



# Scottish **Healthcare** Review

ISSUE 135 - 2022

## **ANTIBIOTIC STEWARDSHIP AND THE HEALTHCARE PROVIDER**

Tackling the rise in  
resistance

### **NEW MAT STANDARDS**

Transforming drug  
treatment in Scotland

### **ASTHMA**

And seasonal allergic  
rhinitis

### **MUSCULAR DYSTROPHY**

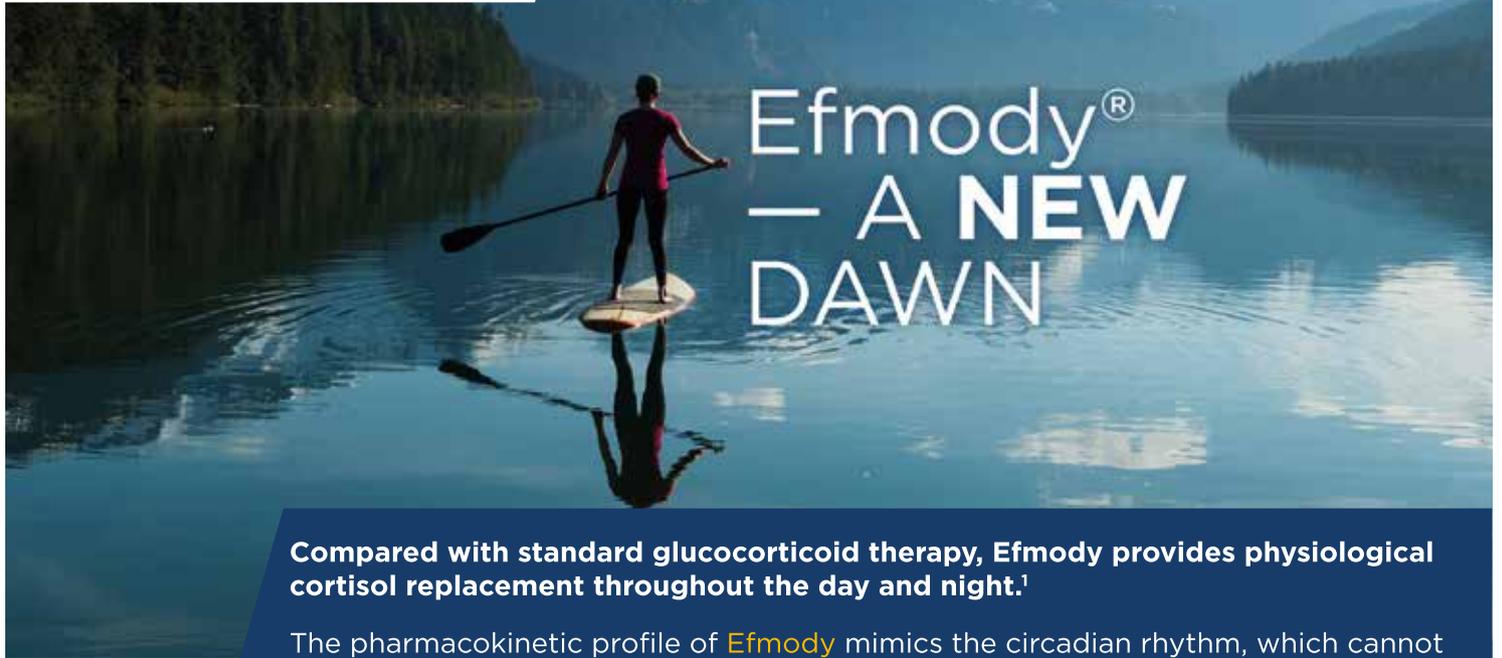
Recovery principles  
for care

### **PAIN MANAGEMENT**

A more open approach?



Hydrocortisone modified-release hard capsules



**Compared with standard glucocorticoid therapy, Efmody provides physiological cortisol replacement throughout the day and night.<sup>1</sup>**

The pharmacokinetic profile of **Efmody** mimics the circadian rhythm, which cannot be achieved with immediate release or long-acting glucocorticoids in **CAH** patients.<sup>2</sup>

**Abbreviated prescribing information for Efmody® 5 mg and 10 mg modified-release hard capsules (hydrocortisone).**

Modified-release hard capsules containing 5 mg and 10 mg of hydrocortisone respectively.

**Indication** Treatment of congenital adrenal hyperplasia (CAH) in adolescents aged 12 years and over and adults. **Dosage** Dosage should be individualised according to response & the lowest possible dose used.  $\frac{2}{3}$  to  $\frac{3}{4}$  of the dose should be given at bedtime and the rest on waking. During excessive stress, it may be necessary to increase the dose of Efmody or add additional hydrocortisone as oral or parenteral treatment. **Contraindications** Hypersensitivity to the active substance or any of the excipients. **Warnings and precautions** Patients should be advised of symptoms of acute adrenal insufficiency and adrenal crisis and the need to seek immediate medical attention. Sudden discontinuation of therapy risks adrenal crisis and death. During adrenal crisis parenteral hydrocortisone in high doses should be administered according to current guidelines. Infection should be taken seriously and an increase in steroid dose initiated, and expert advice sought early. Efmody is not recommended in patients with increased

gastrointestinal motility. No data are available in patients with reduced gastrointestinal motility. Impaired glucose tolerance, growth retardation, early sexual maturation, diabetes and reduced bone mineral density may occur with long term use of corticosteroids. Excessive weight gain, decreased height velocity or symptoms of Cushing syndrome indicate excessive glucocorticoid treatment. Children should be assessed frequently and their dose adjusted according to individual response. Visual disturbances have been reported in patients receiving oral corticosteroids. Should this occur, consult an ophthalmologist. **Interactions** Hydrocortisone is metabolised by cytochrome P450 3A4 (CYP3A4). Concomitant administration of medicinal products or foodstuffs inhibiting or inducing CYP3A4 may require dose adjustment of Efmody and close monitoring. **Fertility, pregnancy and lactation** Hydrocortisone for replacement therapy can be used during pregnancy and breast feeding. No data are available for any effect on fertility. **Ability to drive and use machines** Efmody has minor influence on ability to drive and use machines. **Adverse Events** The commonest adverse events in the trial programme were fatigue, headache, increased appetite, dizziness and increased weight. The most common serious adverse event was acute adrenal insufficiency.

**Legal Classification: POM**

Product (50 capsule bottle)	Basic NHS Cost	MA Number
Efmody 5 mg modified-release hard capsules	£135.00	PLGB 50616/0011 EU/1/21/1549/001
Efmody 10 mg modified-release hard capsules	£270.00	PLGB 50616/0012 EU/1/21/1549/002

**Marketing Authorisation Holder**

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Prescribers should refer to summary of product characteristics for full prescribing information.

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2. [https://www.ema.europa.eu/en/documents/assessment-report/efmody-epar-public-assessment-report\\_en.pdf](https://www.ema.europa.eu/en/documents/assessment-report/efmody-epar-public-assessment-report_en.pdf)  
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# SHR

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# WELCOME

## EDITOR'S LETTER

Welcome to the latest edition of Scottish Healthcare Review!

The hour change has not only paved the way for lighter evenings (and temporary confusion), but brighter spirits too. Everywhere I turn, plans are being crafted for the summer – from road trips and luxury retreats, to camping site stays and holidays abroad. I've allowed myself to get swept up in the excitement too, spending my commutes reminiscing about my holidays in the sun of years gone by. How the first thing my brothers and I would do upon arrival to any hotel was race to the edge of the pool and jump in – not pausing once to consider our surroundings nor disapproving stares.

As we get older, this act of diving deep straight-off seems less common. Even just last week, I met up with my cousin – one of my favourite people – but I quickly realised that our conversation was littered with what can only be described as 'niceties'. We were merely skimming the surface, and giving one another the robotic responses which society has made us accustomed to. I had to give myself a shake, break off the topic, and ask 'How are you REALLY doing?'. The conversation then turned into one that mattered to us both.

It's still as important as ever to bravely aim beneath the surface – not just in how we engage with others, but in our ambitions, identification of what really matters, and pursuit of change. It's a theme that you'll see running through this edition of SHR as our contributors dig deep. The Scottish Drugs Forum delve into why the new Medication-Assisted Treatment Standards are a welcomed addition for drug treatment in Scotland (page 10), and Anne Wilson, Head of Development at Children's Health Scotland, advises on the importance of listening and responding to the worries of children about war (page seven). Professor Colin Garner of Antibiotic Research UK highlights the profession's key role in antibiotic stewardship too (page nine).

This issue's patient stories are a stark reality check too – from the true extent of sepsis' challenges (page 20), to the lived experience of Parkinson's during the pandemic (page 18), and the deepening ovarian cancer crisis (page 40).

Before you go, don't forget to find out more about the future of neuromuscular care in Scotland (page six).

Happy reading!



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# Royal Pharmaceutical Society

## Members' hub

We are thrilled to have launched our brand-new Members' hub at our office at 44 Melville Street, Edinburgh.

RPS Members can:

- Work at a hot desk
- Meet colleagues on a 1:1 basis
- Book one of our rooms for larger meetings

Book a hot desk online (for free) at:  
<https://www.rpharms.com/scotland/scotland-members-hub>

Book a meeting room by phoning 0131 556 4386  
or emailing: [scotinfo@rpharms.com](mailto:scotinfo@rpharms.com)



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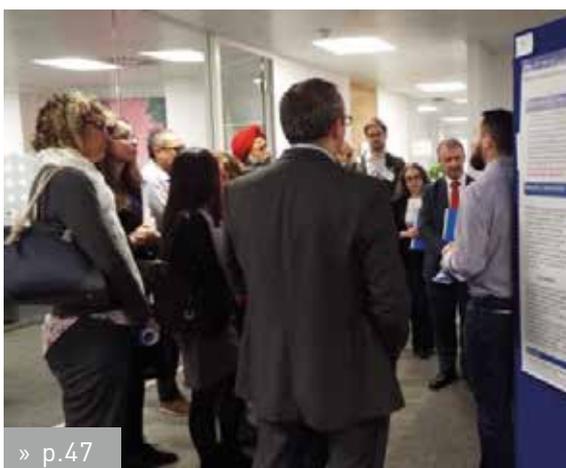
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# THE ROAD TO IMPROVEMENT

From promoting the profession, to championing the safe and effective use of medicines, the Royal Pharmaceutical Society Scotland have been imprinting their mark on the wider healthcare arena. What have been some of the latest momentum-building moves?



Clare Morrison

## HEALTHCARE PROFESSIONS JOIN FORCES ON SUSTAINABILITY

Healthcare professionals from across Scotland met recently to discuss the environmental impact of prescribing and explore how prescribers can support NHS Scotland's target to achieve net zero by 2040.

Medicines account for around 25 per cent of carbon emissions in the NHS. If Scotland is to achieve net zero, strategies for reducing carbon emissions from prescribing and medicines waste need to be tackled.

The Royal Pharmaceutical Society (RPS) Scotland and the Academy of Medical Royal Colleges and Faculties in Scotland brought together healthcare leaders to discuss how everyone can work together to make prescribing more environmentally sustainable.

A representative of every healthcare profession who prescribe medicines was invited to the meeting, including GPs, hospital doctors, pharmacists, nurses and allied health professionals.

At the meeting, key strategies to work in a more sustainable way were discussed, including:

- How to prescribe more sustainably, by ensuring that information about the environmental impact of medicines is available for prescribers and patients to encourage use of medicines which have a lower carbon footprint, such as low carbon inhalers
- How to reduce medicines waste through regular medication reviews and improving repeat prescription ordering systems, as well as ensuring that waste medicines are disposed of safely
- How patients, healthcare professionals and politicians can think more dynamically about healthcare and reducing reliance on prescribing by involving patients in decisions

# ROYAL PHARMACEUTICAL SOCIETY

about whether to take a medicine or consider a clinically suitable alternative, such as exercise or activity programmes

It's important to note that all prescribing decisions must be made on an individual basis in consultation with the patient, to ensure that decisions are clinically appropriate and right for the patient, in line with the principles of Realistic Medicine.

Speaking about the roundtable discussion, Clare Morrison, RPS Director for Scotland, said, 'Climate change is everyone's responsibility. As prescribing healthcare professionals, we are very aware of the significant responsibilities we have in achieving net zero, both within the NHS and across society.

'I'm proud of the leading role RPS is playing together with our colleagues from Scottish Academy of Medical Royal Colleges, to bring together healthcare professionals from across Scotland to discuss this very important issue.

'Clinicians being more mindful about the prescribing process will not only benefit the environment, but also patients, as a key part of this is ensuring that we're always thinking about how we prescribe in a patient-centred way that will enhance each patient's outcomes.'

Dr David Shackles, Joint Chair of the Royal College of General Practitioners Scotland, added, 'On behalf of the Academy of Medical Royal Colleges and Faculties in Scotland, I am delighted to help bring together colleagues from across healthcare in Scotland to explore how we can help reduce the carbon footprint of our NHS. Reducing the environmental impact of prescribing is incredibly important if we are to reach net zero and as prescribers, we all have a role to play in helping to achieve this.

'Bringing together healthcare leaders to explore this issue is a landmark step. I very much look forward to the discussions and crucially, building on areas of progress to ensure we can work together and alongside policymakers to achieve the very best outcomes for the health of our patients and the planet.'

## PHARMACY CAN DELIVER EVEN MORE

Clare Morrison has also provided evidence to the Scottish parliament's Health, Social Care and Sport Committee as part of their alternative pathways into primary care inquiry.

Pharmacy already provides various alternative pathways into primary care through community pharmacy services, pharmacists working in GP practices, and specialist pharmacy services in community settings.

In the evidence session, Clare Morrison highlighted that pharmacists have the ability to deliver more in primary care, but that to realise this, the following needs to happen:

- There needs to be proper workforce planning for pharmacy teams (in the same way there is for doctors and nurses). This should include investment in more pharmacy technicians and pharmacy support

workers who will release pharmacists' capacity to expand their roles into areas such as: advising on medicines, acting as a first port-of-call for common clinical conditions and ensuring that medicines are safe and effective

- Training places for independent prescribing should be expanded, so that by 2030 most pharmacists can prescribe, which will improve quality and accessibility of care for patients
- There should be investment in digital technologies, such as electronic prescribing and a single shared patient record, to improve patient experience, quality, and safety

During the evidence session, Clare Morrison highlighted a recent Ipsos MORI survey of 1,107 adults in Scotland showing very clear public support for the professional roles of pharmacists:

- 95 per cent of people support pharmacists advising on medicines
- 87 per cent of people think that it's important that pharmacists prescribe medicines
- 89 per cent of people think that pharmacists should be the first port-of-call for common clinical conditions
- 81 per cent think that pharmacists should be monitoring, reviewing and adjusting medicine for long-term conditions.

Commenting on the evidence session, Clare Morrison said, 'Pharmacy already delivers so much within primary care across a variety of settings, including GP practices, community pharmacies and specialist pharmacy services in community settings.

'Pharmacy teams have the potential to be delivering even more, but to do this, it is vital that there is investment in areas such as independent prescribing, getting the right skillmix across pharmacy teams and the introduction of new digital technologies like electronic prescribing and a shared patient record.'



**ROYAL  
PHARMACEUTICAL  
SOCIETY**

## MUSCULAR DYSTROPHY

# THE FUTURE OF NEUROMUSCULAR CARE IN SCOTLAND



### How can health services be improved to support people living with muscle-wasting conditions?

Across the UK, there are around 110,000 people living with a muscle-wasting condition. These are rare and complex conditions that carry a multitude of serious health complications, meaning that it's vital that well-co-ordinated multidisciplinary health and social care is in place.

Muscular Dystrophy UK recognised that the COVID-19 pandemic was widening many pre-existing gaps in care, so undertook detailed research among its community. The charity then produced four reports that highlighted how the pandemic had affected those living with muscle-wasting conditions. The reports were called, 'Shining a Light on the Impact of COVID-19' and, as well as producing a UK-wide version, the charity also wrote one for each of the three devolved nations.

Most importantly, each of these reports included tailored recommendations on how care for people living with muscle-wasting conditions can be improved in the future. This is because it's essential that people living with a muscle-wasting condition have access to specialist healthcare, regular exercise, daily essentials, care packages, family support systems and physiotherapy to lead safe and healthy lives.

### STRIDES TOWARDS STRENGTHENING CARE

In January, the charity presented its Scotland report before the Cross-Party Parliamentary Group on Muscular Dystrophy. The report highlighted priority areas to strengthen neuromuscular care going forwards.

In Scotland, there has been a range of challenges in neuromuscular care provision over the years due to a lack of care co-ordination and stretched staff capacity.

During the meeting, Muscular Dystrophy UK shared testimony from families about delays to accessing critical appointments, the impact on their mental health of not seeing their family and carers while shielding, and the loss of mobility and muscle weakness due to being unable to exercise. The charity also reported the experiences of neuromuscular clinical teams and the impact of the pandemic on staffing, service gaps, access to appointments and treatments.

The report revealed that, while neuromuscular staff go above and beyond to co-ordinate care and ensure that everyone has specialist access, over the years there has been little investment to increase staffing numbers, particularly outside of the central belt of Glasgow. This issue has been greatly exacerbated over the past two years and must be addressed. The social care system has also been impacted amid the pandemic, and there is deep concern that it will take years to recover which will severely impact the quality of care that people living with muscle-wasting conditions receive.

### RECOVERY PRINCIPLES

During the meeting, Muscular Dystrophy UK outlined core recovery principles. These are:

- Increased investment in the national neuromuscular teams with more neuromuscular consultant, physiotherapy, nurse specialist and psychology time
- Appointing a full-time network manager with administration support for the Scottish Muscle Network
- Reduce waiting lists, address the growing backlog of new and follow-up appointments by implementing virtual outreach clinics in local areas
- Consider flexibilities into the yearly growth of block contracts to reflect the growing neuromuscular population and increase in complex care needs

*You can read the report in full at [www.muscular dystrophyuk.org](http://www.muscular dystrophyuk.org).*

### WHAT'S NEXT?

Since presenting its findings before the Scottish Cross-Party Group, Muscular Dystrophy UK responded to an inquiry from the Scottish Cross-Party Group on Mental Health, highlighting the psychological impact that the pandemic has had on those with underlying health conditions. The charity also met with the Scottish government to discuss the need to strengthen the neuromuscular workforce and improve provision of psychological support for people with muscle-wasting conditions.

