancer within primary care is becoming increasingly important.**

The *NHS Long Term Plan* (NHS England, 2019) outlines the introduction of personalised care across the NHS, using the comprehensive model for personalised care. Interventions that support personalised care for people with

cancer include a personalised care and support plan (PCSP) based on a holistic needs assessment (HNA), end of treatment summary (EOTS), health and wellbeing information and support, and a cancer care review (CCR) (Macmillan Cancer Support, 2022). There is growing recognition of the essential role for primary care in supporting this group of patients, with a specific role in conducting CCRs. Primary care may be provided to people with cancer by GPs, general practice nurses (GPNs) or allied health professionals (AHPs), as part of their generalist role providing an integrated approach to, and maintaining continuity of, care (Adam and Watson, 2018; Blane and Lewandowska, 2019; Cavers et al, 2019).



Intrinsic to this model of care is personalised, stratified follow-up, whereby shared decision-making with patients enables novel approaches to caring for someone after completion of their cancer treatment. The increasing number of patients managed in stratified patient-initiated follow-up (PIFU) pathways is, however, adding to the demand for cancer care in primary care. Evidence suggests that there are several barriers to patients on PIFU pathways getting support from their hospital team (Moore et al, 2022). Instead, patients contact their primary care services, particularly their GP for help and support.

Comorbidity in those with a cancer diagnosis is common, with 70% having at least one other long-term condition (LTC) and 29% having three or more LTCs (Macmillan Cancer Support, 2021a). Multimorbidity brings complexity of needs and concerns, which are increasingly being understood as wide-ranging: physical, psychosocial, and practical. The National Institute for Health and Care Excellence (NICE, 2016) outlines best practice for people living with multimorbidities and emphasises the importance of an integrated and holistic approach to care. To fully address the needs of patients, a shift away from a medical model of care is increasingly being advocated and being adopted as NHS policy; this is embodied in the *NHS Long Term Plan* with the adoption of the ethos of personalised care (NHS England, 2019).

The National Cancer Patient Experience Survey (NCPES) (Picker, 2022a) includes some metrics on personalised care. Results from this survey consistently demonstrate that patients' experience of care 'out of hospital' is poorer than their experience of hospital-based care and that there is a need for more effective personalisation in cancer care (Picker, 2022b). Historical data from the survey identified that the key times patients report needing support from their primary care team is during and after treatment. Furthermore, Black, Asian, and other minority ethnic groups consistently report poorer experience than their

white counterparts across the cancer pathway (Macmillan Cancer Support, 2017a; NHS England, 2020).

In addition to NCPES data, quality of life (QoL) surveys at 18 months now provide a metric at a point when many patients will have completed treatment (NHS England, n.d). This survey uses both the generic EQ-5D and cancer-specific EORTC QLQ-C30 tools. It is completed only once at a fixed time point. This provides comparison data across different types of cancers at that time point and is providing data about the needs of people 18 months after a cancer diagnosis that

**“ It is promising to know that there is now a small, but growing number of GPNs developing their expertise in the management of people with cancer as those with a long-term condition.**

is useful for clinicians, researchers, and commissioners of services. The limitation with this intervention lies in the use of EORTC QLQ-C30, which has been validated for cancer clinical trials and not as a measure of QoL after cancer treatment.

As outlined above, people with cancer frequently have other LTCs and have regular contact with primary care teams. GPNs are key to the provision of care to those living with LTCs in primary care. This care is most often nurse-led by GPNs with expertise in the management of asthma, diabetes, chronic obstructive pulmonary disease (COPD) and so on. Knowledge and skills in cancer care are not typically regarded as core to GPN practice (Dyer and Dewhurst, 2020). However, this is changing as more GPNs are accessing cancer care education and training. Courses, such as the practice care nurse course offered by Macmillan Cancer Support, equip primary care nurses to become involved in interventions, such as CCRs in general practice.

It is promising to know that there is now a small, but growing number of GPNs developing their expertise in the management of people with cancer as those with a long-term condition. However, there are GPN recruitment and retention challenges nationally with a current shortfall of 1700 full time equivalents in 2022, which is predicted to grow to 6,400 vacancies by 2030–31 if current trends continue (Health Foundation, 2022). The GPN workforce shortfall has been addressed strategically in England through the 'GPN 10-point plan' (NHS England, 2018). The Sonnet Advisory and Impact report (Sonnet Impact, 2021), a legacy intervention of this strategic work, clearly demonstrates the value of the GPN and articulates their unique, holistic, and personalised approach to care in the primary care setting. This holistic and personalised approach is likely to be transferable to managing cancer as a LTC in primary care, including the delivery of CCRs.

## CANCER CARE REVIEWS

A CCR has been defined as a conversation between a patient and a doctor or primary care nurse (Macmillan Cancer Support, 2021b). CCRs are funded in England through the Quality Outcome Framework (QOF) as part of the GP contract (Sonnet Impact, 2021), however, conducting a CCR is not mandatory. QOF data consists of self-reporting that a CCR has taken place and the Cancer Outcomes and Services Dataset (COSD), which is the national standard for reporting cancer activity in England, does not currently collect data on CCR (NHS England, 2021). It is, therefore, difficult to measure current CCR activity in England.

Following a national consultation in 2020 (Lavender et al, 2022), changes to the QOF for cancer have come into place from 1 April 2021. These changes provide an opportunity to improve the quality of CCR and improve cancer patients' experiences. A contact within three months of being diagnosed with cancer will provide an opportunity for primary care teams to offer support and signpost to relevant services or

a social prescriber. The requirement to offer a CCR up to 12 months after diagnosis enables this to be conducted at the end of treatment for most patients. The QOF requirement for a structured template to be used, facilitates a comprehensive and holistic review.

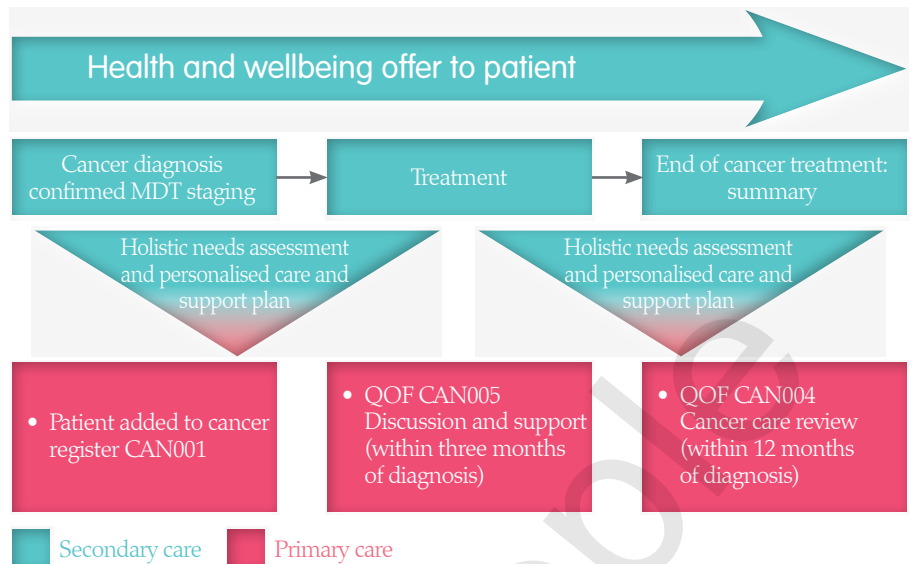
### CCR: WHAT IS BEST PRACTICE?