Michaela Regan, Head of Policy and Campaigns at the charity, said, 'Many services, including specialist neuromuscular service referrals and diagnostics were halted or significantly reduced throughout the pandemic, leaving people in Scotland with delayed diagnosis and no access to expert care. Consequently, many living with these conditions have been unable to receive the full treatment and care they need and are at severe risk of faster progression of their conditions. Muscular Dystrophy UK urges stakeholders in Scotland to implement the recommendations from our report to ensure people with a muscle-wasting condition receive the care they need to improve overall health outcomes and quality of life as we continue to navigate a post-pandemic era.'

### ABOUT MUSCULAR DYSTROPHY UK

Muscular Dystrophy UK is a charity that brings individuals, families and professionals together to help fight muscle-wasting conditions. It offers practical and emotional support for the 110,000 people with a muscle-wasting condition and their families at every stage, and funds vital research into the conditions. The charity also co-chairs Changing Places, which leads the campaign for fully-accessible toilets.

*For more information about the work that Muscular Dystrophy UK does, visit [www.muscular dystrophyuk.org](http://www.muscular dystrophyuk.org).*

# CHILDREN'S HEALTH SCOTLAND



## THE WEIGHT OF THE WORLD



As harrowing reports and images of the reality of the war in Ukraine escalate, parents are having to carefully navigate the concerns of their kids. To help, Anne Wilson, Head of Development at Children's Health Scotland, advises on the importance of listening and responding to the worries of children about war.



Anne Wilson

Our daily news is now full of violent images, threats and foreboding news regarding the war in Ukraine. As a result, universal awareness of childhood adversity is spreading like wildfires as we watch the emotionally devastating images of children driven from their homes. As parents, carers and health professionals within the early years sector, our thoughts lie with the children and young people of

Ukraine and their families. Then they turn very quickly to our own children who we love and support.

As much as we want to protect our children from news, to prolong the innocence and optimism of youth, there's no bubble that can withstand 24-hour news reports, social media notifications and playground chatter. Of course, we can't control everything they hear but in the absence of the truth they might piece snippets together and create their own narrative.

Therefore, it is important to keep asking our children what they are hearing, their worries, and how they are feeling, while listening to their responses. Try to validate feelings and remember that none of us like to be told to calm down or to stop worrying. We are talking about the feelings of children which are very real so being allowed to express them helps them to feel understood. With the situation in Ukraine, and the possibility of a major European war and even the threat of nuclear war, children are asking questions, such as:

- Will the war come here?
- Why aren't people doing more?
- What will happen to us?
- How will we stay safe?

Quite frankly these are questions that most adults will struggle to answer, as we simply do not know, yet it is important to acknowledge them and provide a safe space for children to ask them and share

# CHILDREN'S HEALTH SCOTLAND

fears.

Even if we set aside the personal worry children may have about what might happen to them and their families and friends, they may be worrying about other children and young people in Ukraine and the indescribably hurtful things that are happening to them. If they put themselves in their shoes, they will of course be sad and anxious, and this response will be far more complex and concerning in children who are already affected by childhood trauma. For example, for some care experienced children and young people, what is happening in Ukraine may cause them more extreme fear and alarm as they are reminded of their own early childhood experiences. They need us to be mindful of this resurfacing trauma and to offer them help and support.

As adults we may find ourselves desperately wanting to do something for Ukraine – anything rather than standing powerless on the sidelines with nothing to do but worry. But as we can't influence the political situation, what can we and our children and young people do?

The very first and most important thing we can do to help our children and young people is to let them see that we are not overwhelmed by worry and anxiety about the situation and that we are in control of ourselves at least. It is like putting on our own oxygen mask in an emergency so that we are then able to help others. Remember your children will take their cue from you. Are you modelling a calm and measured attitude? Open conversations will help to deal with exaggerations and hysteria that may develop and remember that children are like little sponges who absorb the mood of the room or whispered conversations. They will mirror how you are feeling so it is important to embrace active listening which involves giving children our full attention and repeating back what they have said to ensure that we understand their point of view. How we respond will obviously depend on their age and emotional maturity but always try to be honest and reassuring at the appropriate level.

## SOME DOS AND DON'TS

- Don't lecture them – find out where they are in their thinking and understanding of the situation. This will of course vary for different ages and stages
- No news is not good news! Don't take silence to mean there are no worries. Check in with them and invite them to share what they are thinking and worrying about with you
- They might be shielding / protecting you if they sense you are worried. So, sit down together and share things. Be honest with them but in a measured and controlled way
- Accept that you won't have all the answers but get informed together with your children. (BBC Newsround is really good for this)
- Let them know that they are not alone, and it is okay to have these worrying feelings. There is a really good video from Newsround – if you are upset by the news – that is worth watching. It focuses on talking and sharing worries with a trusted adult
- Last thing before you go to sleep, think of three things which make you feel happy or three good things which have happened in the day. For example, the car started first thing, a friend sent you an Easter card, you had a lovely lunch with a friend

## SUPPORTING HEALTH AND WELLBEING

There are some really good resources which can help support health

alongside your young person and put them in the driving seat? (See references at the end)

## FIVE WAYS TO WELLBEING

- You will have heard of your five-a-day, well this is something similar you can do for your mental health and wellbeing, especially in relation to the Ukraine situation. You could also turn it into an activity to do with your children. Think of an activity you can do for each of the five ways. You can find an example on pages 12 and 13 of our spring magazine: [www.childrenshealthscotland.org/the-exciting-spring-2022-edition-of-our-magazine-is-now-available-online](http://www.childrenshealthscotland.org/the-exciting-spring-2022-edition-of-our-magazine-is-now-available-online)
- **Connect:** Talk to your friends and family or reach out to someone you don't know very well in your class or maybe a refugee from the war
  - **Give:** Give your time to help in your local community, a charity, your church, or your school. You can give money you have raised to support Ukraine or clothes and supplies. (For more ideas, see the references section)
  - **Take Notice:** Try to notice what is going on in your local community or school. How are other people feeling? Can you give them a smile?
  - **Keep Learning:** Use BBC Newsround or other outlets to keep yourself informed and up to speed on what is going on – not too much though and beware of fake news!
  - **Be Active:** Run, cycle, or bake to raise money for Ukraine or for a charity that supports the health and wellbeing of children and young people. We would welcome your support: [www.childrenshealthscotland.org/how-you-can-help/fundraise-or-donate](http://www.childrenshealthscotland.org/how-you-can-help/fundraise-or-donate)

## REFERENCES

- Parent Club – [www.parentclub.scot/articles/talking-your-child-about-current-events](http://www.parentclub.scot/articles/talking-your-child-about-current-events)
- BBC Newsround – [www.bbc.co.uk/newsround#more-stories-2](http://www.bbc.co.uk/newsround#more-stories-2)
- Scary world news – [www.mentalhealth.org.uk/publications/talking-to-your-children-scary-world-news](http://www.mentalhealth.org.uk/publications/talking-to-your-children-scary-world-news)
- How to talk to your children about conflict and war – [www.unicef.org/parenting/how-talk-your-children-about-conflict-and-war#R265811-a42F6BA7-3GHF3KEM](http://www.unicef.org/parenting/how-talk-your-children-about-conflict-and-war#R265811-a42F6BA7-3GHF3KEM)
- Advice if you are upset by the news – [www.bbc.co.uk/newsround/13865002](http://www.bbc.co.uk/newsround/13865002)
- What can people in the UK do to help? – [www.bbc.co.uk/newsround/60619050](http://www.bbc.co.uk/newsround/60619050)
- Parenting leaflet for families fleeing war – a small team of psychologists based at the University of Manchester have produced a parenting leaflet which they're distributing to families fleeing the war in Ukraine

## ABOUT CHILDREN'S HEALTH SCOTLAND

Children's Health Scotland are the leading Scottish children's healthcare charity, first founded in 1961 as Mother Care for Children in Hospital. The health and wellbeing of children and young people lies at the heart of their work. They deliver health and wellbeing services directly to children and young people and are the only charity dedicated to informing, promoting, and campaigning on behalf of the needs and rights of all children and young people with health conditions.

For more information, visit [www.childrenshealthscotland.org](http://www.childrenshealthscotland.org).

## ANTIBIOTIC RESISTANCE

## ANTIBIOTIC RESISTANCE AND THE HEALTHCARE PROVIDER: HELP IS AT HAND

Professor Colin Garner, CEO and founder of Antibiotic Research UK, updates us on the current state of play of antibiotic resistance, in addition to the sector's contribution to antibiotic stewardship – particularly in helping their patients navigate a responsible way forward.



Professor Colin Garner

Antibiotic resistance is on the rise around the world. Bacteria are becoming resistant to antibiotics, resulting in infections that can no longer be treated with the drugs available. New research published in January 2022 in the Lancet confirms what public health experts have long known: the overuse of antibiotics risks making the drugs useless. The researchers reported that about five million deaths were associated with bacterial antimicrobial resistance in 2019. 1.27 million of these deaths were directly attributable to bacterial antimicrobial resistance. Antimicrobial resistance kills more people annually than either AIDS or malaria, and the numbers of deaths are rising.

Despite the real and immediate global health risk posed by antimicrobial resistance, the devastating reality is that we do not have enough new antibiotics under development to tackle the rise in resistance.

### HEALTHCARE PROVIDERS AND THEIR KEY ROLE IN ANTIBIOTIC STEWARDSHIP

Solutions will need to come from many sectors, and healthcare providers have an important role to play. Healthcare providers need to ensure that they are using existing

antibiotics judiciously and advising patients wisely so that future generations – our children and grandchildren – will have the benefits of antibiotics that current generations have relied on to keep common infections from turning deadly. Antibiotic stewardship to keep our current antibiotics working is an important component of antibiotic use since resistance is driven by antibiotic mis- or overuse.

Striking the balance between providing enough information and not overwhelming patients can be tricky. Please know that Antibiotic Research UK – the charity for which I am the CEO and founder – has resources to help both healthcare practitioners and patients. In fact, Antibiotic Research UK provides the only Patient Support Service ([www.antibioticresearch.org.uk/patient-support/find-support](http://www.antibioticresearch.org.uk/patient-support/find-support)) specifically for people with antibiotic-resistant infections.

Our general advice to healthcare providers is to start by explaining bacteria, infections and antibiotics in simple terms. As you know, many patients don't know the difference between bacterial and other infections. Then, talk about how bacteria become resistant to antibiotics due to their incorrect use.

### DIFFERENT CONVERSATIONS FOR DIFFERENT PATIENTS

The best way to raise awareness of the importance of using antibiotics responsibly is to be prepared for conversations from all kinds of patients:

- Some patients may not have been prescribed antibiotics when they expected them. Explain that by not taking antibiotics for things they do not work for, they are helping to keep them working when we need them most
- Patients who are frequently prescribed antibiotics might want to know more about preventing resistance. You can talk to them about completing the course, not sharing antibiotics, and disposing of unused antibiotics through the pharmacy
- Patients who have recurrent infection can be encouraged to talk to their GP about



treatment options. You can also tell them to contact our Patient Support Service if they need support, or information about bacterial infections

Also, consider giving a delayed prescription, which has been found to be a safe and effective strategy for most patients. <BMJ 2021;373:n808>

### OUR PATIENT SUPPORT TEAM OFFERS ONE-TO-ONE SUPPORT

We know healthcare providers are already juggling so many things. We are here to help.

The patients supported through the charity tell us time and again that they didn't know where to turn for information. Sharon, for example, had sepsis twice due to a resistant urinary tract infection.

'I was left in an isolated room with all these questions. I really wanted someone to sit down and explain what it all meant, and what it means for my future,' Sharon told our Patient Support Team at Antibiotic Research UK.

### ABOUT ANTIBIOTIC RESEARCH UK

Antibiotic Research UK offers one-to-one help through a confidential phone and email service. We also offer online patient support groups to meet other sufferers. We can answer their general questions, help patients work out what they want to ask healthcare professionals, and provide ongoing support during this difficult time. We do not offer medical advice. Please tell patients and your colleagues that they can find information at [www.antibioticresearch.org.uk/PatientSupport](http://www.antibioticresearch.org.uk/PatientSupport).

We also have a range of leaflets that you can print and share with your patients, such as 'Antibiotic-Resistant Infections; Are you at Risk?'. Use the QR code below, or find them at [www.antibioticresearch.org.uk/resources](http://www.antibioticresearch.org.uk/resources).



# SCOTTISH DRUGS FORUM

## SETTING THE STANDARD

**New standards in the treatment and care of people who have a drug problem promise to transform drug treatment in Scotland. The new Medication-Assisted Treatment Standards came into force in April and are being implemented across the country.**



David Liddell

In Scotland medication-assisted treatment (MAT) is chiefly focussed on opiate substitution and the prescription of methadone or a preparation of buprenorphine but the standards apply to any such substitution – heroin-assisted treatment, for example or for the prescription of benzodiazepine to replace the use of ‘street valium’.

David Liddell, CEO of Scottish Drugs Forum, a national charity and membership organisation that serves as a national

resource of expertise on drug issues, has welcomed the introduction of MAT Standards, stating, ‘The standards represent the most fundamental change in treatment in over 20 years. Historically, there have been issues with both the quality and consistency of service provision in Scotland. The source of a lot of the issues has been the marginalisation and vulnerability of patients who are in MAT. The standards implicitly acknowledge this and go some way to addressing the core issues.’

There are 10 standards. Standards one-to-five deal with the quality of treatment services and their accessibility. Standards six-to-10 address issues in the wider treatment system. They offer an opportunity to deliver the quality of treatment and care laid out in previous attempts to improve services: The National Care Standards (2002), The Quality Principles: Standard Expectations of Care and Support in Drug and Alcohol Services (2014), Drug Misuse and Dependence: UK Guidelines on Clinical Management (2017).

Liddell views the standards as better designed and more likely to succeed than previous attempts to address the issue of improving services: ‘The fundamentals have been laid out previously. For example, there has been an acknowledgement of the importance of a patient-centred approach and the importance of dignity and realising potential, but the new standards lay out more tangible and measurable changes than previously.’

‘Fundamental weaknesses in the current system are addressed – no longer will people have a delayed start to treatment. Presently, some very vulnerable and sometimes desperate people are being held for weeks before being prescribed medication. Presently, some people with significant mental health issues are being excluded from mental health treatment because they are in MAT for drug dependency. Presently, people in MAT often report that they have little or no choice of medication or of the dose they are on. And of course, people are too often pushed or allowed to drop out of treatment which contributes to the low numbers of people who could benefit from treatment actually being in treatment. This means we fail to protect people from overdose deaths.’

‘The broadest aim of treatment is to empower people. The details of that empowerment will vary from patient-to-

-patient and change for individuals as they progress in treatment. But there is a need to acknowledge the disempowerment experienced by people and the relative power of service providers. Having a real choice of medication, and of dosing, will be a huge innovation in many services. Patients defining the immediate aims and priorities of their treatment is crucial. For many people the key to this will be in the right to advocacy laid out on standard eight.

‘From a community pharmacy perspective, over time we can envisage a broader range of medication and a more flexible treatment regimen in terms of supervision. With empowerment people may have higher expectations of service that can be articulated by patients, and between services, and so closer joint working between services and a therapeutic alliance with patients will evolve.’

### THE NEW MAT STANDARDS

1. All people accessing services have the option to start MAT from the same day of presentation
2. All people are supported to make an informed choice on what medication to use for MAT, and the appropriate dose
3. All people at high risk of drug-related harm are proactively identified and offered support to commence or continue MAT
4. All people are offered evidence-based harm reduction at the point of MAT delivery
5. All people will receive support to remain in treatment for as long as requested
6. The system that provides MAT is psychologically informed (tier one); routinely delivers evidence-based low intensity psychosocial interventions (tier two); and supports individuals to grow social networks
7. All people have the option of MAT shared with primary care
8. All people have access to advocacy and support for housing, welfare, and income needs
9. All people with co-occurring drug use and mental health difficulties can receive mental healthcare at the point of MAT delivery
10. All people receive trauma-informed care



# Carrying naloxone is easier than carrying a mate's coffin.

Naloxone can help reverse an opioid overdose. So if you use opioids or know someone at risk of an overdose, don't wait. Speak to your local drug service centre about getting a free kit.

**Carry  
naloxone.**  
It could help  
save a life.

Opioid overdoses kill thousands every year in the UK.<sup>1</sup> But those deaths could have been prevented – with naloxone. It's a drug that can help reverse an opioid overdose and help save lives. Signs of an opioid overdose include pinpoint pupils, unconsciousness, or breathing problems. Always call an ambulance first if you think someone is having an opioid overdose. For more information, go to [naloxone.org.uk](http://naloxone.org.uk). This campaign is sponsored by Ethypharm and made in conjunction with real naloxone carriers.

LEE  
NOTTINGHAM

# NHS SCOTLAND RECRUITMENT BOOST

Scottish health boards have recruited more than 1,000 additional healthcare support staff and almost 200 registered nurses from overseas to help address the unprecedented challenges facing the NHS.

The support staff recruitment drive, backed by £15 million, was launched by Health Secretary Humza Yousaf last October. The new employees will be working in a variety of roles, both in acute hospitals and in community health teams.

Under a separate £4.5 million initiative, offers of employment have been signed with 191 nurses from countries including India and the Philippines, with some already arrived and in posts in hospitals across the country, while agreements are in place with recruitment agencies for a further 203. The figure is likely to increase significantly over the coming months as boards take advantage of new infrastructure for employing qualified international staff.

All international recruitment is in line with the Scottish Code of Practice for health and social care personnel, which demonstrates Scotland's commitment to ethical recruitment to protect the healthcare systems of developing countries.

Health Secretary Humza Yousaf explained, 'The pandemic has been the biggest shock our NHS has faced in its 73-year existence. To help deal with winter pressures and pressure brought on by the current COVID wave we are expanding and investing in our NHS workforce.'

'Our hardworking and compassionate health and social care staff have been on the frontline of patient care throughout the pandemic and I am incredibly grateful to them all.'



## RISK OF DEMENTIA IN FORMER FOOTBALLERS TO BE STUDIED

A new research study is to investigate ways to reduce the risk of dementia in former professional footballers.

The four-year BrainHOPE project will use brain imaging and a range of tests to compare brain health in mid-life former footballers with members of the general population.

This new study builds on the FIELD study, which found that the risk of dementia and related disorders among former professional footballers was around three-and-a-half times higher than expected.

BrainHOPE also involves the PREVENT dementia study, which aims to identify risk factors for dementia in mid-life. It has recently opened up to individuals who have played elite or professional rugby and football, to investigate whether there are any increased risks of developing dementia after having played these sports.

The new project is a collaboration between the Universities of Glasgow and Edinburgh, Imperial College London and the wider PREVENT Dementia research partners, which has received £1.3 million of funding from the Football Association and FIFA.