There is currently limited guidance to support best practice for cancer care review.

The QOF Indicator for Cancer QOF review in 2020 (NICE, 2020) is based on expert consensus rather than research. This outlines the timing of the two interventions as shown in *Figure 1* (CAN004 and CAN005) and the QOF requirement to use a template aims to introduce holistic elements into the consultation, as the template includes psychosocial elements of care.

Identification of patients for a CCR is dependent on maintenance of a cancer register, which is a QOF indicator (QOF CAN001). Additionally, accurate and consistent primary care coding is essential to ensure support through CCR and to ensure that patients with a cancer diagnosis can have their long-term needs identified and met appropriately by primary care (Picker, 2022a).

A regional comparison of primary care registers and National Cancer Registry Ireland (NCRI) identified a discrepancy with up to 25% of cancer cases missing in the primary care registries in London (Zalin et al, 2020). It is estimated that in London this data discrepancy amounts to 18,000 patents missing from primary care cancer registers across the capital (Health London Partnership, 2019). Health London Partnership's guidance on clinical coding in primary care provides a case study of a standardised approach in one locality (clinical commissioning group [CCG]) in Northeast London (Healthy London Partnership and Tower Hamlets CCG, 2019). This case study reported a 25% increase in recorded prevalence in primary care following an incentivised initiative



**FIGURE 1.** Personalised care for cancer: QOF cancer care review.

to standardise coding. Undoubtedly, identification of patients is the crucial first step to offering a CCR.

Evidence on the quality of CCRs is currently extremely limited. NCPES data collection on this question started in 2021, with only 18% of patients recognising that they had been offered this intervention despite high QOF achievement reported in previous years (reporting of QOF dimensions has been limited since 2019 due to the Covid-19 pandemic).

Published evidence about patients reporting limited experience of CCRs is consistent with the NCPES data (Adams et al, 2011), as well as NHS England data (SW London CCG, 2020) and anecdotal experience of the authors.

NCPES data has historically highlighted that large numbers of patients feel unsupported by their primary care team after a cancer diagnosis and after completion of primary treatment. A recent scoping review highlights the lack of evidence to support the value of CCR (Gopal et al, 2022); with most of the evidence reviewed pre-dating the changes to QOF in 2020/21 and education initiatives for GPs and GPNs. They conclude that more research is required to understand the needs of patients and how a CCR may be of benefit. They note that patients from lower socio-economic groups and

minority ethnic groups may not have participated in the research described in the reviewed papers.

The authors of this paper hypothesise that CCR is a complex, personalised, supportive care intervention that has the potential to enable patients to access appropriate and timely support and increase their self-efficacy. If the CCR is to be used in this way, healthcare professionals in primary care require specialist knowledge and skills. However, training needs analyses from London have demonstrated that high numbers of GPs, GPNs and other clinical staff within the health and care system are not confident in supporting people with cancer as a LTC (Transforming Cancer Services Team for London, 2016; Dyer and Dewhurst, 2020).

There are nurses in general practice who are developing their practice to better support people after a cancer diagnosis and to deliver CCRs as a personalised care intervention. An example of a standard protocol is given in *Figure 2*. Inviting patients for a consultation and use of Macmillan Cancer Support's Concern checklist (2017b), or a text-based questionnaire (Accurx, 2022) would be expected to enable patients to be both prepared for the consultation and to promote a personalised consultation. This service improvement is being

adopted in London and nationally by a number of practices and clinicians, but is yet to be evaluated and/or studied to provide evidence of improvement to patient experience and outcomes.

## DISCUSSION AND RECOMMENDATIONS

Assessing the needs of people living with cancer requires the use of advanced and specialist skills to provide high-quality and holistic care. GPNs who provide care for people with LTCs already possess advanced practice skills that could be transferred to cancer care (Macmillan Cancer Support, 2011). These skills include:

- Advanced communication skills
- Consultation skills
- Ability to prioritise and anticipate needs
- Use of motivational interviewing techniques
- Shared decision-making
- Developing PCSPs.

In the authors' clinical opinion, the capability and capacity of staff with cancer-specific knowledge in primary care could be addressed through additional education, particularly freely accessible online education, and supported through peer-to-peer learning or communities of practice. For GPNs who are developing their knowledge in cancer care as generalists, there has until recently been no guidance on the level and aspects of knowledge and skills required. The Health Education England Aspiring Cancer Career and Education Development (ACCEND) programme aims to launch a new capabilities and education framework for nursing and allied health professionals early in 2023 (Health Education England, 2021). The framework will provide guidance for educators, employers, and individual clinicians on the education, knowledge and skills required to provide high quality CCRs.

## CONCLUSION

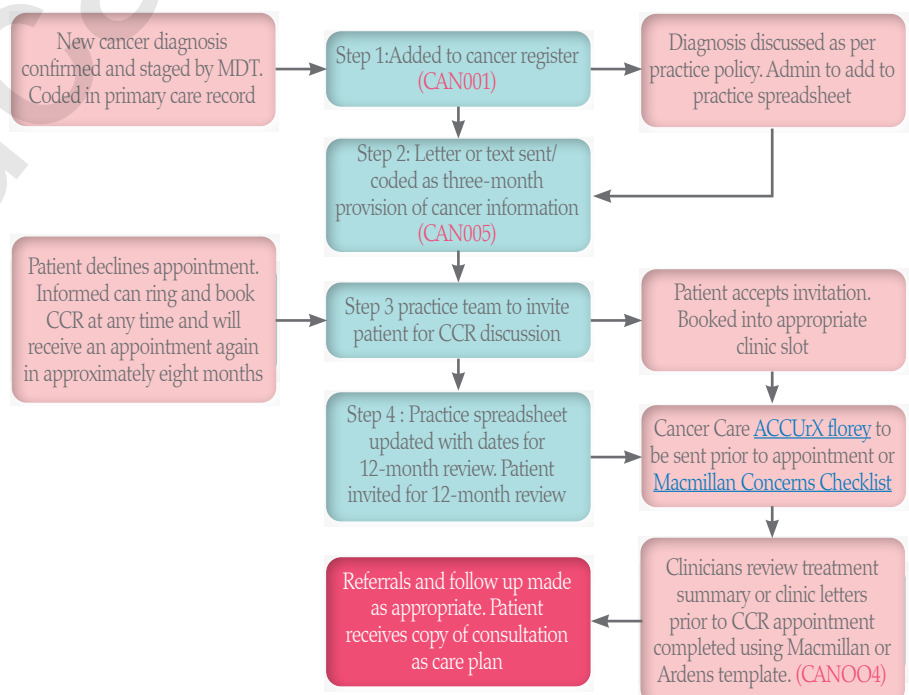
Cancer care reviews are a funded intervention in primary care that provide an opportunity for personalised care at the end of cancer

treatment or within 12 months of diagnosis. This intervention provides an opportunity to develop a therapeutic relationship between the patient and their primary care clinicians, which may in turn support patients managed on PIFU pathways. There is, however, a lack of evidence on how CCRs affect patient outcomes and experiences. More research is needed to identify patients' and clinicians' perceptions, experiences of a cancer care review, patient outcomes, and health service outcomes from this intervention. Interventions to standardise practice and aim to personalise care need to be evaluated. Particular attention should be given to seeking the views of minority patient groups who consistently report poorer experience across the patient pathway, as previously discussed.