Professor Craig Ritchie, BrainHOPE co-lead, Chair of the Psychiatry of Ageing, Director of Edinburgh Dementia Prevention at the University of Edinburgh, and lead on the PREVENT Dementia Programme, explained, 'This is such an important study aligned to the main PREVENT Dementia Programme and solidifies an exceptionally strong academic collaboration between the Universities of Edinburgh and Glasgow and Imperial College London. This work will help us understand in detail the association between playing football and brain health and in doing so have a great impact on the wellbeing of current and retired players.'

Researchers will explore whether footballers' brain health might benefit from using techniques designed to try and reduce the risk of dementia. BrainHOPE will recruit 120 former professional footballers aged 40-to-59 years old to compare against 700 general population controls. The team will conduct brain scans and tests with the footballers after two years to explore how effective the management of risk factors has been.

## INCREASE IN INDEPENDENT PRESCRIBING TRAINING FOR PHARMACISTS ADDRESSES SERVICE DEMAND

The largest ever cohort of pharmacists will undertake the practice certificate in independent prescribing in 2022. As a result of increased service demand NHS Education for Scotland is funding a total of 186 additional places. These will go to community, hospital and primary care pharmacists working in Scotland who were already on the 2021 / 2022 waiting list.

The increase supplements 244 places funded in 2021 / 2022 and supports the ambitions of pharmacy in Scotland across all sectors. The Dundee Clinical Skills Collaborative will provide additional consultation and clinical assessment skills to enhance the training.

These initiatives will support the delivery of:

- The NHS Pharmacy First Plus service in community pharmacy
- Pharmacist-led clinics in primary care as part of the pharmacotherapy service
- Inpatient and outpatient prescribing in secondary care

Professor Alison Strath, Chief Pharmaceutical Officer, Scottish government, explained, 'Pharmacist independent prescribers are already playing a vital role in the delivery of high-quality pharmaceutical care in community, primary care and hospital pharmacy services across Scotland. As the NHS recovers from the pandemic, new models of care are emerging in both planned and unscheduled care, delivered by integrated multidisciplinary teams.'

'This additional funding will support our ambitions to build greater clinical capacity and capability, better manage demand, improve safety, and support the redesign of traditional professional roles and boundaries to advance patient care. These developments, alongside the advances in the initial education and training of pharmacists, offer a wonderful opportunity to ensure that pharmacists' specialist knowledge in medicines is utilised to best effect for the health and wellbeing of the people of Scotland.'

# A MATTER OF LYME

Did you know that Lyme disease is increasing in incidence, and currently represents the most common tick-borne disease in the Northern Hemisphere? Lyme Disease UK share a snapshot of the bacterial infection, and how healthcare professionals can help individuals sculpt a plan of both caution and action to keep the risks at bay.



Infected ticks can be found throughout the UK. Some areas are known to be higher risk than others, but infection can occur anywhere in the UK. Ticks are mainly found in grassy areas and woodlands but have also been found in urban parks and gardens.



Ticks live in grassy areas and look for food by questing. This is when a tick waits on a blade of grass for a host to brush by. It transfers onto the host and then finds a spot to embed itself. The tick will feed and eventually fall off if the host doesn't realise it's there. They can feed for up to six days. Ticks are most active between spring and autumn, but with our changing climate, ticks in some areas now appear to be active all year-round.



If a patient presents with an embedded tick, it must be removed with a tick-removal-tool or fine-tipped tweezers only. Never stress the tick by smothering or burning it. This may increase the risk of transmission, because a stressed tick can regurgitate the contents of its stomach into the host's bloodstream.

If a tick tool is available, slide the fork-like part of the tool underneath the tick, twist the tool (to loosen the grip of the tick) and pull upwards. If using fine-tipped tweezers, grasp

the tick as close to the skin as possible and pull straight upwards. Cleanse the area and provide the patient with advice about what symptoms to look out for over the next few weeks.



If the tick is not removed cleanly and the mouthparts remain embedded, the body will dispel them like any other foreign body, but the patient should be advised to observe for any signs of localised infection that might need treatment. Retained mouthparts do not increase the risk of contracting Lyme disease.

Preventative treatment after a tick bite is not usually recommended by the NHS but the Royal College of GPs' Lyme disease toolkit does suggest that it can sometimes be considered for certain high-risk cases. It is estimated that only about 10 per cent of ticks carry the bacteria that causes Lyme disease which can be reassuring when a person seeks advice after a tick bite.

The most obvious sign of Lyme disease is an Erythema Migrans (EM) rash, sometimes referred to as a bullseye rash. However, it's estimated that about 30 per cent of those infected don't develop a rash. As well as the typical bullseye presentation, the rash can have a solid or bruise-like appearance. It can appear very differently on darker skin tones and be harder to spot. The behaviour of the rash is very important when considering diagnosis. It's always delayed in appearance from three days to three months, is generally not itchy or painful, and slowly spreads outwards.

The spreading is the tell-tale sign of an EM rash. In some cases, EM rashes can become huge. Any redness, itchiness or swelling immediately after a bite is likely to be a histamine reaction. Other things to look out for are flu-like symptoms.

If an EM rash is diagnosed, treatment with antibiotics should begin immediately, with no need for a blood test. Antibiotics should be prescribed as per the NICE guideline. Antibiotic dosages for children with Lyme disease are much higher than for other infections and are based on the child's age

and weight. The guideline should always be consulted if the clinician is not familiar with prescribing for Lyme disease.

## PUTTING IT TO THE TEST

If Lyme disease is suspected, but there is no EM rash present, serology testing should be carried out. Testing for Lyme disease in the UK is a two-tier system. The first tier is an Elisa test and if this returns a positive or equivocal result, it should be followed by the second tier of testing, an Immunoblot. Both are antibody tests, and it is important to remember that the immune system can take some time to make antibodies, possibly up to four weeks or more. Therefore, testing straight after a bite is likely to return a negative result even if the person has been infected. If a test is carried out during this early window, it should be repeated. The NICE guideline states to consider starting treatment while waiting for the results of testing if there is high clinical suspicion of Lyme disease and also for clinicians to be aware that testing can produce both false positive and false negative results.

## IMMEDIACY IS KEY

Early recognition and treatment of Lyme disease is essential for a complete resolution of symptoms. But many people who contract Lyme have no recollection of being bitten by a tick, and this is because ticks can be as small as a poppy seed and are easily missed. If there is no EM rash present and a patient does not recall a tick bite, it is essential that diagnosis is based on a combination of careful history, clinical presentation and, if necessary, serology testing. Lyme disease should not be ruled out based on a negative testing alone.

Late diagnosis or misdiagnosis can lead to long-term debilitating symptoms, and it's very important that healthcare professionals who are presented with a patient with a possible Lyme infection are aware of the complexities of the disease.

## USEFUL RESOURCES

- [www.nice.org.uk/guidance/ng95](http://www.nice.org.uk/guidance/ng95)
- [www.elearning.rcgp.org.uk/mod/book/view.php?id=12535](http://www.elearning.rcgp.org.uk/mod/book/view.php?id=12535)
- [www.lymediseaseuk.com/hcp-further-resources/](http://www.lymediseaseuk.com/hcp-further-resources/)
- [www.lymediseaseuk.com/prevention/](http://www.lymediseaseuk.com/prevention/)

*Lyme Disease UK (www.lymediseaseuk.com) is a registered charity (1182212). We work hard to provide support and raise awareness of Lyme disease among the UK public and healthcare systems.*

## PROMOTION

# FREE UP YOUR TIME TO BETTER SERVE YOUR COMMUNITY AND PATIENTS

Never has there been more of a need to operate efficiently in your pharmacy. With increased demand for services like Pharmacy First, PGDs, extra scripts... need we go on? All of this comes at a cost of time and there is a need to concentrate on these great services. Here, the Edinpharm team explain more – and delve into the added efficiency and effectiveness which their offerings can bring your business.

### WHAT DOES OUR ORDERING SYSTEM DO?

Our system allows you to build the order on your PMR over the course of the morning or afternoon and be ready to transmit when you need to meet those cut-off times with wholesalers. Once submitted, the order is routed, in order of price, to each of our five suppliers and then an email is sent with details of where everything is coming from. This allows you to easily know when to expect your items in. Better still, we can block over tariff items to allow you and your teams to make the decision on whether you want to order these (sometimes very expensive) items directly.

### DO YOU PREFER NEGOTIATING YOUR PRICES YOURSELF?

It is a fair point that you 'may' find that little gem of a price for a product by shopping around for them... but you have to ask yourself:

How much time does that take you or your staff? Could you have instead carried out several services in that time, thus giving you an income from the time?

When getting that little gem of a price, did you also then order several other items whilst you were on? If so, what price did you pay for them? Chances are that your overall basket is higher than it should be.

We look after 250 members to negotiate pricing for you. This gives you peace of mind that we are getting competitive pricing across the range of products.

### WHO DO EDINPHARM PARTNER WITH?

We have five main suppliers in the form of Alliance, Aver, Bestway, Ethigen and Phoenix who tender for business each month. We also

partner with AAH as a back-up, meaning you have six opportunities to get the stock that you require into your pharmacy.

Our main suppliers are fully supportive of Edinpharm and this means that we have been able to negotiate the removal of low spend surcharges for members, preferential rates on products and services and a hotline to key personnel when you need something resolved. We treat our suppliers with the respect they deserve for supporting Edinpharm, and this has helped us build the business with them over the years.

### CAN WE SAVE YOU MONEY?

Honestly? We can provide the tools for you to operate more efficiently, we can negotiate pricing for you, we can direct products to the best supplier. Sadly, we can't 100 per cent say we can save you money on every product... but 250 members are happy with what we do, so clearly we are doing something right!

### LOOKING FOR MORE INFORMATION?

Please do get in touch and have a chat about what you need for your business and let's see if we can make life easier for you, while saving you money too! We would love to be your extended staffing team by supporting you as an Edinpharm member.

*For more information, visit [www.edinpharm.com](http://www.edinpharm.com), email [joinus@edinpharm.co.uk](mailto:joinus@edinpharm.co.uk), or call 0131 441 3773.*





# edinpharm

supporting independent pharmacies

**“The buying power of a multiple, whilst retaining your independence.”**

Edinpharm is a buying group with over 235 members and growing. Founded in 1996, we support independent pharmacies while allowing members to retain their independence and unique identity in the marketplace.

## Key Benefits of Membership

- Very Competitive Pricing
- Key Generic, PI and H&B lines tendered for monthly on your behalf
- Efficient Order Management System
- Place one single order via your PMR and it routes to the relevant suppliers
- Automatic cascading of orders for out of stock items, so no need for re-ordering
- Email with combined responses from all suppliers, making it easier to see where items are coming from
- Relationship with key suppliers
  - Alliance Healthcare; Phoenix Healthcare Distribution;
  - Aver Generics; Ethigen;
  - Bestway Medhub
- Exclusive agreements in place with Cegecim, PSL and EMIS for your PMR solution
- Professional and commercial support
- Partnerships with many suppliers of additional products and services for your business needs
- Close partnership with Numark to gain benefit from their membership offerings, with an Edinpharm based rebate for routing your membership via us
- Support Network - Benefit from the collective knowledge and experience of other independent pharmacies
- A stronger, collective voice for feedback of ideas or raising concerns to suppliers and CPS
- Make your own decisions about your business

Want to discuss our membership further? Get in touch...

info@edinpharm.co.uk | www.edinpharm.co.uk | 0131 441 3773

# ANOTHER LEVEL

From prevalence to precautionary measures, and diagnosis to the value of the medical community’s contribution to patient care, Joanne Whitmore, Senior Cardiac Nurse at the British Heart Foundation, gives SHR the cholesterol insight.

## WHAT IS THE ROLE OF CHOLESTEROL? WHEN DOES IT TRANSITION FROM BENEFICIAL TO PROBLEMATIC?

Cholesterol is a fatty substance found in blood. It’s produced naturally by the body in the liver, and around 20 per cent comes from our food.

Cholesterol has three main functions:

- It forms part of the outer protective layer of each cell
- It is needed for the production of vitamin D and steroid hormones which help keep bones and muscles healthy
- It helps the body digest food by helping to produce bile

High cholesterol (hypercholesterolaemia) is when there is too much cholesterol in the blood. This can increase a person’s risk of heart and circulatory diseases, such as heart attack and stroke.

There are two main types: good (HDL) cholesterol and bad (non-HDL) cholesterol. LDL cholesterol was previously used as the main measure of bad cholesterol but we now know that other forms of non-HDL cholesterol are also harmful. If someone has too much bad cholesterol in their blood and not enough good cholesterol, it can increase their risk of heart and circulatory diseases, such as a heart attack and stroke.

Non-HDL takes cholesterol from the

liver to the cells around the body. Too much bad cholesterol (non-HDL) can be harmful because it sticks to the inside walls of your arteries. This can lead to fatty material (atheroma) building up – the process of atherosclerosis. It makes it harder for blood to flow through, which can lead to a heart attack or a stroke.

## CAN YOU TELL US ABOUT FAMILIAL HYPERCHOLESTEROLAEMIA?

It’s important to differentiate between hypercholesterolaemia and familial hypercholesterolaemia (FH). Hypercholesterolaemia is a general term meaning that a person’s cholesterol level is high. Familial hypercholesterolaemia (FH) is an inherited condition, passed down through families, where cholesterol levels are raised from birth. This puts people at increased risk

of having a heart attack or stroke at an earlier age.

The condition is caused by a genetic mutation that means that the liver is unable to remove excess non-HDL cholesterol. Research has shown that the risk of developing coronary heart disease is up to 13 times higher in people with untreated FH.

FH is usually diagnosed with a genetic test. If the person is found to have a faulty gene that causes FH, close family can then also be tested to see if they have inherited the gene. This process (called cascade testing) is the main way of identifying people with FH. British Heart Foundation research has found that cascade testing is highly cost-effective and widespread adoption could prevent thousands of premature heart attacks.

Around one-in-250 of the UK population has FH, although many people are unaware they have it.

Location	Estimated Prevalence of FH
England	220,000
Northern Ireland	7,600
Scotland	22,000
Wales	13,000
UK	270,000



## WHAT SIGNS AND SYMPTOMS ARE SUSPECT OF THE CONDITIONS?

There aren't usually any signs and symptoms that somebody has hypercholesterolaemia. It is picked up via a blood test called a lipid profile, which will show raised levels.

FH can be hard to diagnose for the same reasons. There are some physical changes that might be present, but these are usually very late signs. Symptoms can include tendon xanthomata (swelling made from cholesterol usually found on knuckles, knees or the Achilles tendon), xanthelasmas (small lumps of cholesterol near the inner corner of the eye), or corneal arcus (a pale white ring around the iris).

## WHAT'S THE RELATIONSHIP BETWEEN HYPERCHOLESTEROLAEMIA AND STROKE?

Having high cholesterol causes a gradual build-up of fatty material in the coronary arteries (atheroma). This build-up prevents healthy blood flow to vital organs, such as the heart and brain. This puts someone at higher risk of having a heart attack or stroke.

If atheroma is present in the coronary arteries, there is an increased risk of a heart attack. If atheroma is present in the arteries supplying the blood supply to the brain, there is an increased risk of stroke or 'mini-stroke' (TIA).

## ARE THERE ANY OTHER HEALTH-RELATED IMPLICATIONS OF HYPERCHOLESTEROLAEMIA – BOTH IN THE SHORT AND LONG-TERM?

Hypercholesterolaemia can lead to atheroma, which can affect any part of the circulatory system. In addition to increasing the risk of

heart attacks and strokes, other conditions caused by atheroma include vascular dementia and peripheral arterial disease.

## WHAT VALUE DO PHARMACISTS AND GPs PROVIDE IN HELPING INDIVIDUALS STAY ON TOP OF THEIR CHOLESTEROL LEVELS?

Pharmacists and GPs can offer and perform NHS Health Checks in which cholesterol levels are checked. They should also use this opportunity to discuss the risk of developing hypercholesterolaemia.

Both pharmacists and GPs can advise on lifestyle factors, which help someone reduce their risk of developing atheroma, and signpost to local lifestyle support services. Both can advise on and prescribe medication (with the right qualifications and governance for pharmacists), and they can also perform lifestyle and medication reviews. If someone is deemed at risk of FH, pharmacists and GPs can signpost a patient to local FH testing services.

## WHAT SUBSEQUENT TREATMENT IS REQUIRED ONCE A DIAGNOSIS OF HYPERCHOLESTEROLAEMIA IS CONFIRMED?

Everybody with hypercholesterolaemia should be offered tailored lifestyle advice which will include:

1. Stopping smoking
2. Healthy eating, especially reducing their intake of saturated fats and increasing their fruit and vegetable intake
3. Increasing activity levels

Health professionals can visit our website for more information on tailored lifestyle advice ([www.bhf.org.uk/information-support/](http://www.bhf.org.uk/information-support/)

[www.bhf.org.uk/information-support/support/healthy-living/understanding-risk-factors](http://www.bhf.org.uk/information-support/support/healthy-living/understanding-risk-factors)).

Depending on the lipid profile results and any pre-existing conditions, statins may be indicated.

The following links are useful resources on this topic:

- Primary prevention – [www.cks.nice.org.uk/topics/lipid-modification-cvd-prevention](http://www.cks.nice.org.uk/topics/lipid-modification-cvd-prevention)
- Secondary prevention – [www.cks.nice.org.uk/topics/lipid-modification-cvd-prevention/management/lipid-therapy-secondary-prevention-of-cvd](http://www.cks.nice.org.uk/topics/lipid-modification-cvd-prevention/management/lipid-therapy-secondary-prevention-of-cvd)

## ARE THERE ANY SELF-HELP SUGGESTIONS FOR INDIVIDUALS IN ADAPTING THEIR LIFESTYLES TO REDUCE THEIR CHOLESTEROL?

While diet alone can't cure FH, patients can be advised to follow healthy lifestyle advice on how to eat a healthy balanced diet, maintain a healthy weight, and do plenty of exercise. This can help regulate levels of non-HDL cholesterol.

## ARE THERE ANY AIDS / TOOLS / RESOURCES WHICH CAN HELP HEALTHCARE PROFESSIONALS HARNESS THEIR HYPERCHOLESTEROLAEMIA KNOWLEDGE?

The British Heart Foundation has a wealth of support materials and professional resources on its website. You can access them at [www.bhf.org.uk/for-professionals/healthcare-professionals](http://www.bhf.org.uk/for-professionals/healthcare-professionals).

## PARKINSON'S

# RAISING THEIR VOICES

The roll-out of new research is turning society's attention to the effects of the pandemic on individuals with Parkinson's – from symptoms, to access to health and care services.

Researchers at Lancaster University recently worked with Parkinson's UK to run two UK-wide surveys to gather insights from people living with Parkinson's and their families who provided unpaid care during the pandemic. The first ran in April and May 2020 and the second in August 2021 – allowing researchers to measure the change in symptoms over the course of the restrictions and the pandemic.

### WORSENING SYMPTOMS

The findings demonstrate that both motor and non-motor symptoms were heavily impacted. Overall, eight-in-10 people with fatigue (86 per cent), stiffness (83 per cent) and slowness of movement (88 per cent) reported a decline in these symptoms.

Anxiety and depression also increased considerably, with seven-in-10 people reporting that their anxiety had worsened in 2021, more than doubling the percentage from the previous year. And almost four times as many people with the condition said that their depression got worse (rising from 13 per cent-to-48 per cent).

Slowness of movement, fatigue and sleeping issues all doubled year-on-year, while muscle cramps increased three-fold. Parkinson's UK believe that significant declines could be in part because of government restrictions that limited people's access to physical activity. Also, they know that the Parkinson's community had reduced access to physiotherapy, as services struggled to meet the needs placed on them.

### LIMITED ACCESS TO SERVICES

As well as a deterioration in symptoms, the Parkinson's UK community shared that they weren't able to access their healthcare services in quite the same way.

In the three months before the 2021 survey, over half (54.3 per cent) of people

with Parkinson's had an appointment with their care provider cancelled, with consultants cancelling slightly more frequently than nurses (31 per cent compared to 28 per cent). Other appointments that had been cancelled included physiotherapist (18 per cent), speech / language therapist (18 per cent), occupational therapist (14 per cent) and psychologist (six per cent).

### VIRTUAL APPOINTMENTS

Almost three-in-five people with Parkinson's (58 per cent) had a phone or online appointment with their Parkinson's nurse and over a third (35 per cent) had one with their consultant. While aspects of these were seen positively, only four-in-10 (40 per cent) said that they were pleased with the outcome of their consultant appointment.

Just under half (46 per cent) of people with Parkinson's surveyed felt that their doctor could understand them well, and fewer than a quarter (23 per cent) felt that the connection with their doctor was comparable to that of a face-to-face appointment.

Only one-in-10 (12 per cent) would recommend online or phone appointments to another person with Parkinson's.

### LIVED EXPERIENCE

Gary Berry, 59, from Shepperton, reflected, 'It's been 10 years since my Parkinson's diagnosis, and generally now I feel much more in control of managing my condition than the initial period after my diagnosis. However, the pandemic has really heightened my anxiety which has a knock-on effect on my physical symptoms. I had to be really cautious when it comes to socialising and this has increased my isolation and brought me down. My self-confidence and self-esteem have really been knocked.'

'I have only had one face-to-face

appointment with a healthcare professional since the start of the pandemic, my neurologist. The problem is that when everything is done over the phone it's really difficult to describe all my symptoms. I feel more at ease when I see someone in-person, how can they assess my gait, for example, over the telephone?

'Parkinson's has both physical and mental symptoms that are easier to effectively assess properly when seen.'

### CALLS TO IMPROVE SERVICES

Throughout the pandemic, Parkinson's UK have been monitoring Parkinson's services and escalating their concerns with the NHS and governments. They are arguing that Parkinson's services are given resources so that they can provide the care and support that people with the condition need.

The NHS is facing the biggest backlog of appointments in its history and is planning how it can change and flex its services to meet these increased demands. Parkinson's UK don't want people with Parkinson's and carers to miss out, which is why they're calling for governments across the UK to tackle the NHS backlog and enable people with Parkinson's to:

- Receive the right care and treatment at the right time supported by robust workforce planning
- Access therapy services to keep them well, including advanced therapies, like Deep Brain Stimulation, which are time-sensitive
- Prioritise access to mental health services for people with Parkinson's and their carers to enable them to recover from the strains of the pandemic

Caroline Russell, CEO of Parkinson's UK, commented, 'As restrictions ease and everyone looks forward to a new normal, we have taken stock of the real impact that the pandemic has had on the Parkinson's community at large.'

'Over the last two years, we've worked with Lancaster University to gather insight into the reality of restrictions on exercise, isolation, virtual appointments, and so much more.'

'Two years of being, at 'best', clinically-vulnerable has taken its toll on people living with the condition and those providing vital, unpaid care for them.'

'As the world reopens and as the NHS refocuses, we won't allow the ever more urgent needs of people with Parkinson's and their carers to be forgotten. With our newly-acquired insights, we'll be making sure that their needs are being heard by key decision-makers so that the future looks a lot brighter.'

For more information, visit [www.parkinsons.org.uk](http://www.parkinsons.org.uk).

## NEW SERVICE FOR PATIENTS WITH HEART FAILURE

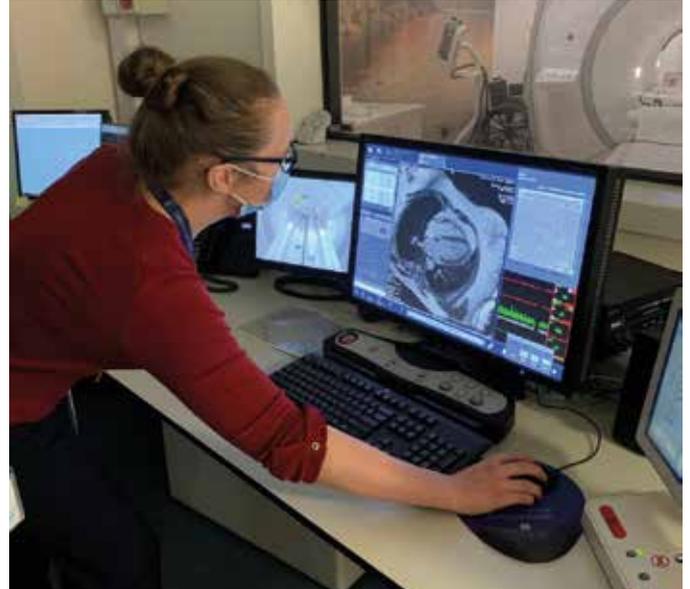
Life for local patients with heart failure has become a little easier, thanks to a new service introduced by NHS Forth Valley.

Specialist cardiac MRI scans are now able to be carried out locally, rather than patients having to travel to hospitals in other health boards in the Central Belt, such as Edinburgh and Glasgow.

NHS Forth Valley Consultant Radiologist, Dr Lindsey Norton, said that radiographers within the department had been working above and beyond to secure top-class imaging, supported by colleagues from the West of Scotland Regional Heart and Lung Centre based at the Golden Jubilee University National Hospital in Clydebank. The centre provided specialist training for a number of NHS Forth Valley radiographers, helping them to gain valuable knowledge and experience which they have used to develop the new local service.

She explained, 'The aim of the new cardiac MRI service is to provide high-quality imaging for patients in the Forth Valley area which will complement the pre-existing cardiology service.'

'MRI plays an important role in diagnosis and management decisions in many cardiac conditions so a local service is a great asset. A recent success saw patients being scanned locally prior to urgent implantable cardiac defibrillator insertion. Previously this often would have required transfers to and from another hospital and an extended inpatient stay before the device could be inserted.'



NHS Forth Valley Consultant Radiologist, Dr Lindsey Norton, reviews a cardiac MRI scan

## £3.6 MILLION TO EXPAND HOSPITAL AT HOME PROVISION

A further £3.6 million is being made available to support the expansion of hospital at home services, with the aim of doubling current capacity by the end of 2022.

The purpose of the service is to reduce hospital admissions for elderly patients by providing treatments in the comfort and familiarity of their own home; enabling people to receive treatments that would otherwise require them to be admitted to hospital, such as an intravenous drip or oxygen supply. It also provides access to hospital tests under the care of a consultant in their own home.

Evidence shows that those benefitting from the service are more likely to avoid hospital or care-home stays for up to six months after a period of acute illness. For older patients, it means being able to stay at home longer without losing their independence and this has contributed to overall improvements in patient satisfaction. It also helps alleviate pressure on hospital beds.

The Scottish government's total investment in these services is now £8.1 million since 2020.

As well as hospital at home, the outpatient parenteral antimicrobial treatment scheme and respiratory community response teams now offer more than 600 virtual beds to treat patients for conditions that would traditionally need hospitalisation, an increase of more than a third from 440 virtual beds at the start of January 2022.

Health Secretary Humza Yousaf announced the further funding, saying, 'Hospital at home is one of the many ways we are providing more care in the community and reducing pressure on hospitals. From the success of the scheme so far, we can see that there is a real benefit to treating people at home where possible.'

## TAILORED TREATMENT COULD TRANSFORM TYPE 2 DIABETES CARE

Moving away from a 'one-size-fits-all' regime has the potential to transform care for people with type 2 diabetes, a University of Dundee study has indicated.

Experts at the university's School of Medicine have established a means of determining how people with type 2 diabetes differ from each other, and how clinical variation between them affects their long-term risks and response to treatment.

The research, conducted with colleagues from the University of Exeter and Madras Diabetes Research Foundation, has been published in *Nature Medicine*.

The study analysed data from more than 23,000 people with type 2 diabetes, utilising it to develop a new way to visualise how much people with the condition differ from each other based upon nine clinical characteristics.

Ewan Pearson, Professor of Diabetic Medicine at Dundee, commented, 'Our study demonstrates how we can look at an individual with type 2 diabetes and illustrate in an intuitive way the main reasons they have diabetes and use this to manage them better to reduce their individual risks.'

'Imagine three women diagnosed with type 2 diabetes at the age of 60. One may only be slightly overweight and have developed diabetes due to reduced insulin production from the pancreas. She will have slow progression of her diabetes and lower risk of complications. The second may have particularly high blood pressure and be more prone to eye complications. The third may be very overweight with high blood fats and be more resistant to the effects of insulin, meaning she would be at increased risk of heart disease. They all have type 2 diabetes but for very different reasons and with very different profiles, meaning that different treatments may result in better outcomes, depending on their circumstances.'

SEPSIS

# SEPSIS: A STORY SHARED

As the primary cause of preventable death in the world, sepsis continues to carve its impact on countless individuals and their families. Here, one patient's story sheds a stark light on the true extent of sepsis' challenges, trauma, and drives forward the essential role of early symptoms awareness and intervention.



Sepsis is a life-threatening condition caused by the body's response to an infection. Our immune system protects us from illnesses and infections, but sometimes it can overreact, triggering widespread inflammation which can lead to shock, multiple organ failure, and death. It's vitally important that healthcare professionals are knowledgeable about the signs and symptoms of sepsis in order to quickly diagnose it in patients, resulting in treatment being administered in time. For every hour treatment for sepsis is delayed, a person's chance of survival reduces by over seven per cent.

## TOBY'S SEPSIS JOURNEY

**Sepsis Research FEAT is the UK's only sepsis charity dedicated to research. It also raises awareness of sepsis among the public and within the medical community. A huge part of the charity's awareness-raising work happens thanks to the stories of people who have been affected by the condition.**

**Helen Grimberg's son Toby contracted sepsis in February 2018 when he was 10 years old. Here she explains how Toby survived thanks to medical staff who quickly diagnosed him with sepsis and administered life-saving treatment.**



Toby Grimberg

The first signs that Toby was poorly were like a typical cold, recalls Helen. A weekend of feeling under the weather and a sore throat didn't hold him back from heading off to school on Monday. Then a trip to the local GP with a slight temperature on the Wednesday, followed by bed rest and some medicine, seemed to improve things enough for an all-important hockey match he was desperate to get back to school for on the Friday. But, after sitting out for most of the match with little energy, sickness and diarrhoea kicked in that evening, accompanied by a temperature.

Friday night was spent sleeping next to Helen, where she could monitor him. By the morning, his temperature was high, he was thirsty, sleepy but still alert. Having checked for rashes, Helen got back onto the NHS, via 111, and was quickly advised that an

ambulance would be arranged. When the paramedics arrived to assess Toby, the word 'sepsis' was mentioned for the first time, and the family suddenly found themselves being blue-lighted to hospital. Helen remembers the excellent care given by their A&E nurse – another Helen – who quickly started administering antibiotics, while the paediatric team narrowed down the potential diagnoses.

'It was all a blur,' says Helen, looking back on the events of that day.

'We were told that Toby had a 60 per cent chance of survival and needed to be transferred to another hospital with an intensive paediatric unit. I remember it was pouring with rain, and I thought 'How could we have come to this in less than 24 hours? What had gone so wrong?'

Toby was very sick. He had contracted sepsis when his simple sore throat had developed into streptococcus. This, combined with the flu, had led his body to become overwhelmed and its response was to fight back, but against itself, rather than the infection.

A harrowing three-to-four hours later, the amazing 'angel' transfer doctor had stabilised Toby sufficiently to transport him by ambulance to intensive care in another hospital. Toby spent four days in intensive care, intubated for breathing, with a feeding tube up his nose and intravenous drips in his groin and his arm.

'The care that Toby was given was unbelievable,' continues Helen.

'As the intensive care team chased to get ahead of the infection, my husband and I never left his side. It was so traumatic, being away from home, having had to leave our other son at home. We were all in an utter state of shock.'

About four times a day, blood was taken from Toby and checked, his skin colour was assessed, and doctors pressed his flesh to see how quickly the blood returned to the surface. He had physio to remove fluid settling on his lungs. He had his hair combed, his body washed and his teeth brushed. Helen says the care was so kind.

'After about 48 hours we started to feel a slight shift and less anxiety around Toby and, on day three, we were told that they were ahead of the infection.'

When Toby was 'brought round' after five days he did not have a clue what had been going on.

Transferring back to a general hospital ward at the original hospital was a sign that Toby was well on the mend, but it was still a challenging time for Toby's parents. After three more days in hospital, Toby finally made it home, with regular visits back to the hospital for intravenous antibiotics. It took

him around six months to recover his full strength, and, while he was back at school, he needed to have a sleep during the day in order to keep going.

Now, four years on, Toby is fit and strong. He was awarded Sportsman of the Year at school, competes in County Cricket, and has been selected for the Saracens Rugby Development Programme. He has survived and is a typical boisterous teenager. But it is an experience that will have a lasting effect on both Helen and her family for a long time to come.

Helen remarked, 'How different my story could be if we had not been assessed so quickly by 111 and at A&E, and had the intervention of such amazing doctors and nurses. I will never hear a bad word about the NHS.'

## RAISING SYMPTOMS AWARENESS

Sepsis Research FEAT is working to raise awareness of the five key symptoms of sepsis.

These are:

- Very high or low temperature
- Uncontrolled shivering
- Confusion
- Passing less urine than normal
- Blotchy or cold arms or legs

On their own, these symptoms can be an indication of other health problems. But a combination of two or more of these symptoms, becoming progressively or rapidly worse, indicates sepsis and urgent medical attention should be sought.

Someone with sepsis might not show all of these symptoms at once and other symptoms they could have include:

- Difficulty breathing
- Rapid heartbeat
- Feeling dizzy or faint

Colin Graham, Chief Operating Officer at Sepsis Research FEAT, said, 'Five people in the UK die every hour from sepsis. Despite this shocking figure, many people are still unaware of how serious the condition is. Our charity works to raise awareness of sepsis among both the public and the medical community. If more people have a better understanding of sepsis and the signs to look out for then this could lead to more lives being saved.'

'Helen's story about her son Toby illustrates how important it is for medical staff to be knowledgeable about sepsis, its symptoms, and how to treat it. From the paramedics who assessed Toby after Helen called 111, to the doctors and nurses who

treated him in hospital, they all played a part in him being alive today.'



Colin Graham

## MORE INFORMATION ABOUT SEPSIS RESEARCH FEAT

Sepsis Research FEAT was founded by Craig Stobo in memory of his wife, Dr Fiona Agnew, and their unborn daughter, Isla, who died from sepsis in 2012. The charity will mark its 10th anniversary in 2023.

Sepsis Research FEAT's main aims are funding research, awareness-raising, campaigning and shaping policy. It is currently helping fund the Genetics of Mortality in Critical Care (GenOMICC) study at the University of Edinburgh's Roslin Institute which is being led by Professor Kenneth Baillie. This world-leading study researches the ways our genes can influence how vulnerable our bodies are to serious conditions, such as sepsis.

The biological processes that cause sepsis are not understood and that is why research is needed. It is the only way to develop new treatments which doctors and health professionals can use to treat sepsis in the future and save more lives.

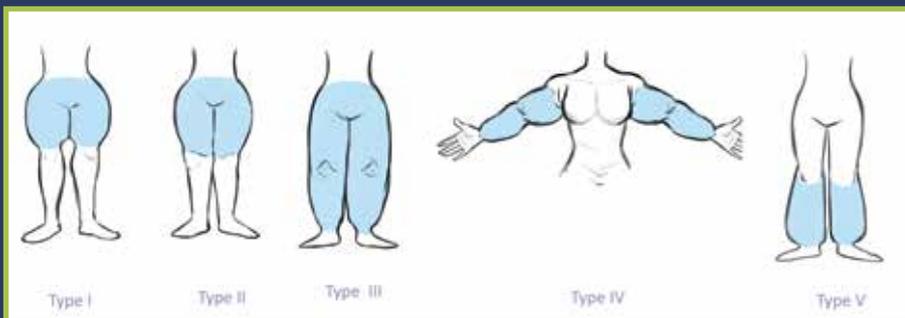
For more information, visit [www.sepsisresearch.org.uk](http://www.sepsisresearch.org.uk).



LIPOEDEMA

# TAKING SHAPE

Although many women with lipoedema lead full and active lives, the chronic condition can be debilitating, and impose on individuals a lack of confidence and reduced mobility. Get the lowdown on lipoedema and the delays in diagnosis with expert insights from Sharie Fetzer, Chair of Lipoedema UK, and Jane Wigg, Director and Clinical Nurse Consultant at Lymphoedema Training Academy.



Lipoedema is reported to affect one-in-11 women; breast cancer affects one-in-eight women; and cancer one-in-three people. For a condition with such a high incidence you would think that as healthcare professionals and as the general public, we would know more about this condition and how to treat it.

Lipoedema is predominantly a female-related condition and is the abnormal laying down of fat, usually from the hips to the ankle, from the waist to the hips or knees, and sometimes occurs only below the knee. In rarer cases, lipoedema sometimes includes the arms.

Lipoedema can be tender to touch, with reports of easy bruising, and associated varicose veins. The skin can feel like it has tiny pieces of rice or peas under it. One of the easy detection signs is that the shape changes from the ankle, but with no foot swelling until the later stages, when it can develop into lipolympoedema with swelling.

For many women, they unfortunately don't know that they are living with lipoedema. It can start very subtly as a teenager and could be considered 'as part of you' and that they think they are 'just like my mother'. Sometimes ladies exercise profusely but the shape never changes, and it's common

to lose fat from the top half of the body, even becoming emaciated and anorexic, but it never reduces on the bottom half.