The authors propose that GPNs are well placed to deliver CCRs that count for patients, but access to education and standardised practice-wide processes are needed to support this service change. Effective use of the CCR in primary care through GPN-led services will benefit patient outcomes and experiences and innovate the delivery of cancer care services. **GPN**

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**FIGURE 2.** Example of standardised process for CCR. Credit: merged protocols from SE London ICS Southwark CCR project and Windrush Medical Practice Oxfordshire.



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## Revalidation Alert

Having read this article, reflect on:

- Your confidence to deliver cancer care reviews (CCRs)
- How you can develop your practice to better support people with a cancer diagnosis
- CCRs as a personalised care intervention.

Then, upload the article to the free GPN revalidation e-portfolio as evidence of your continued learning: [www.gpnnursing.com/revalidation](http://www.gpnnursing.com/revalidation)

# National care bundle for children with asthma: what does it mean?

The national care bundle for children with asthma is the first phase of a national plan to improve asthma care, focusing on integration of systems and effective communication. It follows several high-profile reports, national and global guidelines, with the aim of training clinicians to consistent standards, keeping children and young people (CYP) with asthma well, improving diagnosis, patient pathways and encouraging self-management. This article, the second in a two-part series, explores practical ways to implement the bundle in clinical practice and how to meet its requirements.

## KEY WORDS:

- Care bundle
- Asthma
- Diagnosis
- Exacerbations

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The first article in this two-part series explored the national care bundle for asthma introduced by NHS England in 2021 (King, 2022). This second piece looks at organisation of care, the environmental impact of asthma therapy, early and accurate diagnosis, effective preventative medicine, management of exacerbations, severe asthma, data and digital, and the tiered training system. In doing so, it follows on with ways to embed the principles in everyday care, building on the bundle itself to suggest practical ways to implement the bundle in your area.

## ORGANISATION OF CARE

Each organisation should have a lead, i.e. someone with an interest in asthma, who is confident consulting with children and young people (CYP) and prepared to lead and teach the rest of the team.

The NHS Digital Quality Outcomes Framework [QOF] is an



annual rewards scheme, offering incentives to primary care for practice achievement results. It is voluntary and aims to resource and reward good practice, rather than being a performance management programme (NHS Digital, 2023). There are five domains: clinical, public health (which is broken down into public health, vaccination/immunisation, quality improvement, and additional services). Practices can score points according to their level of achievement of indicators (Table 1) to a maximum value — for 2021–22, the maximum was 635 points against 72 indicators, and, of these, ten relate to asthma.

## ENVIRONMENTAL IMPACTS

This was discussed at length in the previous article in this two-part series (King, 2022). The most significant consideration here is the context, i.e. if using a pressurised metered-dose inhaler (pMDI) as a preventer is the best course of action for your patient, ensure that they are using it

as effectively as possible to optimise asthma control. Poor control will mean more pMDI use from the reliever inhaler, increasing carbon emissions. Ongoing poor control resulting in an exacerbation will multiply this, and an ambulance journey or hospital admission will increase this many, many times.

## Air quality

Smoking is a huge factor for both young people and their families when considering environmental pollutants and indoor air quality.

## EARLY AND ACCURATE DIAGNOSIS

Early and accurate diagnosis for those who are suspected to have asthma can be life-changing. If you are not diagnosed (but are being treated as such, with suspected diagnosis) you are less likely to be called for asthma review, to have your medicines optimised, to effectively self-manage, and far less likely to have

a personalised asthma action plan [PAAP]. Furthermore, if the patient does not hold a PAAP, they are four times more likely to have an attack (Asthma + Lung UK, 2023).

The importance of effective history-taking was introduced in the first article in this two-part series. When we consider this in practice, some fundamental aspects need to be covered, namely:

- The child or young person’s history (birth, infancy, when they first wheezed, if/when they have had attacks), atopy
- Family history of atopy — asthma, eczema, allergic rhinitis (hayfever), allergies
- Possible or known trigger factors
- Symptom burden, pattern, consistency, interval or with viral illness
- Objective measures of asthma control (e.g. Asthma Control Test [ACT], GlaxoSmithKline [GSK], 2023; Table 2 — <https://rethinkyournormal.gsk.com/the-asthma-control-test/>)
- Treatment burden (if they are on therapy) and their behaviour around it.

## OBJECTIVE MONITORING

### Pharmacy referral scheme

The Pharmacy Quality Scheme presents quality criteria in three domains:

- Clinical effectiveness
- Patient safety and
- Patient experience.

One domain is respiratory which includes inhaler technique checks, inhaler waste management, spacer use in 5–15 years and PAAPs (NHS England, 2022).

Further to this, which clearly supports effective preventative medicine, a scheme arose (Pharmaceutical Services Negotiating Committee, 2021) that allowed pharmacies to refer patients back to their practice if:

- They have been prescribed a pMDI without a spacer
- They do not have a PAAP
- They have used three or more reliever inhalers with no preventer inhalers in the last six months.

**Table 1:** Indicators from the Quality and Outcomes Framework (QOF) for asthma (NHS Digital, 2022)

Indicator	Points	Threshold	Description
AST001	4		Establish and maintain a register of patients with asthma, who have been prescribed asthma therapy in the last 12 months
AST002	5	45–80%	Percentage of patients eight years or over with asthma* on the register with a documented measure of variability/reversibility recorded either three months prior to, or post-diagnosis *diagnosed on/after 1st April 2006
AST003	20	45–70%	Percentage of patients on asthma register who have had an asthma review in the prior 12 months including assessment of asthma control using three Royal College of Physicians’ (RCP) questions
AST004	6	45–80%	Percentage of patients diagnosed with asthma, aged 14–20 years who have a documented smoking status in the 12 months prior
SMOK002	25	50–90%	Percentage of patients with conditions including asthma, with a noted smoking status in the prior 12 months
SMOK005	25	56–96%	Percentage of patients with conditions including asthma, recorded as current smokers and recorded offer of support/treatment in prior 12 months

**Table 2:** Asthma Control Test (GlaxoSmithKline, 2023)

Asthma Control Test — in the last four weeks:				
1. How often has your asthma stopped you getting as much done at home, school or work?				
All of the time (1)	Most of the time (2)	Some of the time (3)	A little of the time (4)	None of the time (5)
2. How often have you been short of breath?				
More than once a day (1)	Once a day (2)	3–6 times per week (3)	Once or twice per week (4)	Not at all (5)
3. How many nights have you had symptoms, e.g. cough, wheeze, waking at night or earlier in the morning?				
4 or more nights per week (1)	2–3 nights per week (2)	Once a week (3)	Once or twice (4)	Not at all (5)
4. How often have you needed your rescue inhaler?				
3 or more times per day (1)	Once or twice per day (2)	2–3 times per week (3)	Once a week or less (4)	Not at all (5)
5. How would you rate your asthma control?				
Not controlled (1)	Poorly controlled (2)	Somewhat controlled (3)	Well controlled (4)	Completely controlled (5)
Under 16 = very poor control; between 16 and 20 = poor control; over 20 = well controlled				