Lipoedema progresses through stages, where the tissues and shape changes, but in some cases it can stay the same life-long. Many women with lipoedema are also hypermobile, meaning that they have more flexible joints and often more stretchy skin.

Fortunately, treatment is available and this consists of good healthy living, exercise for strengthening, compression hosiery to support the limbs, and sometimes surgical intervention. Learning to live with and self-manage lipoedema is also key to successful treatment.

It's important that those living with this life-long condition receive the correct information and support, but sadly many women still find it extremely difficult to get a diagnosis. In Lipoedema UK's survey in 2014, the average woman took 30 years to get a diagnosis, and then only five per cent were diagnosed by their GP. Since the publication of the Royal College of GPs' e-learning course on lipoedema and more awareness of lipoedema in recent years, the percentages are slowly improving, but not quickly enough for most patients to receive a diagnosis in the

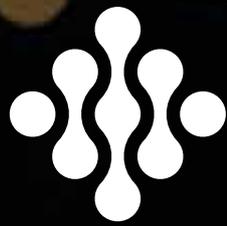
early stages.

Lipoedema legs are often heavy and painful, and can often be the subject of cruel comments. Due to the pronounced differences between the upper and lower bodies, finding suitable clothes of any kind is an enormous challenge and patients often become isolated and despondent when they find it difficult to participate in sports, perform their jobs, or join in everyday social activities. The charity Lipoedema UK provides information for both patients and healthcare professionals, including weekly online patient support meetings for their members.

There is still much to learn about lipoedema and research so far has been scant. Many patients have complicated co-morbidities, including obesity, which makes treatment complicated. Non-cosmetic liposuction surgery can make a huge difference, reduce pain and improve mobility, but patients are usually forced to self-fund, may need several operations, and there are few qualified surgeons in the UK.

The Lymphoedema Training Academy provided the first UK lipoedema specialist training course in May 2022. Supported by Lipoedema UK, an expert support group for therapists, and those living with lipoedema, training consisted of two online days provided by international experts and three days of on-site clinical and theoretical skills training.

**For more information, contact the Lymphoedema Training Academy by emailing [training@lymph.org.uk](mailto:training@lymph.org.uk) and visiting [www.lymph.org.uk](http://www.lymph.org.uk); get in touch with Lipoedema UK at [www.lipoedema.co.uk](http://www.lipoedema.co.uk); and access the Royal College of GPs' learning course at [www.lipoedema.co.uk/royal-college-of-general-practitioners-elearning-course-on-lipoedema](http://www.lipoedema.co.uk/royal-college-of-general-practitioners-elearning-course-on-lipoedema).**



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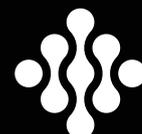
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## MICROSCOPIC COLITIS

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# A GROWING CONCERN

How much do you know about the debilitating gut condition that's 700 per cent more likely to affect women than men? Guts UK is calling for more research to determine the reasons behind this gender disparity in microscopic colitis in the hope that it will lead to prevention, faster diagnoses, and developments in treatments.

Microscopic colitis is an inflammation of the large intestine (bowel) that causes persistent, frequent and watery diarrhoea (throughout the day and night), stomach pain, fatigue, faecal incontinence and weight loss. The charity, Guts UK, has chosen to create specific resources for women after research has shown that 87.5 per cent of people suffering with the condition are female – most of whom are diagnosed between the ages of 50-and-70.

Microscopic colitis is a leading cause of diarrhoea in older adults and it can have a devastating impact on a person's quality of life. Scientists estimate that around 67,200 people are living with microscopic colitis in the UK.

Patients often find it difficult to manage jobs, socialise, travel and take part in family life because of the urgent nature of their symptoms and their need to be near to toilet facilities at all times. Coping with this often leaves sufferers feeling very isolated and can have a significant and detrimental effect on their mental wellbeing.

Many people suffer for years with microscopic colitis but the correct diagnosis and treatment can make a huge and dramatic difference to a person's quality of life.

## THE PATIENT IMPACT

Julie, aged 42 from Sidcup in Kent, was diagnosed with microscopic colitis in 2020.

Julie said, 'The symptoms of microscopic colitis are awful. I experienced crippling stomach pain, nausea, as well as watery diarrhoea, which lasted for several weeks and only stopped when I was diagnosed and began a treatment of steroids. It all had a massive impact on my mental health since this was during lockdown and I worried about what could be wrong.'

'It's a very isolating condition and I can understand why it's called a hidden disability. It's been over a year since I was diagnosed and I'm still having flare-ups. I am constantly thinking about what I am eating and when I am out where the nearest facilities are – it's exhausting.'

'There is very little awareness of microscopic colitis, but I am sure there are many people suffering with it without knowing. My message for anyone with symptoms is that if you feel that things aren't quite right and you're struggling to get a diagnosis then persevere and push for an appointment with a gastroenterologist. The treatments available can certainly improve symptoms.'

## MICROSCOPIC COLITIS



## IS THERE CLARITY ON THE CAUSES?

At least one-in-1,000 people are thought to have microscopic colitis in the UK, with 17,000 new cases being diagnosed each year, but the real number could be a lot higher because it's often underreported and misdiagnosed. One study showed that one-in-three patients with microscopic colitis were initially incorrectly diagnosed with Irritable Bowel Syndrome. It is also a growing disease and the number of patients diagnosed has been increasing over the past 20 years.

Microscopic colitis is named because, unlike other inflammatory bowel diseases, like Crohn's disease or ulcerative colitis, it can't be diagnosed with a colonoscopy alone and a sample of tissue taken from the bowel must be examined under a microscope to identify the condition. However, once confirmed, treatment with prescribed medicine (a steroid called budesonide) is available and has shown to be very effective and often life-changing.

The causes of microscopic colitis and the reason it affects women disproportionately are still unclear. As it is a relatively new disease (first described in 1976) it has led to a presumption that it is environmental, as opposed to genetic, factors that are responsible for its occurrence.

## TIME FOR CHANGE

Prior studies have suggested that a range of medications including proton pump inhibitors – which are used to reduce stomach acid – nonsteroidal anti-inflammatory drugs such as ibuprofen, statins, antidepressants, aspirin, and beta blockers may be associated with the disease, as well as cigarette smoking and a co-diagnosis of an autoimmune disease.

What is clear is that women are at substantially higher risk of having microscopic colitis than men. Despite this marked gender

discrepancy, the literature on reproductive and hormonal factors is very limited. Some scientists have hypothesised that there is a link with microscopic colitis and the use of oral contraceptive pills and HRT but more research is needed for this to be conclusive.

Julie Harrington, CEO of Guts UK, said, 'Thousands of people across the country are quite literally housebound with symptoms of microscopic colitis and we now know that the rates are increasing and are likely to grow further as the population ages.'

'Further research is desperately needed to identify risk factors and find out why women are far more likely to suffer from microscopic colitis so we can move to a place where prevention and faster diagnosis is possible.'

Professor Shaji Sebastian, Consultant Gastroenterologist at Hull University Teaching Hospitals NHS Trust and Guts UK trustee, added, 'Scientists still don't fully understand what causes microscopic colitis and further research is clearly needed to determine what could be a combination of factors.'

'What we do know is that the condition can be very debilitating but with the right tests it's also very treatable. Early diagnosis is crucial to prevent patients from suffering when they don't have to, so my main message is don't suffer in silence and seek help from your GP if you're experiencing symptoms.'

## ABOUT GUTS UK

Guts UK is the UK's charity for the digestive system from top to tail; gut, liver and pancreas. Through strong connections with the British Society of Gastroenterology and membership of the Association of Medical Research Charities it is able to support a diverse portfolio of research work that is of the highest quality.

Guts UK also provides expert information on a range of digestive conditions and symptoms for patients, and raises awareness of digestive health.

*For more information, visit [www.gutscharity.org.uk](http://www.gutscharity.org.uk).*



# BREATHE A WORD

**Through heightening COVID pressure and rapidly altering circumstances, the sector's commitment to patients' continuity of respiratory care has shone through. As a Lead Practice Based Pharmacist, John Hamill discusses his first-hand experiences and the lessons which can empower the future footing of asthma management.**

Services to diagnose asthma during COVID-19 had been very limited given that reversibility testing using spirometry as the gold standard had ceased, being deemed too high a risk. Those patients presenting with symptoms and / or suspected of having asthma were assessed as before, but without the ability to do lung function testing; clarity of such needed to be ascertained by other means. Their PMR was read coded to state 'suspected asthma' with a 'referral for spirometry' when the services reopened, documented for future assessment.

With limited face-to-face opportunities, the review process for patients took on a different slant, with more than not undertaking remote and virtual reviews / assessments either using encrypted technology or telephone / video reviews. Although this was not in any means perfect, it helped the healthcare professional glean an understanding of current management of patients' underlying respiratory conditions.

Obviously this process had flaws, including restrictions on checking and demonstrating inhaler technique, lung function testing and displaying as much empathy, as would be the case in a F2F process. It did allow me scope as a respiratory independent prescriber to analyse current prescribing trends and target reviews towards those from whom evidence obtained appeared to need my input most urgently. These included over-use of SABA and reduced compliance with preventer therapies.

One of the benefits I believe from the lockdown scenario was that I was able to target many more of my patients, especially those

of whom had failed to attend for annual review / follow-up, and as such I was better positioned to get an idea of their self-management and optimise their treatments. Also, many remarked on how they appreciated the contact, especially those furloughed or house-bound due to immunosuppression.

When asthma was suspected, we would offer serial peak expiratory flow (PEF) meters with clear advice of how to monitor their breathing capacity and strict timelines for feedback and follow-up where appropriate. Those with worsening symptoms were advised to either contact the practice, out-of-hours or A&E if necessary.

Given presenting symptoms were very likened to COVID – namely SOB, cough etc. – it was always essential to screen patients and refer to COVID centres for assessment if the circumstances negated that. Following feedback from the centre, the next steps would be agreed with the patient.

I took it upon myself to contact the majority of my asthmatic patients to advise them that as a practice we didn't routinely invite patients into the surgery, but if they felt any concerns over poor management of their symptoms, they could contact the practice, and be triaged and reviewed in-house or at one of the COVID centres. I was all too aware that patients may be struggling and thinking our services had been stopped and wanted to clear this up. Many practices did reduce footfall but I firmly believe that most maintained the necessary arrangements to cater for patient need within the pressures they were under.

Looking ahead, there is light at the end of the tunnel in diagnosing patients with the involvement of respiratory hubs for spirometry. These are being set up for practices to refer for assessment of patients whom they believe to have asthma, COPD or require lung function testing to identify or rule out underlying respiratory disease. This initiative must be commended and will help identify quickly the diagnosis of patients on practice lists who have been 'referred for spirometry'.

As a GP practice and GPP respiratory practitioner I welcome the ease out of lockdown post-COVID with hope and determination to engage more fully with patients in a face-to-face format, while still using some of the virtual tools to review those hard-to-reach asthmatic patients – as had been done over the past 24 months or so.

I think that many respiratory patients were concerned about their lung health over this time. We need to hang onto that momentum and utilise their interest to maximise outcomes in their future management and support them going forward. It has been a great opportunity to educate patients on correct inhaler use, compliance with dosing regimens, and an understanding of why they need to use which inhaler and when and what to do when things go wrong.

Many GPPs have played a crucial role in the management of respiratory patients as part of their day-to-day tasks and as a lead GPP I am very proud of the efforts they have all made to ensure continuity of care and given the pressures the NHS has been under have excelled in their contribution within this field.

We must all reflect on the learnings over the last two years and play to our strengths when it comes to asthma management. Multidisciplinary working with community and hospital colleagues is more important than ever. Look to maximise the basics, including improvement in compliance with ICS and reduced reliance on SABAs. Ensure inhaler technique is assessed and corrected if necessary, give clear personal management plans, and when things are not going to plan, reassess at the earliest opportunity.

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 – in patients not adequately controlled with inhaled corticosteroids and “as needed” inhaled short-acting  $\beta_2$  adrenoceptor agonists.  
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 – in patients already adequately controlled on both inhaled corticosteroids and long-acting  $\beta_2$  adrenoceptor agonists.

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The carbon footprint of DuoResp Spiromax has been measured and certified as 0.63 kgCO<sub>2</sub> by the Carbon Trust.<sup>2</sup> For more details on the Carbon Trust, see carbontrust.com.

1. DuoResp Spiromax Summary of Product Characteristics. 2. Data on File 226. Teva UK Limited.

Intended for healthcare professional audience only.

Approval code: DUOR-GB-00059 Teva UK Limited, Ridings Point, Whistler Drive, Castleford, West Yorkshire, WF10 5HX Date of preparation: January 2022



**Please refer to the Summary of Product Characteristics (SmPC) for full details of the Prescribing Information.**  
 DuoResp<sup>®</sup> Spiromax<sup>®</sup> (budesonide/formoterol) 160mcg/4.5mcg inhalation powder and DuoResp<sup>®</sup> Spiromax<sup>®</sup> (budesonide/formoterol) 320mcg/9mcg inhalation powder  
**Abbreviated Prescribing Information.** **Presentation:** DuoResp<sup>®</sup> Spiromax<sup>®</sup> 160/4.5: Each delivered dose contains 160mcg of budesonide and 4.5mcg of formoterol fumarate dihydrate. This is equivalent to a metered dose of 200mcg budesonide and 6mcg of formoterol fumarate dihydrate. DuoResp<sup>®</sup> Spiromax<sup>®</sup> 320/9: Each delivered dose contains 320mcg of budesonide and 9mcg of formoterol fumarate dihydrate. This is equivalent to a metered dose of 400mcg budesonide and 12mcg of formoterol fumarate dihydrate.  
**Inhalation powder. Indications:** Asthma: Treatment of asthma, where use of a combination (inhaled corticosteroid and long-acting  $\beta_2$ -adrenoceptor agonist) is appropriate. COPD: Symptomatic treatment of patients with COPD with forced expiratory volume in 1 second (FEV<sub>1</sub>) < 70% predicted normal (post bronchodilator) and a history of repeated exacerbations, who have significant symptoms despite regular therapy with long-acting bronchodilators. **Dosage and administration:** For use in adults and adolescents 12 years and older for Asthma, and adults aged 18 years and older for COPD. Not for use in children < 12 years of age. **Asthma:** Not intended for the initial management. If an individual patient should require a combination of doses other than those available in the combination inhaler, appropriate doses of  $\beta_2$ -adrenoceptor agonists and/or corticosteroids by individual inhalers should be prescribed. The dose should be titrated to the lowest dose at which effective control of symptoms is maintained. When control of symptoms is achieved titrate to the lowest effective dose, which could include once daily dosing. DuoResp<sup>®</sup> Spiromax<sup>®</sup> 160/4.5: maintenance therapy - regular maintenance treatment with a separate reliever inhaler. **Adults (18 years and older):** 1-2 inhalations twice daily (maximum of 4 inhalations twice daily). **Adolescents (12 years and older):** 1-2 inhalations twice daily. DuoResp<sup>®</sup> Spiromax<sup>®</sup> maintenance and reliever therapy: For patients taking DuoResp as reliever, preventative use of DuoResp Spiromax for allergen or exercise-induced bronchoconstriction should take into consideration the frequency of need. In case of frequent need of bronchodilation without corresponding need for an increased dose of inhaled corticosteroids, an alternative reliever should be used. Regular maintenance treatment and as needed in response to symptoms: should be considered for patients with: (i) inadequate asthma control and in frequent need of reliever medication (ii) previous asthma exacerbations requiring medical intervention. **Adults and adolescents:** The recommended maintenance dose is 2 inhalations per day, given either as one inhalation morning and evening or as 2 inhalations in either the morning or evening. For some patients a maintenance dose of 2 inhalations twice daily may be appropriate. Patients should take 1 additional inhalation as needed in response to symptoms. If symptoms persist after a few minutes, an additional inhalation should be taken. Not more than 6 inhalations should be taken on any single occasion. A total daily dose of up to 12 inhalations could be used for a limited period. Patients using more than 8 inhalations daily should be strongly recommended to seek

medical advice. DuoResp<sup>®</sup> Spiromax<sup>®</sup> 320/9: Only to be used as maintenance therapy. **Adults (18 years and older):** 1 inhalation twice daily (maximum of 2 inhalations twice daily). **Adolescents (12 years and older):** 1 inhalation twice daily. **COPD:** **Adults:** 1 inhalation twice daily. **Elderly patients ( $\geq 65$  years old):** No special requirements. **Patients with renal or hepatic impairment:** No data available. **Contraindications:** Hypersensitivity to the active substance or to any of the excipients. **Precautions and warnings:** If treatment is ineffective, or exceeds the highest recommended dose, medical attention must be sought. Patients with sudden and progressive deterioration in control of asthma or COPD should undergo urgent medical assessment. Patients should have their rescue inhaler available at all times. The reliever inhalations should be taken in response to symptoms and are not intended for regular prophylactic use e.g. before exercise. In case of frequent need of bronchodilation without corresponding need for an increased dose of inhaled corticosteroids, an alternative reliever should be used. Patients should not be initiated during an exacerbation. Serious asthma-related adverse events and exacerbations may occur. If asthma symptoms remain uncontrolled or worsen, patients should continue treatment and seek medical advice. If paradoxical bronchospasm occurs, treatment should be discontinued immediately. Paradoxical bronchospasm responds to a rapid-acting inhaled bronchodilator and should be treated straightaway. Visual disturbance may be reported with systemic and topical corticosteroid use. Such patients should be considered for referral to an ophthalmologist for evaluation of possible causes. Systemic effects may occur, particularly at high doses prescribed for long periods. Potential effects on bone density should be considered, particularly in patients on high doses for prolonged periods that have co-existing risk factors for osteoporosis. Prolonged treatment with high doses of inhaled corticosteroids may result in clinically significant adrenal suppression. Additional systemic corticosteroid cover should be considered during periods of stress. Treatment should not be stopped abruptly – tapering of dose is recommended. Transfer from oral steroid therapy to a budesonide/formoterol fumarate fixed-dose combination may result in the appearance of allergic or arthritic symptoms which will require treatment. In rare cases, tiredness, headache, nausea and vomiting can occur due to insufficient glucocorticosteroid effect and temporary increase in the dose of oral glucocorticosteroids may be necessary. To minimise risk of oropharyngeal Candida infection patients should rinse mouth with water after inhaling the dose. Administer with caution in patients with thyrotoxicosis, pheochromocytoma, diabetes mellitus, untreated hypokalaemia, or severe cardiovascular disorders. The need for, and dose of inhaled corticosteroids should be re-evaluated in patients with active or quiescent pulmonary tuberculosis, fungal and viral infections in the airways. Additional blood glucose controls should be considered in diabetic patients. Hypokalaemia may occur at high doses. Particular caution is recommended in unstable or acute severe asthma. Serum potassium levels should be monitored in these patients. As with other lactose containing products the small amounts of milk proteins present may cause allergic reactions. There is some evidence of an increased risk of pneumonia with increasing steroid dose but this has not been demonstrated conclusively across all