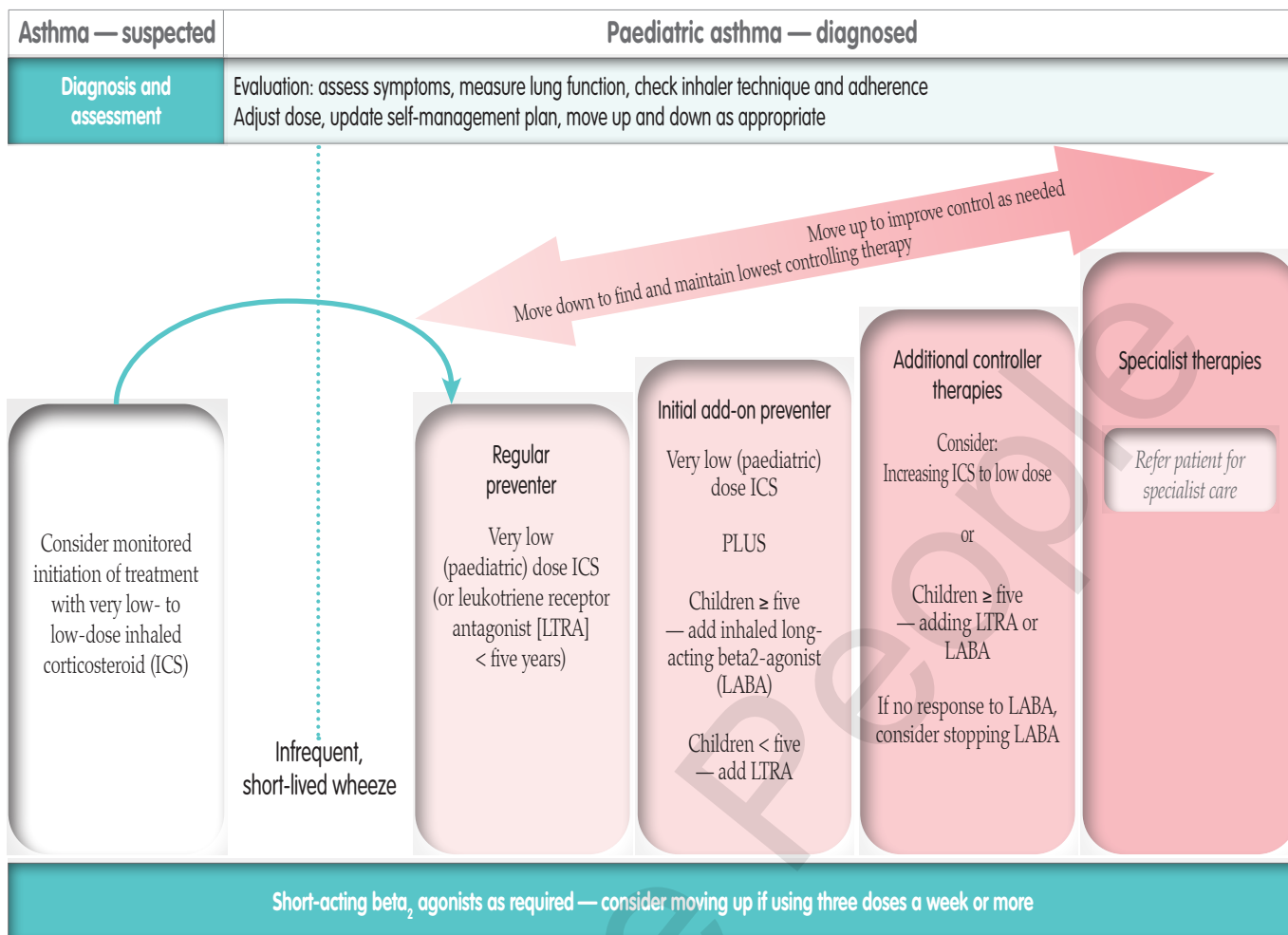
Common asthma mimickers include poorly understood and poorly managed allergic rhinitis, gastro-oesophageal reflux and psychological issues such as anxiety (British Thoracic Society/Scottish Intercollegiate Guidelines Network [BTS/SIGN], 2019; Global Initiative for Asthma [GINA], 2022).

### Allergic rhinitis

As many children that wheeze are

also atopic, it is common for asthma-like symptoms driven by rhinitis (such as nocturnal cough) to make diagnosis and ongoing management more complex. Once atopy and familial atopy is established, one of the most useful questions to ask is when the child or young person coughs. Generally speaking, if they cough when they first lie flat, it is likely that the cough is due to post-nasal drip. If the cough is in the





**FIGURE 1.**

*Asthma management in children. This figure is reproduced from BTS/SIGN British Guideline on the management of asthma by kind permission of the British Thoracic Society and Scottish Intercollegiate Guidelines Network (BTS/SIGN, 2019).*

middle of the night or first thing in the morning, it is more likely to be due to asthma.

Some children have asthma that is driven by allergic processes in the nose — the one airway model (the concept that the upper and lower airways are joined, and inflammation in one will impact the other) tells us that poorly managed rhinitis will inflame the lower airways and vice versa. Simply speaking, you should manage both well to ensure inflammation is minimised (Bousquet et al, 2003; Braunstalhl, 2005).

### Gastro-oesophageal reflux

Gastro-oesophageal reflux can be a similarly problematic comorbidity in many children. It can present with chest pain, burning sensation in the throat and unpleasant taste in the mouth, similar to adults (National Institute for Health and Care Excellence [NICE], 2019). Often, because these sensations occur after

eating or at night time, they can be mistaken for asthma and allergy. Children who have not experienced this sensation before, but have felt chest tightness and shortness of breath, may well assume that this is an asthma symptom and treat with salbutamol. Of course, if there is no airway constriction, this will not improve symptoms and often it is found that young people will take multiple puffs of reliever, assuming that they need more.

### Anxiety

Similarly, anxiety can confuse when it presents — some children and young people experience chest tightness, a racing heart, muscle tension which they may associate with historical asthma exacerbations or with poor control (Asthma + Lung UK, 2023; Katon et al, 2004). As with reflux, they may take their reliever hoping it will ease the sensation, but it may actually exacerbate the issue as the short-acting beta agonist triggers the

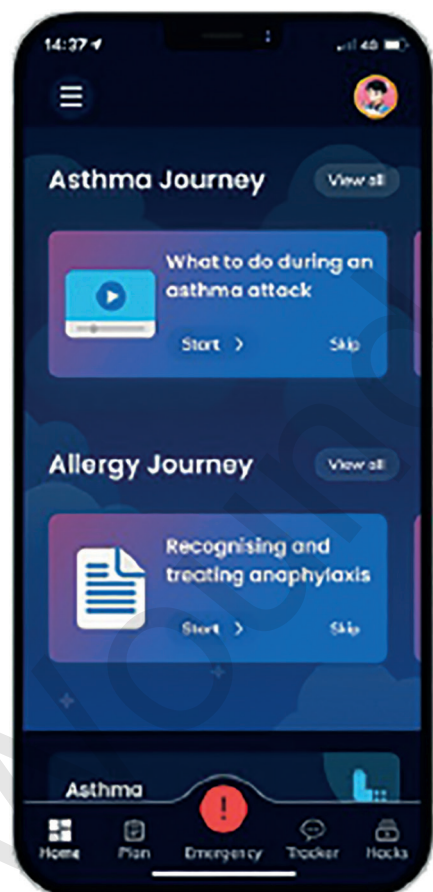
parasympathetic nervous system into a 'fight or flight' response (Edgell et al, 2016; Alhayek and Preuss, 2022).

### SEVERE ASTHMA

While it is not expected that true severe asthma is managed solely in primary care, the primary care team remains the child or young person's key universal contact (BTS/SIGN, 2019). What is often considered severe or perhaps historically called brittle asthma — whether by parents, carers or clinicians — is now quite often found to be more accurately labelled difficult-to-treat asthma. This means that the pathology may actually be mild in terms of inflammation or complexity, but the situation or diagnosis is muddled by comorbidities, extraneous factors that are difficult to isolate, and of course modifiable factors such as environmental considerations and emotional wellbeing (BTS/SIGN, 2019). The latter is notoriously

prevalent anecdotally in those deemed 'severe', or who have had multiple treatment regimens or hospitalisations. Often, in the author's experience, cause and effect is surprisingly difficult to gauge. For some young people, their sense of self can almost form around their identity as someone who is chronically sick and self-limit their activities to the point where it is difficult to tell their true ability physically.

Considering this in the context of someone who perhaps does not have truly severe asthma, but asthma plus another comorbidity such as reflux, what commonly happens is that inhaled (and sometimes even oral) steroids are stepped up again and again, but with minimal effect. What might appear to be steroid-resistant asthma or brittle asthma, might actually be mild asthma with comorbid additional symptoms, such as chest pain and cough on exertion and/or lying down, confusing the story. In the author's clinical experience, while it can feel frustrating for the patient and family



**FIGURE 2.** Digital Health Passport App (Tiny Medical).

to revisit the history and basics, it can be helpful to consider the clinical picture more objectively.

If the clinician has done so, and also ensured adherence is optimal, therapy can be stepped up in line with BTS/SIGN (2019) guidance, with respect for the referral thresholds indicated (Figure 1).

### EFFECTIVE PREVENTATIVE MEDICINE

There are several routes into effective prevention of deterioration. First and foremost, carrying out asthma reviews at least annually with an effectively structured consultation sets the groundwork to notice subtle signs of worsening asthma control (BTS/SIGN, 2019; NICE, 2021). National guidance outlines key components, namely:

- Measure of symptom control (such as the cACT or ACT)
- Objective measure of airway constriction
- Structured medicines review, including adherence and prescription uptake
- Device technique. (BTS/SIGN, 2019; NICE, 2021)

Sleep hygiene can be a significant factor for some children, especially those who have allergy-driven asthma. In particular, those with house dust mite allergy and allergic rhinitis may require anti-allergy bedding, minimal soft furnishings and additional cleaning measures (Allergy UK, 2023).

Adherence to prescribed therapy is perhaps the most common fallback when it comes to problem-solving poor asthma control (Royal College of Physicians [RCP], 2015). This comes hand-in-hand with sleep hygiene and routine; even in small children establishing preventer use and optimal technique in the daily routine can be helpful to build good habits and the importance of self-management (BTS/SIGN, 2019; NICE, 2021).

Ways to aid adherence include setting alarms on smartphones, keeping the devices themselves (if safe depending on ages of children in the household) somewhere obvious, such as placing by the toothbrush,

## Practice points

Applications that may aid day-to-day practice include:

- Digital Health Passport — personal health record app for CYP (Figure 2)
- Rightbreathe — inhaler prescribing information.

breakfast crockery or even in the child's school shoes can be helpful as visual aids.

For the neurodiverse, and particularly those with conditions such as attention deficit disorder (ADD), where self-care and routine can be difficult, it might be necessary to discuss additional failsafe methods to minimise missed doses. For those young people who truly struggle with routine, once a day preventers or [S]MART regimens where there is one device used as preventer and reliever therapy can help aid control. The latter almost self-titrates in those who have poor memory for medication: each time they feel symptoms and use their device, they are also self-administering a dose of inhaled steroid.

### MANAGEMENT OF EXACERBATIONS

A PAAP reduces a patient's chances of an asthma attack — if they do not have one they are four times more likely to have an attack (Asthma + Lung UK, 2023). Across the UK, the most common PAAP in use is the Asthma + Lung UK plan, which utilises a traffic-light approach to help the young person or carer gauge where they are on the plan:

- **Green** is what they do every day to stay well. They must take their preventer medication 'even when I'm well', and for mild, occasional cough or wheeze there is a box instructing to give two puffs of Salbutamol
- **Amber** means things are deteriorating, but it is not an emergency. Four to six puffs of salbutamol can be given, but the child/young person still needs to be watched, with parents being alert to more symptoms and seek

non-urgent medical attention if the symptoms continue

- **Red** is an emergency and the emergency dose of the inhaler needs to be given.

## DATA AND DIGITAL

While this section of the bundle often brings to mind applications (apps) and shiny digital platforms, the most effective intervention is searching the practice's own data set to identify those patients considered high risk. These children and young people will, by definition, be more likely to have poor asthma control and are at risk of a life-threatening exacerbation (RCP, 2015). These patients can be identified by searching for:

- High reliever prescription issues (over six in the last 12 months = high risk asthma death [RCP, 2015])
- Low preventer prescription uptake
- Courses of oral steroids
- Patients who have missed their annual review or engage poorly
- Patients who report low quality of life or asthma control scores.

One newer application is the NHS Digital Health Passport, a personal health record app for children and young people with long-term conditions (Figure 2). For asthma, it holds the PAAP, air quality and pollution alerts, symptom diaries for health tracking and health hacks.

It allows users with asthma to:

- Access emergency plans
  - Track their progress
  - Alert the user to changes in air quality
  - Remind the user to take their medication
- (Tiny Medical Apps, 2023).

### Useful resources

- Allergy UK podcasts — [www.allergyuk.org/for-healthcare-professionals/allergy-insights/](http://www.allergyuk.org/for-healthcare-professionals/allergy-insights/)
- Mark Levy Podcast
- Healthy London Partnership toolkit — [www.transtransformationpartnersinhealthandcare.nhs.uk](http://www.transtransformationpartnersinhealthandcare.nhs.uk)