studies. Physicians should remain vigilant for the possible development of pneumonia in patients with COPD as the clinical features of such infections overlap with the symptoms of COPD exacerbations. **Interactions:** Concomitant treatment with potent CYP3A4 inhibitors should be avoided. If this is not possible the time interval between administration should be as long as possible. Co-treatment with CYP3A4 inhibitors, including cobicistat-containing products is expected to increase risk of systemic side effects and the use in combination should be avoided. Not recommended with  $\beta$ -adrenergic blockers (including eye drops) unless compelling reasons. Concomitant treatment with quinidine, disopyramide, procainamide, phenothiazines, antihistamines (terfenadine), and Tricyclic Antidepressants (TCAs) can prolong the QTc-interval and increase the risk of ventricular arrhythmias. L-Dopa, L-thyroxine, oxytocin and alcohol can impair cardiac tolerance. Concomitant treatment with MAOIs, including agents with similar properties, may precipitate hypertensive reactions. Patients receiving anaesthesia with halogenated hydrocarbons have an elevated risk of arrhythmias. Hypokalaemia may increase the disposition towards arrhythmias in patients taking digitalis glycosides. **Pregnancy and lactation:** Use only when benefits outweigh potential risks. Budesonide is excreted in breast milk; at therapeutic doses no effects on infants are anticipated. **Effects on ability to drive and use machines:** No or negligible influence. **Adverse reactions:** Since DuoResp<sup>®</sup> Spiromax<sup>®</sup> contains both budesonide and formoterol, the same pattern of adverse reactions as reported for these substances may occur. No increased incidence of adverse reactions has been seen following concurrent administration of the two compounds. **Serious:** Immediate and delayed hypersensitivity reactions, e.g. exanthema, urticaria, pruritus, dermatitis, angioedema and anaphylactic reaction, Cushing's syndrome, adrenal suppression, growth retardation, decrease in bone mineral density, hypokalaemia, hyperglycaemia, aggression, psychomotor hyperactivity, anxiety, sleep disorders, depression, behavioural changes, cataract and glaucoma, tachycardia, cardiac arrhythmias, e.g. atrial fibrillation, supraventricular tachycardia and extrasystoles, angina pectoris, prolongation of QTc-interval, variations in blood pressure, bronchospasm, pneumonia in COPD patients and paradoxical bronchospasm. **Common:** Candida infections in the oropharynx, headache, tremor, palpitations, mild irritation in the throat, coughing, pneumonia in COPD patients, dysphonia including hoarseness. Consult the Summary of Product Characteristics in relation to other side effects. **Overdose:** An overdose of formoterol may lead to: tremor, headache, palpitations. Symptoms reported from isolated cases are tachycardia, hyperglycaemia, hypokalaemia, prolonged QTc-interval, arrhythmia, nausea and vomiting. Supportive and symptomatic treatment may be indicated. **Price per pack:** DuoResp<sup>®</sup> Spiromax<sup>®</sup> 160/4.5 and DuoResp<sup>®</sup> Spiromax<sup>®</sup> 320/9: £27.97. **Legal Category:** POM. **Marketing Authorisation Numbers:** DuoResp<sup>®</sup> Spiromax<sup>®</sup> 160/4.5: EU/114/920/001, PLGB 00289/2438. DuoResp<sup>®</sup> Spiromax<sup>®</sup> 320/9: EU/114/920/004, PLGB 00289/2439. **Marketing Authorisation Holder/Business Responsible for Sale or Supply:** Teva UK Limited, Ridings Point, Whistler Drive, Castleford, WF10 5HX. **Job Code:** MED-GB-00056. **Date of Preparation:** October 2021.

Adverse events should be reported. Reporting forms and information can be found at [www.mhra.gov.uk/yellowcard](http://www.mhra.gov.uk/yellowcard). Adverse events should also be reported to Teva UK Limited on 0207 540 7117 or [medinfo@teva.uk](mailto:medinfo@teva.uk).

# BENEATH THE SURFACE

Catalysed by an array of experiences and events, Post-Traumatic Stress Disorder (PTSD) can prompt countless life-altering and intrusive symptoms within individuals' lives. PTSD UK help us grasp the causes and science behind the condition, as well as the substantial distress and disruption of social and occupational functioning, and major problems in relationships and jobs, which can result.

The human body is an incredible system, but it is also complex, and full of feedback loops between body parts and brain. If you interfere with any of these loops dramatically (as in the case of experiencing a trauma), you can affect the whole system.

PTSD is a condition that some people develop after experiencing or witnessing a traumatic life-threatening event or serious injury – put simply, PTSD is essentially a memory-filing error caused by the brain 'suspending' normal function during a traumatic situation.

It's estimated that 50 per cent of people will experience a trauma at some point in their life, and although the majority of people exposed to traumatic events only experience some short-term distress, around 20 per cent of people who experience a trauma go on to develop PTSD. It's estimated that in any given week, four-in-100 people in England have PTSD.

Despite its prevalence across the world, PTSD is still a very misunderstood condition and many people have pre-conceived ideas of what PTSD is, and particularly what can cause it.

There is a widespread misunderstanding that PTSD only affects veterans, or those in the armed forces – likely due to its previous name of shell-shock – but it can affect anyone, of any age. It's vital that healthcare providers are aware if they (or a patient or even a loved one) have suffered any trauma, they should be mindful of trauma symptoms, and the possibility of PTSD.

## WHAT CAN CAUSE PTSD?

PTSD is as ancient as humankind and can occur in all people, of any ethnicity, nationality, gender, occupation or culture, and at any age and from any trauma (perceived or actual). The defining characteristic of a traumatic event is its capacity to cause fear, helplessness, or horror as a response to the threat of injury or death. Some examples of traumatic events include:

- Road traffic incidents
- Being told you have a life-threatening illness

- Bereavement
- Violent personal assault, such as a physical attack, robbery, or mugging
- Military combat and service
- Any form of abuse, including childhood abuse and domestic abuse
- Burglary
- Events experienced in employment where you repeatedly see distressing images or hear details of traumatic events
- Caring for a child with a complex medical condition or disability
- Witnessing a suicide or attempted suicide
- Natural disasters, such as flooding or an earthquake
- Terrorist attack
- Being kidnapped or held hostage
- Being bullied (as a child or adult)
- Traumatic childbirth (in people who give birth and birth partners)
- Refugee and asylum-seekers
- Early pregnancy loss (including miscarriage and ectopic pregnancy)
- Sexual assault or rape
- Admission to an intensive care unit

## CAUSES OF COMPLEX PTSD

There is also a second subtype of PTSD, called Complex PTSD, or C-PTSD. This is usually a result of repeated, or sustained traumas, and presents in a similar way to PTSD, but with some additional symptoms too. Any of the causes noted (and many others) can cause C-PTSD if someone has experienced repeated, sustained or a number of different traumas.

## THE SCIENCE OF HOW PTSD IS CAUSED

PTSD isn't 'all in the mind' or something you can just 'get over' or 'move on' from. No matter how much reasoning and coaxing you do, someone with PTSD may find it impossible to achieve sustainable recovery without professional treatment.

That's because PTSD is a form of injury to the brain. Brain scans show that PTSD symptoms and behaviours are caused by biological changes in the brain, NOT by some personal failure.

Modern science has enabled us to get a far clearer picture of the brain and, in fact, the whole neurological system's structure and activities. It has become possible to map and measure the different development paths that each human brain follows.

This form of investigation has clearly shown

that PTSD's impact on the way we think, feel and behave has a physical imprint: markers that you can see on brain scans, such as through SPECT (single photon emission computed tomography), a nuclear medicine study that evaluates blood flow and activity in the brain.

The extreme stress and reactions from PTSD and C-PTSD result in acute and chronic changes in neurochemical systems and specific brain regions, which result in long-term changes in brain 'circuits', involved in the stress response. This is why replacing negative connections and cycles, or finding a way to bypass them, can take a heavy investment of time and therapy.

## AMYGDALA

The amygdala is the part of the brain that formulates a response to stress. It takes this 'alert' from sensory input – such as something you see or hear – and connects it to something from the memory.

In response to perceived danger, it sends out an 'alarm' to warn the rest of the body that various psychological actions are needed. For instance, that to defend yourself you need to activate flight, fight or freeze. Once the danger or perceived danger has passed, new signals are transmitted to calm everything back down.

Someone who has PTSD or C-PTSD often has excessive activity in their amygdala, which can be picked up on brain scans. This is when the amygdala is too sensitive, triggers too easily, or stays on high alert for longer than it should. The symptoms would be hypervigilance and an extreme reaction to perceived threats, including being easily startled and often in a state of anxiety. Having an overactive amygdala creates other physical effects too, including poor sleep patterns.

## HIPPOCAMPUS

This part of the brain works in tandem with the amygdala. It is where we store memories, and also the brain tissue that sorts and retrieves memories. PTSD can make this link 'unstable'.

For example, when someone without the condition hears a loud bang, though it makes them jump, in a split second they make a connection with fireworks and realise one has gone off nearby. The message is relayed to the amygdala that all is well, and it's appropriate to stay calm.

Someone who has experienced trauma may make the connection to an extremely traumatic incident instead. For example, a firework sends them into a state of anxiety

and fear, possibly creating flashbacks and extreme behaviours – their mind thinking it's someone breaking into their house, a gun shot, a terrorist attack etc. In this situation, the hippocampus does not supply the amygdala with the message to calm everything down. It's believed that this sort of constant activity can reduce the size of the hippocampus, so again the physical effect of PTSD can be seen on scans. Also, re-experiencing the trauma can create other physiological symptoms, such as sweating, insomnia and severe headaches.

## MEDIAL PREFRONTAL CORTEX

The prefrontal cortex – situated around the forehead – deals with emotions and impulses, and therefore has a substantial role to play in someone's actions. Under normal circumstances, it would act in tandem with the hippocampus, sending signals to the amygdala to 'switch off the alarm system' when a situation calms down. It's like a 'brake' system for physical responses to stress, reassuring the body and mind that all is well.

When someone has PTSD or C-PTSD, this part of the brain is often underactive. It is 'dampened down' by the trauma. This can manifest as someone being withdrawn, irritable and appearing 'cold' or showing avoidance behaviours.

It's an involuntary defence mechanism, creating emotional numbness so that they don't have to relive the intense feelings created by their trauma. Low activity in the prefrontal cortex means that it doesn't interact efficiently with the hippocampus and its store of memories and interferes with the amygdala alarm system's 'off switch'. Alternatively, a malfunctioning medial prefrontal cortex could make fear the dominant emotion. This, too, keeps the amygdala on high alert.

Importantly, the frontal lobe is also the part of the brain that deals with language skills. PTSD can therefore result in the individual struggling to articulate their emotions and thoughts.

## CORTISOL LEVELS

Cortisol is a stress warning to your body, and therefore it heightens alertness and creates fear. When the brain 'decides' to put the body on full alert, the amount of cortisol produced increases. It can alter or even shut down certain functions, to keep the body ready for 'fight or flight' for example.

When the perceived danger is gone, the brain again adjusts the production of cortisol, calming it down and so allowing

the rest of the body to 'reset' back to normal. What happens if this 'calm down' message is never issued? The alarm system is switched on around-the-clock and the body is continuously in stress mode.

This then impacts on the core bodily functions like digestion, skin repair and sleep. Someone with PTSD may also have problems with moods, memory and concentration, as well as anxiety or depression.

## THE PERFECT STORM IN YOUR BRAIN

These changes in the brain as a result of trauma really create a 'perfect storm'. The amygdala is over-active – but the system to calm it down is not effective – leaving someone continuously or repeatedly in 'danger' mode which leads to extreme reactions and actions, that to someone else, looks out of proportion to the situation.

Therapies such as EMDR (Eye Movement Desensitisation Reprocessing) for PTSD and C-PTSD will often focus on 'rewiring' the connection between memories, emotions and behaviours to give someone new associations and coping strategies, to dismantle negative cycles and create healthier brain function.

There is evidence from a variety of studies that successful treatment of PTSD with therapies such as EMDR and CBT do produce measurable structural changes in brain regions associated with fear conditioning.

These studies show why it's possible to reverse the effects and heal from PTSD and C-PTSD.

*Thanks to this publication, throughout the year, we'll be bringing you more information about PTSD to help you support not only patients or clients, but also your friends and family around you who may be affected by PTSD. We'll be taking a more in-depth look at a variety of aspects of PTSD – but if you'd like more information about PTSD in the meantime, please do visit our website: [www.ptsduk.org](http://www.ptsduk.org).*

*If you or your workplace would be willing to have a stand with / hand out leaflets and booklets about PTSD – please do drop us an email at [info@ptsduk.org](mailto:info@ptsduk.org) with your name, address and some information about what you need.*

# MS: A FLARE DEAL

For many people with multiple sclerosis (MS), relapses are a considerable part of their condition, yet confusion about their occurrence and the most effective action to take may still linger. Here the MS Trust team discusses what information patients should be aware of, in addition to how relapses can be identified and dealt with.



## WHAT IS A RELAPSE?

A relapse is a relatively sudden (over hours or days) episode of new symptoms or a worsening of existing MS symptoms. People call relapses by different names, including an attack, a flare up, an episode, a blip or an exacerbation.

If your patient has relapsing remitting MS, they may have episodes of symptoms (a relapse) that occur for a period of time (usually days, weeks or months) which then improve either partially or completely (remission). They tend to happen most often in the first few years after being diagnosed with MS but people can experience a relapse at any time.

If the individual has secondary progressive or primary progressive MS, they may also experience relapses, but much less frequently.

To be considered a new MS relapse:

### OLD MS SYMPTOMS MUST HAVE BECOME WORSE OR NEW SYMPTOMS APPEARED

Most people with MS experience some symptoms continuously, but between relapses this background level will remain more or less stable. It's when symptoms change that they may be having a relapse.

### SYMPTOMS MUST LAST FOR AT LEAST 24 HOURS

However, relapse symptoms generally last for days, weeks, or even months.

### SYMPTOMS MUST OCCUR AT LEAST 30 DAYS FROM THE START OF THE LAST RELAPSE

MS symptoms should have been stable for about one month before symptoms become worse or new symptoms appear.

### THERE MUST BE NO OTHER EXPLANATION FOR THE SYMPTOMS

Heat, stress, infections and other factors can make symptoms worse and can be mistaken for the start of a relapse. When these factors are resolved, the patient's symptoms should improve.

If the individual isn't sure whether they are having a relapse, they could wait a day or two to see if their symptoms improve before contacting a health professional. With time, the patient will become an expert on their own MS and will develop a better feel for whether they're having a relapse or if it's just the day-to-day fluctuation of their symptoms.

Any MS symptom can be associated with a relapse, but the most common ones include issues with fatigue, dizziness, balance and co-ordination, eyesight, bladder, weakness in a leg or arm, areas of numbness, pins and needles or pain, memory and concentration, and mobility. The patient can experience one or several of these symptoms together during a relapse.

Whatever symptoms are experienced, they're likely to get gradually worse over a few days, or perhaps longer, and then level off. After a time (typically weeks, though this varies) the symptoms will usually subside and the patient will gradually start to recover. Sometimes the symptoms of a relapse go away completely but, in other cases, they may not fully disappear.

Both the frequency and severity of relapses are very variable and unpredictable. A UK study in 2012 found that on average, people with relapsing remitting MS have around one relapse every two years.

However, some people may have several relapses in one year, while others may go for several years without having a relapse.

During pregnancy, women are less likely to have a relapse, although the risk of relapse increases in the six months after the birth. This is thought to be due to changes in the level of hormones, particularly oestrogen, in the body during and after pregnancy.

Some relapses have relatively little impact on what the individual can do day-to-day and their symptoms may improve within a few weeks. However, other relapses may be more severe and could require a stay in hospital followed by a recovery period. Recovery from a relapse usually happens within the first two-to-three months, but may continue for up to 12 months.

## WHAT HAPPENS IN A RELAPSE?

When the immune system attacks the myelin covering of nerves, it causes inflammation and damage to the myelin (demyelination). Messages pass along demyelinated nerves more slowly, or may even be completely blocked. This can lead to a variety of symptoms, depending on the part of the brain or spinal cord that is affected.

When the inflammation subsides it is possible for the damaged myelin to be replaced, a process known as remyelination. Messages are able to pass along the affected nerves more easily and symptoms gradually improve. Although the new myelin can work effectively, it tends to be thinner than unaffected myelin and so messages through the affected nerves may not be as fast as before the relapse.

It should be noted that inflammation doesn't always result in a relapse. It can occur in a part of the brain which isn't associated with symptoms, or the brain may be able to adapt rapidly and re-route messages around an area of inflammation. These are known as silent lesions, or a subclinical relapse, and can only be seen using MRI scans. Increasingly, these subclinical relapses are being seen as an important marker of MS activity and one of the measures which make up the NEDA (no evidence of disease activity) treatment goal.

## WHAT SHOULD AN INDIVIDUAL DO IF THEY THINK THEY'RE HAVING A RELAPSE?

If the patient thinks that they're having a relapse they should report it to their MS team as soon as possible.

Relapses can be a sign that their MS is becoming more active so it's important to report each one, even if they don't think they need medical treatment. If the MS is becoming more active, it may be necessary to consider starting one of the disease-modifying drugs or switching to a different one.

Soon after diagnosis, the MS nurse should explain what to do if the patient thinks that they're having a relapse. If they haven't been told what to do, they could ask their MS nurse or neurologist for advice. Different centres have different approaches to reporting and managing relapses. For many people, their MS or neurology nurse will be the first point of contact. For others, it could be their neurologist or GP. Some MS nurses will discuss the individual's concerns by phone or email, others may book an appointment to see them. Some MS teams have relapse clinics that they can attend at fairly short notice.

The MS nurse will ask the individual about the symptoms they're experiencing, when they started, what has changed, and how these symptoms are affecting them on a day-to-day basis. Their MS nurse will also want to know if there's anything happening that could be making their symptoms worse, such as any signs of a possible infection

– this will often include having a test for a urinary tract infection. Some women find that their MS symptoms worsen around the time of their period, so the MS nurse may ask about their menstrual cycle.

## HOW ARE RELAPSES TREATED?

Once the patient's MS nurse has confirmed that they're having a relapse, they should discuss their symptoms with them and decide whether they need treatment for the relapse itself or any of the symptoms they are experiencing.

Not all relapses need treatment. The symptoms of a relapse will generally improve on their own.