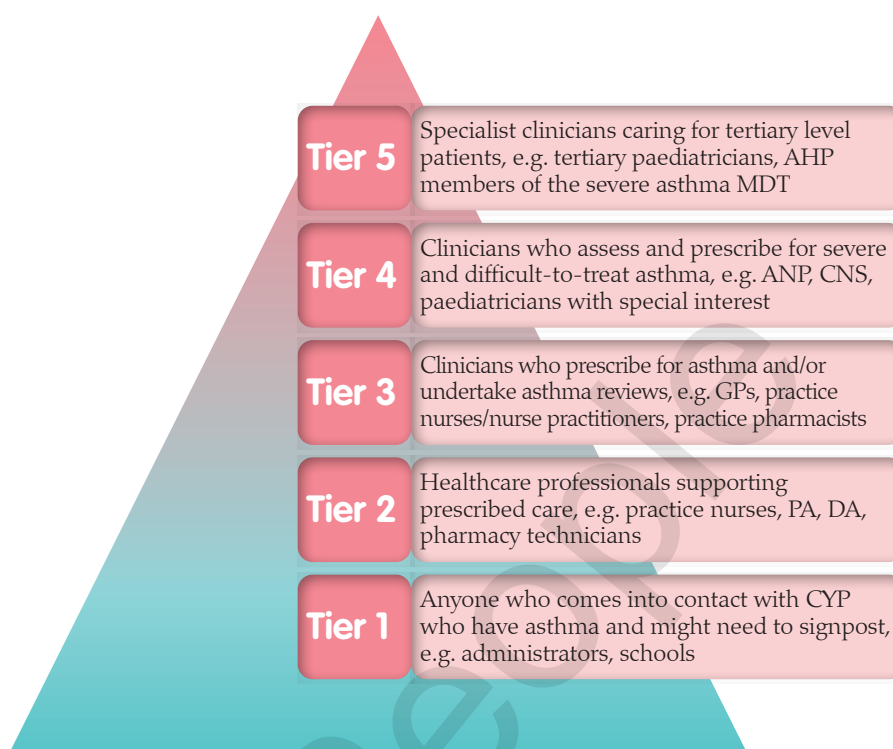


FIGURE 3. Tier training framework (NHS England, 2021).

Primary care clinicians might wish to contact area leads to query whether there are any projects, data searches or templates which other settings or patches are using to aid their asthma work. Templates for health systems such as EMIS are available to aid asthma reviews, so GPNs should use their time effectively and ensure the attainment of QOF points as well as adherence to the bundle. See the resources box for more information.

## CAPABILITIES AND TRAINING NEEDS

One of the most useful aspects of the bundle is the tiered training model, which outlines the training required for asthma dependent on role. There are accredited courses for tiers 1–4 (Figure 3; Useful courses box), which are endorsed by appropriate organisations. Tiers 1, 2 and 3 are also free.

Administrative staff at GP practices should be tier 1 trained, as anyone transcribing clinical codes or taking patient calls that might result in appointments or decisions being made would benefit from a better awareness of asthma as a condition. They should undertake the 'asthma care together' course.

Healthcare professionals supporting prescribed care such as primary care nurses, healthcare assistants (HCAs), physician's associates and other team members who are clinical and providing care for CYP with asthma or wheeze should undertake Health Education England's 'Asthma: Children & Young People' course.

Clinicians who prescribe for asthma, and/or carry out reviews (post-attack and annual) should be trained to tier 3, namely the course provided by BeatAsthma.

Clinicians who assess and prescribe for severe or difficult-to-treat asthma should be trained to tier 4, e.g. the Advancing Paediatric Asthma Care course provided by Rotherham Respiratory (see Useful courses box for the above courses).

There are also plenty of respiratory-focused networks available to join, such as the National Paediatric Respiratory and Allergy Nurses' Group (NPRANG) (Kennedy, 2022).

## CONCLUSION

This two-part series has introduced the national care bundle for children's



asthma, signposted to supporting information and learning, and finally identified ways to implement it in practice. The author hopes that this is helpful not only in practical implementation and in supporting learning for a condition that spans the life cycle, but also for social domains and all spheres of care from the almost-diagnosed preschooler to the complex asthmatic. **GPN**

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## Key points

- The national care bundle for children with asthma is the first phase of a national plan to improve asthma care, focusing on integration of systems and effective communication.
- This article explores practical ways to implement the bundle in clinical practice and how to meet its requirements.
- Early and accurate diagnosis for those who are suspected to have asthma can be life-changing.
- Common asthma mimickers include poorly understood and poorly managed allergic rhinitis, gastro-oesophageal reflux and psychological issues such as anxiety.
- What is often considered severe or perhaps historically called brittle asthma — whether by parents, carers or clinicians — is now quite often found to be more accurately labelled difficult-to-treat asthma.
- A PAAP reduces a patient's chances of an asthma attack — if they do not have one they are four times more likely to have an attack.

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## Useful courses

- **Tier 1: Education for Health (2023) Supporting children & young people's health: improving asthma care together.** Available online: [www.educationforhealth.org/course/supporting-children-and-young-peoples-health-improving-asthma-care-together/](http://www.educationforhealth.org/course/supporting-children-and-young-peoples-health-improving-asthma-care-together/)
- **Tier 2: Health Education England (2023) Asthma: children & young people course.** Available online: [www.e-lfh.org.uk/programmes/children-and-young-peoples-asthma/](http://www.e-lfh.org.uk/programmes/children-and-young-peoples-asthma/)
- **Tier 3: BeatAsthma (2023) Beat Asthma course for healthcare professionals.** Available online: [www.beatasthma.co.uk/courses/](http://www.beatasthma.co.uk/courses/)
- **Tier 4: Rotherham Respiratory — Advancing Paediatric Asthma Care.** Available online: <https://rotherhamrespiratory.com/lungs-courses/advancing-paediatric-asthma-care-course-online/>

# Diabetes digest: NICE guidance for management of type 2 diabetes

Here, Callum Metcalfe-O'Shea, advanced nurse practitioner diabetes specialist and co-chair for the Practice Nurse Diabetes Forum for Norfolk, provides the first in a series of articles with direct insight into the changing practice of diabetes in primary care and how general practice nurses (GPNs) can keep up to date with new evidence. This article looks at new guidance from the National Institute for Health and Care Excellence (NICE) for type 2 diabetes, identifying how the implementation of sodium-glucose co-transporter-2 inhibitors (SGLT-2i) as second-line therapy now takes place and how you can use these guidelines to advance practice. Consideration will be given to SGLT-2i use in practice, while recognising the importance of patient preference and individualised care at all stages.

Keeping up to date with changing new evidence across the many disciplines that general practice nurses (GPNs) are involved in, and then applying to ensure individualised evidence-based patient care can be challenging (Farmer et al, 2021). In the author's clinical experience, this is particularly so for patients with diabetes. With the rise in the number of people with type 2 diabetes, which is attributed to an increase in obesity, metabolic syndrome, and sedentary lifestyles (Lam et al, 2020), all linked to insulin resistance, GPNs should discuss diet and lifestyle recommendations at every opportunity (Lam et al, 2020). However, we are also now experiencing a high diagnosis rate of patients with cardiovascular and renal disease linked to poorly controlled diabetes (Lawson et al, 2021; Moran et al, 2022). Thus, type 2 diabetes management guidance from the National Institute for Health and Care Excellence has changed to reflect this (NICE, 2022).

It is important that GPNs are aware of the guidelines' key changes to provide effective and holistic treatment that covers a wide range of physiological systems (Moran et al, 2022). GPNs are at the forefront of managing diabetes in general practice, and while not all will be independent prescribers, their influence on prescribing practice is crucial. Therefore, GPNs need to remain up to date and aware of current evidence (Whicher et al, 2020).

This article focuses on key differences in oral drug therapies for patients with type 2 diabetes from the

NICE 2015 guidance to the recently updated 2022 version (NICE, 2022).

## WHAT HAS CHANGED FROM THE PREVIOUS GUIDELINES?

Despite major advances in the treatment of diabetes and obesity globally, obesity still remains the modifiable risk factor for cardiovascular disease, increasing insulin resistance, glucose intolerance, inflammation and dyslipidaemia (Piché et al, 2020). NICE (2022) has thus revised guidance to combat this ever-growing issue while helping with blood pressure management and weight loss (Bailey and Bellary, 2022).

The key change in NICE (2022) guidance indicates early use of sodium-glucose co-transporter-2 inhibitors (SGLT-2i) as first- or second-line therapy in combination with metformin, or even first-line if metformin not tolerated (NICE, 2022), particularly in those with established cardiovascular or renal disease (Moran et al, 2022). From reviewing the visual representation of the oral drug treatments from NICE (2022), the emphasis on not only managing hyperglycaemia, but also end-organ damage caused by cardiovascular and renal disease is clear (Moran et al, 2022). This move to implementing a whole systems approach is vital in supporting patients to reduce long-term complications, such as renal and cardiovascular disease (Bailey and Bellary, 2022). In the author's clinical experience, GPNs are well placed to manage this for patients who present with diabetes, no matter

how high their haemoglobin A1c (HbA1c) may be.

The updated NICE recommendations have expanded to include the complicated aspects of cardiovascular and renal disease for patients with diabetes due to the evidence from randomised trials using SGLT-2i (Moran et al, 2022). These changes are important to consider when assessing oral therapies for patients with type 2 diabetes, and GPNs should use the NICE (2022) guidance in line with patient preference to establish a care plan that considers a whole systems approach (Bailey and Bellary, 2022).

## RISK OF CARDIOVASCULAR AND RENAL DISEASE FOR PATIENTS WITH TYPE 2 DIABETES

Although patients with type 2 diabetes are at increased risk of cardiovascular disease, recent randomised trials for the use of SGLT-2i treatment focused on two groups:

- People with established cardiac disease (including coronary heart disease [CHD], acute coronary syndrome, previous myocardial infarction [MI], stable angina, previous coronary or other revascularisation, cerebrovascular disease, ischaemic stroke and transient ischaemic attack, and peripheral arterial disease [PAD])
  - People at greater risk of cardiac disease
- (Moran et al, 2022).

Therefore, it is essential that GPNs are aware of how to assess cardiovascular risk before considering

treatment (Moran et al, 2022). This can be efficiently done using the QRISK<sup>®</sup>2 calculator (NICE, 2022), which is embedded in many clinical systems such as Ardens (Ardens Healthcare Informatics, 2022). Indeed, this tool defines those at risk of cardiovascular disease as:

- QRISK<sup>®</sup>2 cardiovascular risk score >10% in adults aged ≥40 years
- Elevated lifetime risk of cardiovascular disease (defined as the presence of ≥1 cardiovascular risk factor) in someone aged <40 years.

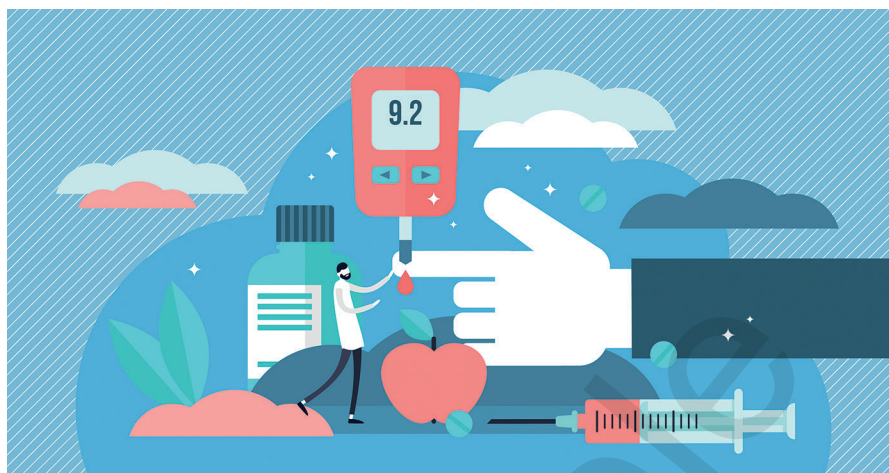
Diabetic kidney disease can be defined as a persistently raised urinary albumin-to-creatinine ratio (ACR) >30mg/g or a consistent reduction in estimated glomerular filtration rate (<60ml/min) over a six-month period (Williams et al, 2020).

Such screening is vital when considering treatment as a GPN, and NICE (2022) demonstrates this importance through its recommendations of oral therapies.

### WHAT IS FIRST-LINE TREATMENT AND HAS THIS CHANGED?

For most patients, metformin still remains the first-line treatment option for type 2 diabetes (NICE, 2022), dependent on patient preference, tolerability and renal function (Moran et al, 2022). This is due to its ability to inhibit hepatic gluconeogenesis, reduce absorption of glucose from the intestines and increase glucose uptake by tissues, as well as its cost effectiveness in the national formulary (Baker et al, 2021).

Linking back to cardiovascular disease, evidence indicates that those with type 2 diabetes are at a two



to four times greater risk of death from cardiac complications than those without diabetes (Baker et al, 2021). Despite the long-standing history of metformin use, there is limited cardiovascular outcome data, although its effects on renal function are known (Baker et al, 2021). However, it is still commonly initiated in patients for type 2 diabetes and should remain part of the 'clinical toolkit' for GPNs when considering oral treatment.

NICE (2022), however, indicates that treatment options are dependent on a variety of factors, including:

- A person's individual clinical circumstances, for example, comorbidities, contraindications, weight, and risks from polypharmacy
- A person's individual preferences and needs
- The effectiveness of the drug in terms of metabolic response and cardiovascular and renal protection
- Safety and tolerability of the drug
- Monitoring requirements
- The licensed indications or combinations available
- Cost (if two drugs in the same class are appropriate, choose the option with the lowest acquisition cost).

Such factors therefore allow GPNs to be flexible in their choice of oral therapy to ensure patient-centred treatment which reduces the risk of long-term complications (Holman et al, 2021).

NICE (2022) goes further by providing a visual summary for its

type 2 diabetes guidance, enabling GPNs to have a quick oversight of what is suitable for patients at any point of management.

From reviewing the above, the focus not only on hyperglycaemia but also cardiovascular risk and kidney function can be seen (Moran et al, 2022). Indeed, if patients present with a high risk of cardiovascular disease, established cardiovascular disease, or kidney function alterations (NICE, 2022), treatment should be tailored dependent on these conditions.

It is clear to see the role that SGLT-2i play within the pathway of diabetes management, and unless contraindicated or not tolerated, they now form most second-line therapy options in the UK (NICE, 2022). However, other medications more common to general practice, including sulphonylureas, pioglitazone and dipeptidyl peptidase-4 (DPP-4) inhibitors, are still available and should be considered as additional or initial treatments dependent on patient preference and presentation (NICE, 2022).