### STEROIDS

If the patient's relapse is having a significant effect on what they want to do day-to-day, their MS team or GP may suggest that they take a short course of steroids. Their MS nurse or neurologist should discuss with them the pros and cons of taking steroids so that they can decide together on the best course of action in the particular situation.

Steroids speed up recovery from a relapse by reducing inflammation and ideally should be started as soon as possible after the patient's relapse has been confirmed. However, taking steroids won't affect how well they recover in the long-term from the relapse and won't affect the course of their MS.

Steroids can be taken as tablets, or through an intravenous infusion (drip) in a hospital clinic.

### REHABILITATION

Whether the patient decides to take steroids or not, there may be other treatments to help them with their symptoms. These might include medication for MS symptoms, physiotherapy, occupational therapy to support them at home or at work, neuropsychology, or speech and language therapy. For more severe relapses, the patient may need help from social services, for instance, with aspects of their personal care or preparing meals.

### FOLLOW-UP APPOINTMENT

If required, the MS nurse may arrange a follow-up appointment, which might be either face-to-face or over the phone. This will typically take place about two months after the start of the patient's relapse and is an opportunity for their MS nurse to check how they are and for them to discuss other treatment options if things are still difficult. The MS nurse should also make a record of the patient's relapse and pass this on to their neurologist, so that their MS team has a full record of their relapses and symptoms.

## ABOUT THE MS TRUST

The MS Trust is here for everyone affected by MS, from the moment of diagnosis and throughout their journey. The MS Trust is here for them today, tomorrow and every day after, making sure a life with MS isn't a life defined by MS.

The MS Trust is committed to ensuring that EVERYONE with MS can access the treatments and services they need and deserve.

It is the charity that believes that no-one should have to manage MS alone, whatever their personal or social circumstances.

*For more information, visit [www.mstrust.org.uk](http://www.mstrust.org.uk), call 0800 032 38 39 or email [ask@mstrust.org.uk](mailto:ask@mstrust.org.uk).*

## STROKE

# FOLLOW THE SIGNS

Someone in the UK has a stroke every five minutes and there are around 1.3 million stroke survivors living across the UK. Despite these startling statistics, alerting patients to the symptoms remains more crucial than ever. The Stroke Association further unravels the risks, in addition to the role of healthcare providers in stroke prevention.

### SIGNS AND SYMPTOMS OF STROKE IN THE SPOTLIGHT

A stroke is a brain attack. It happens when the blood supply to part of the brain is cut off, killing brain cells.

There are three different types of stroke; ischaemic strokes, haemorrhagic strokes and transient ischemic attacks.

A stroke can strike anyone, at any time, so it's vital we all know how to spot the signs of a stroke in ourselves or someone else. Individuals can do this using the FAST test:

- Facial weakness: can the person smile? Has their mouth or eye drooped?
- Arm weakness: can the person raise both arms?
- Speech problems: can the person speak clearly and understand what you say?
- Time to call 999: if you spot any signs of a stroke, call 999

### RISK FACTORS FOR STROKE

A stroke can happen to anyone, but there are some things that increase an individual's risk of a stroke. Most strokes (nine-out-of-10 / 89 per cent) are associated with modifiable risk factors, therefore the individual can reduce their risk of stroke, through changes to their lifestyle.

High blood pressure is the biggest risk factor for stroke – a contributing factor to around half of all strokes and atrial fibrillation contributes to one-in-five strokes. The best thing individuals can do

to reduce their risk of stroke is to monitor and manage their blood pressure. With simple checks, their GP can help them understand their risk of stroke, and support them to make the changes necessary to reduce their risk, which might be changes to what the individual eats or medication. If they have been told that they have atrial fibrillation, the individual is advised to attend routine health checks and work with their GP to monitor and treat it. Eating a balanced and healthy diet, exercising and stopping smoking can also help to lower their overall risk of stroke.

### HEALTHCARE PROFESSIONALS AND AWARENESS-RAISING

Stroke is a medical emergency. The FAST test can help recognise the signs. With the support of healthcare professionals, we can raise awareness of the FAST test and ensure that more people know how to recognise the signs of stroke. We have a range of free resources available and healthcare professionals can order free FAST wallet cards or leaflets and download our information pack for them or their patients.

Taking opportunities to check blood pressure and heart rate to identify potential cases of hypertension or atrial fibrillation in pharmacies could help to reduce someone's risk of stroke. It's vital that people who are diagnosed with these conditions are referred to their GP, so that they receive the appropriate medical support and lifestyle advice to help lower their risk of stroke.

Healthcare professionals can also sign up to our professionals network for further updates on our work around stroke prevention.

### IMPACT OF COVID-19 ON STROKE SERVICES

Stroke services have remained open throughout the COVID-19 pandemic, however since the start of the pandemic there has been widespread impacts on the entire health system that have affected stroke services and stroke survivors. COVID-19 affected the treatment and rehabilitation therapies available for stroke survivors, putting their recoveries at risk.

While GPs have worked incredibly hard to maintain service during the pandemic, there have also been fewer face-to-face appointments which means that the diagnosis rate of conditions, including high blood pressure – that increase their risk of stroke – have dropped, putting more people at risk of a stroke. We also saw a rapid move towards telemedicine across healthcare which has been convenient and effective, but stroke survivors must have a choice as to how they access services, so that they can receive the personalised support that best suits them.

We're incredibly grateful to healthcare professionals who have worked tirelessly during the COVID-19 pandemic to deliver stroke services and support stroke survivors to rebuild their lives and who continue to support stroke survivors as services begin to recover.

### AIDS AND RESOURCES

Visit [www.stroke.org.uk](http://www.stroke.org.uk) for more information about stroke and the work of the Stroke Association. Find resources, events and information aimed at professionals providing care and support to those affected, or at risk of stroke at [www.stroke.org.uk/professionals](http://www.stroke.org.uk/professionals).

## PANDEMIC SCIENCE HUB TO DEVELOP BETTER DRUGS TO FIGHT LUNG DISEASE

A new multi-million pound research programme to develop treatments for lung infections, such as COVID-19 and future pandemics, has been announced at the University of Edinburgh with support from a significant donation by Baillie Gifford.

The Baillie Gifford Pandemic Science Hub will use translational genomics – following clues from the human genome to identify and rapidly test new treatments – with experimental medicine methods to quickly evaluate and develop drugs for lung inflammation and injury caused by infection.

It will combine Edinburgh's world-class ability to determine a person's genetic predisposition to lung injury with advanced interventional robotics for drug delivery, cutting-edge sensing and sampling technologies, and innovative clinical trial design.

Baillie Gifford is supporting the launch with a philanthropic gift of £14.7 million. The university aims to secure a total of £100 million investment to accelerate discoveries to drive clinical translation in COVID-19 and other human lung diseases, as well as aiding preparedness for future pandemics.

This investment will accelerate partnerships and translational opportunities with other academic organisations, industry and other

collaborators worldwide.

The hub builds on the success of GenOMICC and STOPCOVID, experimental medicine projects led by Professors Kenneth Baillie and Kev Dhaliwal, respectively.

Professor Kenneth Baillie, GenOMICC's Chief Investigator and Professor of Experimental Medicine at the University of Edinburgh, said, 'The generous donation from Baillie Gifford enables us to build on recent advances in genomics, computing, engineering and experimental medicine – all major strengths at Edinburgh – to speed up the process of drug development, so that we'll be able to find targeted therapies more quickly for new, and old, diseases. The hub will use clues from human genetics to develop new drugs, and then build technologies to rapidly test those drugs in critically ill patients.'

## RECRUITMENT

### CUSTOMER FACING BUSINESS MANAGER – (PHARMACEUTICAL / HEALTHCARE SALES)

LOCATION: FIELD BASED – GLASGOW, AYRSHIRE, DUMFRIES & GALLOWAY

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## CALLS FOR EMPLOYERS TO BETTER SUPPORT CRITICAL EMERGENCY WORKFORCE

A leading medical faculty is calling for employers to take action to better support NHS staff, following the publication of a new report which highlights the growing level of distress experienced by emergency workers.

The Royal College of Surgeons of Edinburgh's Faculty of Pre-Hospital Care has published a series of recommendations to improve working conditions for emergency workers as part of the psychosocial care and mental health of practitioners' programme.

It has been recommended that practitioners who experience distress should have access to bolstered peer support and safe spaces after attending emergencies and disasters. The report highlights how the type of distressing situations faced by the pre-hospital workforce can't be underestimated nor expected not to impact on practitioners – with leaders stating 'we are all human.'

This is well-recognised and usually well-supported by employers through peer support, debriefing and further psychological support when needed. However, what is notable and less well-known is the impact of 'secondary stresses'. It's these recommendations from the report that emergency care staff are looking to employers to address. Typically, these include domestic issues, geographical relocation, long commutes and exams, rather than the difficult cases themselves.

The report, named 'Valuing Staff, Valuing Patients,' outlines a series of key recommendations to help support those working in critical care roles. It has also prompted leaders at the Royal College of Surgeons of Edinburgh to call for action from the NHS to significantly improve working conditions and ensure support for staff – or face a major workforce crisis.

Dr Pamela Hardy, Chair of the Royal College of Surgeons of Edinburgh's Faculty of Pre-Hospital Care, reflected, 'Never has there been such a timely report as the psychosocial and mental health of health service workers, who have been so challenged throughout the past two years. The commission began well before the recent pandemic but its added influence and effect on healthcare workers cannot be underestimated.'

SHR

## PERINATAL MENTAL HEALTH

# A HELPING HAND

Due to insufficient coverage and limited conversation, many parents are having to tackle the toll of perinatal mental health alone. Annie Belasco, Head of Charity, PANDAS Foundation, delves into the condition, the impact of COVID, and how families can be fueled with help and support to move forward in their lives.



Annie Belasco

Perinatal mental health is a much undiscovered subject for many people, including expecting and new parents. Many parents begin their parenting journey with excitement, high hopes and optimism, planning practical arrangements, and having great expectations for the planning and arrival of their new baby. Many parents arm themselves with knowledge and resources to be as fully prepared as possible.

### WHAT IS PERINATAL MENTAL ILLNESS?

Perinatal mental illness is a significant, but manageable, illness which includes pre- and post-natal depression and anxiety, maternal OCD, birth trauma / PTSD and, in extreme circumstances, psychosis.

The symptoms can occur at any time from pregnancy through to birth and beyond. One-in-10 women experience perinatal mental

illness after having a baby, and we also know that the likelihood of a man experiencing post-natal depression can be up to 50-to-75 per cent more likely if their partner has received a mental health diagnosis. We know that the strains and stresses of everyday life and expecting a new baby can be daunting enough, but sadly for some, to then experience perinatal mental illness without the right support can be catastrophic.

Different factors can contribute to perinatal illness. Pre-existing mental health conditions, adverse childhood experiences and birth trauma can be some, but not all, of the triggers for perinatal mental illness. Some of the symptoms can include low mood, anxiety, panic attacks, dark thoughts, loneliness and isolation. There is often lots of warning around the term 'baby blues' which typically lasts around two weeks after the baby is born which can include low mood and anxiety. However, persistent symptoms that don't go away for longer periods can be a glowing red flag for something more sinister within perinatal mental health.

### THE PANDEMIC EFFECT

During lockdown periods between March 2020-and-March 2021 PANDAS Foundation (pre- and post-natal depression advice and support), who support parents, carers and their networks, saw a rise to their helpline of 240 per cent from parents who were terrified of being even further isolated due to not being able to access services, such as antenatal support, aftercare support and regular face-to-face appointments with their GPs, health visitors and midwives. The services were still open, but the communication channels changed, causing and triggering further anxiety for parents who wanted to enjoy their parental journey without the additional challenges.

### BRIDGING THE GAP

Early intervention is crucial for the successful treatment of perinatal mental illness, and this is where PANDAS can bridge the gap between parents and the NHS who are much over-stretched and under-resourced. While we don't offer medical advice, you do not need to have a diagnosis to contact us and we have the most experience from a lived, work and academic experience basis, running our teams with our incredible selfless volunteers who balance their own jobs and home life alongside PANDAS – offering an experienced and empathetic lifeline for many parents who don't feel that their symptoms warrant any advice or support, or parents and carers who have no knowledge or understanding of perinatal mental illness.

Recovery is completely possible with the right knowledge, advice, with someone who is empathetic, and by receiving correct signposting going forward.

*For more information, visit [www.pandasfoundation.org.uk](http://www.pandasfoundation.org.uk).*

## £3 MILLION AWARDED TO LONG-COVID PROJECTS

Projects to improve the care and support available for people with long-COVID are to benefit from an initial tranche of £3 million of Scottish government funding.

Following a thorough planning process undertaken by health boards to determine the key priorities, the first allocations of the Long-COVID Support Fund across 2022 will provide £3 million for boards to introduce care co-ordinator roles, extra resource to support a patient-centred assessment, including a multidisciplinary assessment service, and additional capacity for community rehabilitation to support people with issues affecting their day-to-day quality of life.

Support for people with long-COVID is already available across a full range of NHS services. However, this additional investment has been informed by patient experience and expert views brought together by the Long-COVID Strategic Network set up by the Scottish government – drawing on priorities identified by people affected by long-COVID and recommendations from clinicians.

As well as the awards to boards, NHS National Services Scotland has also been awarded £370,000 to support a national programme

of improvement work led by the National Strategic Network – this includes £200,000 to provide digital tools to support the care of people with long-COVID. The network will also provide an analysis of the specific needs of children and young people living with long-COVID in Scotland

Health Secretary Humza Yousaf, who announced the allocation during a Scottish parliament debate, said, ‘We have already supported thousands of people struggling with long-COVID through a wide range of measures but the investment announced today has been shaped by priorities highlighted by people with long-COVID themselves. We’ve engaged directly with NHS boards, alongside clinical experts and those with lived experience, to identify the support that they need. This will help ensure the investment through our £10 million Long-COVID Support Fund will make the biggest difference to people living with long-COVID.

‘Given the range of symptoms which can be involved, we know there’s no ‘one-size-fits-all’ response and our approach is to support people with long-COVID to access care and support in a setting that is appropriate and as close to their home as practicable.’

## DEENOVA LAUNCHES FIRST EVER PAY-PER-DOSE UNIT DOSE PHARMACY AUTOMATION SERVICE IN ENGLAND

Closed-loop medicines management, enabled by the unit dose approach, offers substantial benefits to patient safety, decreases medicines waste, and reduces nurses’ workload to free up more time for patient care.

In UK hospitals the established way to handle and dispense medicines is in multi-dose packs, which doesn’t allow for closed-loop administration, creates multiple handling of the same pack, and often leads to wasted medicines.

Unit dose is a medicine handling system in which multi-dose packs are separated into individual doses, repacked and labelled with the original packaging information. Up until now, separating packs down into unit doses has largely been a manual process, carried out by a hospital pharmacy.

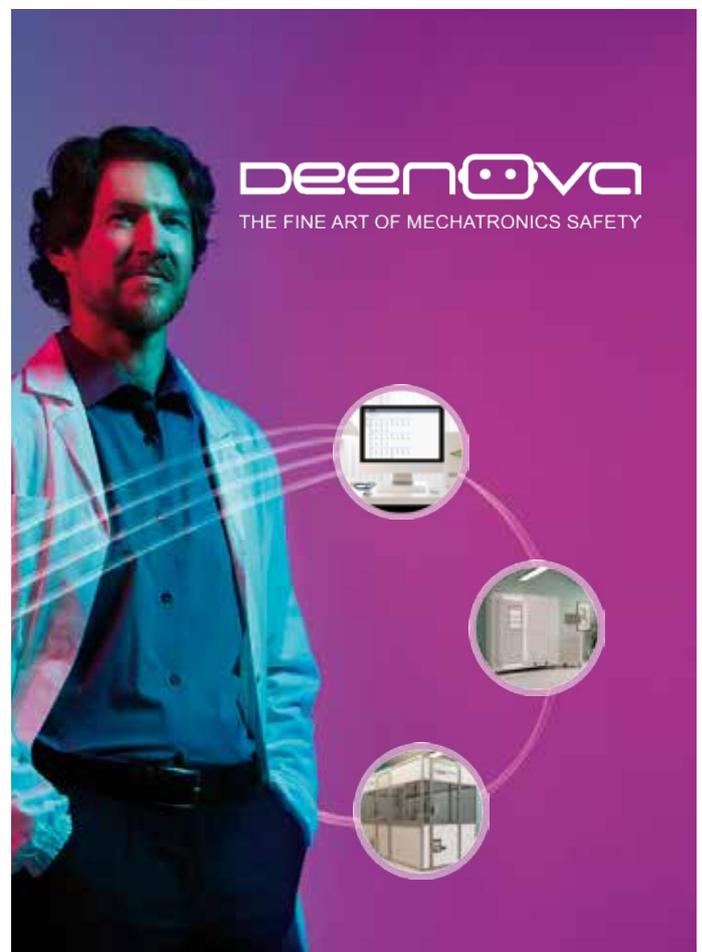
Deenova’s pharmacy technology automates the entire process. It uses off-site facilities for pack splitting while preserving sterility and medicine information, and uses software to track every unit from dispensation to the patient’s bed side.

Deenova offers the only pay-per-dose unit dose pharmacy automation service available in the UK, providing a complete approach which enables closed-loop medicines management. This approach promises to ease growing pressures on healthcare providers, offering significant benefits to NHS hospitals, nurses and hospital pharmacists.

With nearly all UK patients given medication during a hospital stay (around 2.5m doses of medication per hospital per year), and approximately 40 per cent of a UK nurses’ day spent administering medicines or on some medicines-related activity, this innovation cannot come soon enough. It is estimated that around 85 per cent of medicines stocked by a hospital pharmacy can be ‘re-packaged’ into unit doses.

Deenova has been delivering unit dose solutions by providing a complete end-to-end service to hospitals across Europe for 18 years, with more than 70 projects to date. Deenova was recently awarded with a 15-year contract from University Hospitals Leicester.

*To find out more, please contact Andy Lyon, Commercial Director UK&I, Deenova. Email: [a.lyon@deenova.com](mailto:a.lyon@deenova.com)*



PAIN

# A MORE OPEN APPROACH TO PAIN?

NICE published new guidelines in April 2021 that pull apart conventional approaches to the management of chronic pain. A roundtable held in London in December 2021 by the Primary Care Society for Gastroenterology looked at these changes and reviewed some of the alternative options emerging for chronic pain. Dr Patricia Macnair overviews the discussions, lessons gauged – and potential consequences for the future of pain management.

Academic GP Professor Pali Hungin explained that the guidelines caused a ripple of disappointment throughout primary care because they ruled out many drugs usually used to treat chronic pain, leaving few options to work with.

‘They emphatically say DO NOT initiate almost all the drugs we would normally use,’ said Professor Hungin, ‘generating an urgent need for improvements in pain management.’