### WHAT ARE SGLT-2i AND WHY SHOULD THEY BE USED?

SGLT-2i are a class of drug that work by inhibiting renal glucose reabsorption in the early proximal tubule, thereby enhancing urinary glucose excretion and lowering the glucose burden (Vallon and Verma, 2021). Evidence indicates their effectiveness in managing hyperglycaemia through inducing a sustained loss of urinary glucose of

### Practice point

Consider your practice's patient population — do you feel that medications with both cardiovascular and renal benefits are useful? Reflect on the ever-changing complexity of your patients and oral therapy treatments.



## Patient story

A 58-year-old female presented at the author's clinic having had type 2 diabetes for over two years, with a current HbA1c of 65mmol/mol. Assessment gathered the following details:

- Her past medical history included type 2 diabetes and hypertension
- She has a family history of type 2 diabetes (mother) and cardiovascular disease (father has coronary artery disease)
- Symptomatic with tiredness and reduced energy
- She was struggling with weight loss and found that, despite diet and exercise, she was not achieving an optimal weight
- Her current medications included metformin 1g twice daily with meals, atorvastatin 20mg, ramipril 2.5mg
- Her current HbA1c was 65mmol/mol, which had increased in six months from 59mmol/mol with an estimated glomerular filtration rate (eGFR) of >80ml/min
- Her blood pressure was 145/85mmHg
- No risks factors for DKA.

Therefore, as per NICE guidance, with her family history of cardiovascular disease and raised HbA1c, the addition of an SGLT-2i was initiated to help with hyperglycaemia, reduction in cardiovascular disease risk, and weight loss. This was empagliflozin 10mg.

After following up in four weeks to ensure tolerance and no side-effects, the patient returned in three months with positive results.

Her HbA1c had reduced to 53mmol/mol alongside further exercise and diet changes, and her energy levels had increased. Her blood pressure also improved to 139/80mmHg. She has continued the medication and is due another review in three months time.

40–80g per day, which in patients with type 2 diabetes decreases HbA1c levels by 0.5–0.7% (Vallon and Thomson, 2017).

However, as mentioned throughout this article, this benefit of managing hyperglycaemia is also supported through cardiovascular and renal disease management (Vallon and Verma, 2021). The link between heart failure and renal disease is closely associated, both clinically and pathophysiologically (Verma et al, 2019). This is due to studies showing that a declining renal function causes volume retention, thus promoting the development and worsening of heart failure (Verma et al, 2019). How SGLT-2i fit into this domain is that this class of drug reduces the physical stress, glomerular stress and renal transport burden of glucose, which improves and preserves renal function and is also important for heart protection

(Vallon and Verma, 2021). These studies demonstrating the clinical effectiveness of the medication are why NICE (2022) has adopted its use as second- or even first-line therapy, depending on individualised patient assessment.

These key findings for this class of drug demonstrate how SGLT-2i are effective in managing a range of patient complications associated with diabetes (Vallon and Verma, 2021), and why they should be considered at any stage of oral therapy initiation or titration (NICE, 2022). Furthermore, this volume depletion helps with weight loss and blood pressure management in combination with other therapies (Moran et al, 2022).

SGLT-2 inhibitors are also called 'flozins' in general practice, and include medications such as:

- Canagliflozin
- Dapagliflozin

- Empagliflozin
- Ertugliflozin.

See Medscapes UK (2022) information for extra-glycaemic indications for SGLT-2i and initiation principles.

NICE (2022) does not recommend any as superior, and the relevant literature and manufacturer guidance should be reviewed before initiation, again depending on patient preference and presentation (Moran et al, 2022).

## WHAT ARE THE RISKS OF USING SGLT-2i?

As with any medication, risk of side-effects can occur, and appropriate patient counselling and information should be given before introducing or changing treatment (Courtenay and Griffiths, 2022). One particular concern that needs to be discussed with all patients for this class of medication is the potential rare complication of diabetic ketoacidosis (DKA) (Moran et al, 2022).

Factors that increase the risk of developing DKA include:

- Alcohol intake above recommended UK thresholds
  - Use of illegal drugs
  - Use of other medicines — loop diuretics
  - Concurrent illness, injury or planned surgery
  - Very low carbohydrate or ketogenic diet
- (Hamblin et al, 2019).

GPNs should be aware of

## Practice point

You have a patient who has recently been diagnosed with type 2 diabetes with a HbA1c of 65mmol/mol and a history of coronary heart disease. They have normal renal function, are on a statin and blood pressure medication (recent blood pressure 140/80mmHg), and want to lose weight. Reflect on how you would use the NICE guidance (2022) and what treatment could be considered.

individual risks and counsel patients accordingly. The need to promote hydration, good genital hygiene and foot surveillance should be reinforced at every opportunity, and it is vital that patients attend their annual reviews for appropriate checks (Hamblin et al, 2019).

Additionally, 'sick day rule' advice should be given to patients on these medications, including signs to look out for, how to seek advice, and when emergency admission or help is required (TREND, 2020).

With this advice, appropriate monitoring and good patient engagement, these risks should remain relatively low and the class of medication can be used effectively (Moran et al, 2022).

## CONCLUSION

Overall, the new changes to the NICE (2022) guidance represent the ever-changing patient population who are developing type 2 diabetes. It is essential that GPNs are aware of and use the guidance as an aid to clinical judgement when initiating oral therapies for patients with type 2 diabetes. While other classes of medications can still be used as first-, second- or third-line therapy in conjunction with diet and lifestyle changes, SGLT-2i provide a positive step in reducing the risk of long-term complications associated with hyperglycaemia, cardiovascular and renal disease.

The second part in this diabetes digest series will look at other therapies for diabetes, focusing on diet and lifestyle for appropriate management. **GPN**

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## Key points

- GPNs are at the forefront of managing diabetes in general practice.
- The new changes to the NICE (2022) guidance represent the ever-changing patient population who are developing type 2 diabetes.
- The updated NICE recommendations have expanded to include the complicated aspects of cardiovascular and renal disease for patients with diabetes.
- It is essential that GPNs are aware of and use the guidance as an aid to clinical judgement when initiating oral therapies for patients with type 2 diabetes.

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

## Limbo Foot Model Now Also On FP10 Prescription

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Leg Circumference (5cm above ankle bone)	Model	PIP Code
20 - 25cm (8-10")	MP20 Small	416-6476
23 - 34cm (9-13")	MP25 Medium to Large	416-6484



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



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

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\*please visit [www.limboproducts.co.uk](http://www.limboproducts.co.uk)



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

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

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

When zinc oxide and ichthammol compounds are combined, improved healing rates may be achieved due to their antioxidant, anti-fungal and anti-bacterial properties<sup>123</sup>.

Restore skin integrity using zinc oxide paste bandages or medicated stocking and help your patients to get on with their daily life.

Viscopaste  
10% Zinc Oxide



Zipzoc  
20% Zinc Oxide

Ichthopaste  
6.32% Zinc Oxide  
2% Ichthammol



**NHS Catalogue**  
Ichthopaste 7.5cm x 6m  
Viscopaste 7.5cm x 6m  
Zipzoc Stocking

**Order Code**  
EFA 051  
EFA 011  
EFA 029

**FP10 Drug Tarrif**  
Ichthopaste 7.5cm x 6m  
Viscopaste 7.5cm x 6m  
Zipzoc Stocking (4's)  
Zipzoc Stocking (10's)

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