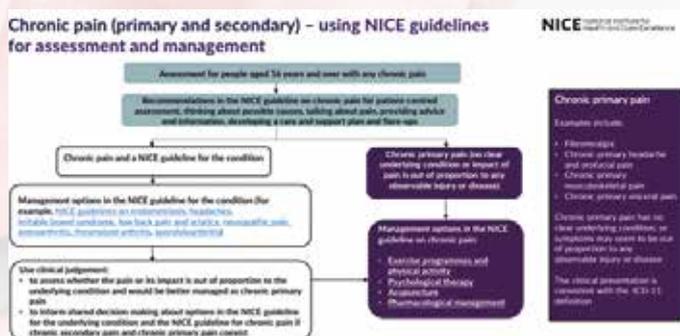


Figure One: NICE guidelines for assessing and managing chronic pain

The guidelines centre on individual patient assessment, especially psychological and emotional factors, and emphasise non-pharmacological treatments, including exercise programmes and physical activity, psychological therapy, acupuncture and finally, pharmacological management.

‘The drug treatments suggested are quite surprising,’ said Professor Hungin. NICE recommend antidepressants, such as amitriptyline, citalopram or duloxetine. Even more radical is advice regarding those drugs which should not be used, described by Professor Hungin as ‘shifting the axis of the world.’ This includes many medicines currently used in chronic pain, including NSAIDs, paracetamol, opioids, local anaesthetics, and neuropathic pain drugs, such as gabapentinoids. Professor Hungin admitted that he found the guidelines challenging. ‘They are not at all helpful to us as clinicians at the point of delivery of healthcare. And who should decide what should be used and where most treatments are to be provided?’

## AN ALTERNATIVE PERSPECTIVE ON PAIN

The NICE guidelines reflect a sea-change in the understanding of chronic pain, establishing how it is not simply a marker of tissue damage, but a complex subconscious phenomenon generated to protect the body when perceived to be under threat. A myriad of biological, psychological and social factors influences this and, as a result, a biopsychosocial model is increasingly used to assess and manage chronic pain.

Professor Roger Jones, Editor of the British Journal of General Practice, enthusiastically reviewed one of several recent books looking at this new approach, ‘The Painful Truth: The New Science of Why We Hurt and How We Can Heal’ by Dr Monty Lyman.

‘Lyman builds a picture to show how pain doesn’t actually come from the ‘painful’ part of the body, it comes from the brain,’ said Professor Jones.

‘Signals are sent to the brain but depending on what’s going on in the brain, pain may or may not be perceived. This turns the whole pain pathway on its head. There’s a lot of evidence to suggest that if the brain doesn’t think the pain is putting you in danger it doesn’t send out much of a pain signal. But if it thinks it needs to keep you safe then it sends out a signal so that you withdraw. This response becomes inappropriate if the pain mechanism continues to fire, and the pain pathway becomes fixed. Then, if you start to feel a twinge and anticipate pain, the brain fires off this embedded mechanism.’

Professor Jones suggested that if the neuroplasticity of the brain can lead to chronic pain, it could also be used to retrain the brain. ‘What’s key is that the author doesn’t mention drugs at all. He takes you seamlessly from the idea that drugs don’t work very well to other things that might work better. If we can change our mindset and include psychological therapies, we might be doing people a favour.’

## PSYCHIATRY CAN PLAY AN IMPORTANT ROLE IN HELPING CHRONIC PAIN

Dr Charlie Bell, Fellow in Medicine Girton College, Cambridge, and a practicing psychiatrist at the Maudsley Hospital, agreed.

‘It’s well-accepted that chronic pain is often associated with psychiatric diagnoses, such as depression and anxiety. But which comes first? Is long-standing pain simply a trigger for depression because of its unremitting nature? Or are pain and depression linked by underlying neurobiological biomarkers? The field is ripe for more studies to identify the neurobiology of chronic pain.’

Building a set of strategies and interventions around a patient-centred approach is key. The pain element is often just the starting point – the wider impact, whether distress, or effect on functioning, or a host of other sequelae, is often just as important as pain itself. Being there for support and advice may be the key role of the medical practitioner, rather than prescribing particular therapies, focusing on the patient’s relationship with pain rather than pain itself. It’s a tricky balance, and one that would be helped by a more open, inclusive and public discussion on chronic pain. ‘We need to get rid of the stigma attached to psychological treatments and put to bed the concept of ‘all in the mind’,’ said Dr Bell. ‘Without a willingness to believe the patient experience, we can achieve very little in the management of chronic pain.’

## HYPNOTHERAPY CAN BE OFFERED IN CHRONIC PAIN

Although not mentioned in the NICE guidelines, hypnotherapy is another useful therapeutic option, and has some evidence in irritable bowel syndrome. Accredited hypnotherapist Vicki Crane put the case for hypnotherapy in chronic pain. Hypnosis can key into a lot of the psychological influences in pain and offers several approaches to help, looking at ways to turn down the perception of pain through intensity reduction, sensory adjustment, analgesia and addressing breakthrough pain. Some of these techniques are drawn from cognitive therapy, such as belief management. Others come from analytical therapy, such as regression techniques, or 'parts therapy' which analyses the 'problem part' of the person. Crane urged people to seek fully-trained hypnotherapists by contacting the National Hypnotherapy Society, the only UK-accredited register of rigorously-trained hypnotherapists. Finally, she reflected on a quote by William James, 'The greatest weapon against stress is our ability to choose one thought over another' and suggested that with help, people can learn to live with pain, adjust to it, and even ignore it.

## DELINEATING THE PROPER USE OF CANNABINOID THERAPIES

Medical cannabinoids offer a group of potentially helpful treatments for chronic pain. Despite being used for 5,000 years for various ailments, cannabis was prohibited in the UK in 1928. Because of this, research into cannabinoids was limited, and in 1970 America influenced the WHO to classify marijuana as a Schedule 1 substance, barring research completely. As a result, modern medicine has taken a very long time to identify the active ingredients.

But in 2017 the American government concluded that there was substantial evidence that cannabinoids are effective for conditions including chronic pain, and the National Institutes of Health, recognising the opioid crisis, recommended cannabinoids as a short-term strategy in chronic pain. Meanwhile, in 2018 the UK Home Office allowed treatment with medicinal cannabis.

According to Dr Rosemary Mazanet, Chief Science Officer for Columbia Care in America, good data lies at the heart of seeing who might be helped by cannabinoids.

'Our mission is to provide patients around the globe with the highest quality, safest medicinal cannabis products available. We are producers of doseable cannabinoid formulations rather than

plant biomass. Unfortunately plant-derived phytocannabinoids are unreliable. Amounts of different cannabinoids in the plant can vary by as much as 70 per cent. There may be one cannabinoid that works well for a patient, but the next time they use the plant there isn't much of that there and it doesn't work anymore.

'If people are going to take something, they deserve to know what's in it and when to take it again. Treatment needs to be predictable; it shouldn't have to be hit and miss,' she said.

## THE IMPACT REGISTRY – A UTILISATION DATABASE

In those American states which allow medicinal cannabinoids, each patient's purchases must be tracked, enabling Columbia Care to develop a utilisation database – the IMPACT registry.

'We can see how often people refill, letting us make some interesting conclusions. If someone buys the same thing at least three times over a period of months there must be some effect, especially as they were paying for it.'

Different drug delivery types are available from the Columbia Care Medicinal Cannabis Program, offering short-acting and long-acting options (Figure 2). Inhalation by vaporisation provides a quick onset of action, with a short duration, which is good for breakthrough pain. Oral formulations were more suitable for people who need a steady blood level.

## SLEEP IS A MAJOR BENEFIT

'One condition that really benefits from medicinal cannabinoids is sleep,' said Dr Mazanet. 'Three-quarters of patients with persistent pain have sleep disturbance, and it's known that sleep has always been one of the important things that cannabis can bring.'

Summarising, Professor Hungin said he was delighted to see the British Medical Journal publish a systematic review and meta-analysis of randomised clinical trials of Medical Cannabis in non-cancer pain in September 2021. Along with this was a Rapid Recommendation providing contextualised guidance based on this body of evidence. It suggested that if standard care was not sufficient, a trial of non-inhaled medical cannabis or cannabinoids could be offered.

'I think this may have implications for the future,' said Professor Hungin.

*You can find a more detailed report at <http://scothealthcare.com/wp-content/uploads/2022/05/A-More-Open-Approach-To-Pain-Report-2022-V2.pdf>.*

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2. Wang L, Hong P J, May C, et al. Medical cannabis or cannabinoids for chronic non-cancer and cancer related pain: a systematic review and meta-analysis of randomised clinical trials. *BMJ* 2021; 374 : n1034 doi:10.1136/bmj.n1034 <https://www.bmj.com/content/374/bmj.n1034>

## COLUMBIA CARE MEDICINAL CANNABIS PROGRAM

### Drug Delivery Types for Unit Doseable Products

#### Inhalation\*

- Vaporization
- Quick onset of action (2-3 mins)
- Short duration of action (2-3 hours)
- Smoking exposes patient to unnecessary risk

#### Oral

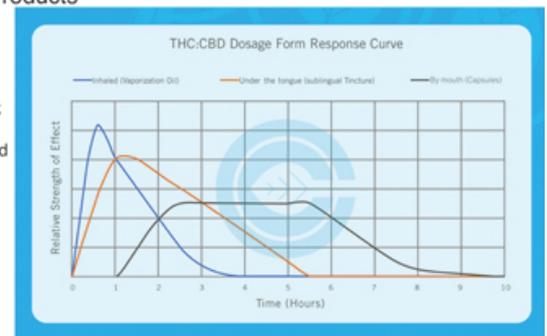
- Capsules, suspensions, edibles, hard-pressed tablets
- Long onset of action (1.5-2 hours)
- Long duration of action (6-10 hours)
- Metabolized in the liver

#### Sublingual

- Sublingual tinctures
- Short onset (~15 mins)
- Intermediate duration of action (4-6 hours)

#### Transdermal

- Lotions, creams, ointments, transdermal patches
- Topical application- local absorption



\*Eisenberg et al 2014  
\*Almong et al 2020  
\*Ben-Ishay et al. 2020

Figure Two: Columbia Care Medicinal Cannabis Program

# PAGET'S DISEASE OF BONE

## CLOSE TO THE BONE

Affecting the normal repair and renewal process of bone, the risk of developing Paget's Disease of Bone increases with age - and is most commonly diagnosed in those over 50 years of age. In this edition, the Paget's Association overviews the condition, and helps us delve deeper into the diagnosis process, patient experience, and subsequent provision of support.

### A DISORDER OF BONE REMODELLING

Characterised by focal abnormalities in bone remodelling at one (monostotic) or several (polyostotic) skeletal sites, Paget's Disease of Bone (PDB) is initiated by enhanced resorption by abnormal multinucleated osteoclasts, followed by disorganised bone formation by osteoblasts. This dysregulation of bone turnover in PDB results in abnormalities of the bone structure, weakening of the bone and enlargement or deformity of the affected bones. Pagetic bone often appears misshapen and enlarged. The focal increases in osteoclast and osteoblast activity in PDB are also accompanied by marrow fibrosis and increased vascularity of bone.

PDB can affect almost any bone, but there is a predilection for the pelvis, spine, femur, tibia, and skull. It is often asymmetrical, and it is unclear why only certain bones are

affected. It is possible that it may be related to mechanical stresses, which are placed on the skeleton at specific sites, or differences in the blood supply to these bones.

### INCIDENCE

In the UK, PDB is the second most common metabolic bone disease after osteoporosis. It has been estimated to affect around one per cent of people, over the age of 55 years, in the UK. In general, it is declining in incidence and severity.

The condition is also common in other European countries, such as France, Spain and Italy, and in people of European descent who have emigrated to other regions of the world, such as Australia, New Zealand, America and Canada.

### AETIOLOGY

The pathogenesis of PDB is not completely understood, but genetic factors play a key role. The most important susceptibility gene for PDB is SQSTM1, which encodes p62, a protein involved in the nuclear factor kappa B (NF- $\kappa$ B) signalling pathway. Mutations in SQSTM1 have been identified in 40 per cent - 50 per cent of familial cases and in five per cent - 10 per cent of patients who do not report a family history.

Environmental factors also play a role in PDB, as evidenced by the fact that reductions in prevalence and severity have been observed in many countries over the past 25 years. Researchers have yet to discover which environmental factors influence the development of PDB.

### ASSESSMENT OF PATIENTS

When PDB is suspected, there must be a detailed assessment process, including any family history of the condition.

### THE PAGET'S ASSOCIATION'S CENTRES OF EXCELLENCE

Most UK hospitals have a specialist who can deal with the condition. If there is no specialist locally, then referral to one of the Paget's Association's Centres of Excellence might be beneficial. The Centre of Excellence Award recognises hospital (NHS) and university departments, within the UK, which demonstrate excellence, in both the care of patients, and research into PDB. Further information can be found on our website [www.paget.org.uk](http://www.paget.org.uk)

# PAGET'S DISEASE OF BONE

## CLINICAL FEATURES

Many clinical features and complications of PDB are thought to be due to the abnormalities of bone remodelling. In many cases, individuals are unaware that they have the condition and may never develop symptoms.

- In those that present clinically, bone pain is the most common symptom
- The blood flow to active areas of PDB increases due to the high rate of bone remodelling. This can sometimes lead to a feeling of warmth over the affected bone
- The affected bone may become enlarged and misshapen

## DIAGNOSIS

The most widely-used biochemical marker to aid diagnosis of PDB is serum total alkaline phosphatase (ALP), which is typically elevated in active PDB.

The condition has characteristic features on x-ray. Individually, these features are not specific, but when they occur in combination, they are usually diagnostic.

Radionuclide bone scintigraphy is widely considered to be a valuable technique for the diagnosis of PDB and to assess the extent of the disease.

## MANAGEMENT

It is recognised that not everyone with PDB requires treatment, because, in many cases, it causes no symptoms nor complications. Decisions to treat PDB should be made by a specialist, on an individual basis.

Specific anti-pagetic treatment involves the use of osteoclast inhibitors to reduce the elevation in bone turnover that is characteristic of active disease. In addition, analgesics, non-steroidal anti-inflammatory drugs, and anti-neuropathic pain agents can be used for symptom control.

### ZOLEDRONIC ACID

For those who require treatment, the current first-line bisphosphonate, due to its potency and prolonged duration of action, is zoledronic acid. It is the bisphosphonate most likely to relieve pain from active PDB. A single infusion of 5mg can be effective for many years.

### RISEDRONATE

Risedronate is also an effective treatment and is given orally once a day, 30mg for two months. Risedronate also helps relieve pain

from active BDB with effects that can last for two years or more. The duration of effect is not as long as that of zoledronic acid.

### PAMIDRONATE

Pamidronate is an effective treatment but has largely been superseded by zoledronic acid. Pamidronate is given in several doses, intravenously and repeated when necessary, depending on symptoms. Doses can vary, but commonly 60mg is given by an infusion and this is repeated on three consecutive days.

### CALCITONIN

In cases where bisphosphonates are not recommended, calcitonin injections may be considered to treat bone pain in BDB.

## FOLLOW-UP

An assessment of the response to treatment should take place between three-and-six months after treatment has been completed.

## CLINICAL GUIDELINE

Commissioned by the Paget's Association, a clinical Guideline\*, for the diagnosis and management of PDB in adults, was published in 2019, on behalf of the Paget's Association, the European Calcified Tissue Society (ECTS), and the International Osteoporosis Foundation (IOF).

The Guideline is a result of work carried out by a Guideline Development Group (GDG), which comprised of a group of experts in the field, with patient involvement. The Guideline was endorsed by the ECTS, the IOF, the American Society of Bone and Mineral Research, the Bone Research Society (UK), and the British Geriatric Society.

### RECOMMENDATIONS

Several recommendations are made in the Guideline. The following were highlighted by the GDG as the most important.

1. Radionuclide bone scans, in addition to targeted radiographs, are recommended as a means of defining, fully and accurately, the extent of the metabolically active disease in patients with PDB.
2. Serum total alkaline phosphatase (ALP) is recommended as a first-line biochemical screening test, in combination with liver function tests, in screening for the presence of metabolically active PDB.
3. Bisphosphonates are recommended for the treatment of bone pain associated with PDB. Zoledronic acid is recommended as

the bisphosphonate most likely to give a favourable pain response.

4. Treatment aimed at improving symptoms is recommended over a treat-to-target strategy, aimed at normalising total ALP in PDB.
5. Total hip or knee replacements are recommended for patients with PDB who develop osteoarthritis, for whom medical treatment is inadequate. There is insufficient information to recommend one type of surgical approach over another.

### FURTHER RESEARCH NEEDED

The GDG found that there was a lack of research on patient-focused clinical outcomes and so they were able to identify several areas where further research is needed. This will assist the Paget's Association when consideration is given to applications for research funds.

### OPEN ACCESS

The Guideline was published in 2019, in the Journal of Bone and Mineral Research\* and has open access. The full Guideline is available to download from our website [www.paget.org.uk](http://www.paget.org.uk).

### \*GUIDELINE REFERENCE

Ralston, S. H., Corral-Gudino, L., Cooper, C., Francis, R. M., Fraser, W. D., Gennari, L., Guañabens, N., Javaid, M. K., Layfield, R., O'Neill, T. W., Russell, R. G., Stone, M. D., Simpson, K., Wilkinson, D., Wills, R., Zillikens, M. C. and Tuck, S. P. (2019), Diagnosis and Management of Paget's Disease of Bone in Adults: Journal of Bone Mineral Research. Vol. 34, p 579-604

## ABOUT THE PAGET'S ASSOCIATION

The Paget's Association is a national UK charity providing information and support to all those affected by PDB. The association funds quality research, raises awareness and supports professionals to achieve excellence in care and research.

*For more information, visit [www.paget.org.uk](http://www.paget.org.uk).*

**Paget's**  
Association

OVARIAN CANCER

# FOR THEIR INFORMATION

New data from Target Ovarian Cancer demonstrates how women are being failed as the awareness crisis in ovarian cancer deepens. With key symptoms continuing to be ignored – both by those experiencing them and their healthcare professionals – how can we transform perceptions and promote vigilance?



In a survey of 1,000 UK women Target Ovarian Cancer found that awareness of ovarian cancer key symptoms is still too low. Four-out-of-five women (79 per cent) don't know that bloating is one of the symptoms. Lack of awareness is just as bad for the others: abdominal pain (68 per cent of women don't know it), feeling full (97 per cent), and needing to wee more urgently (99 per cent).

When symptoms are ignored or passed off as more common conditions like IBS, ovarian cancer has time to advance before it is found. The number of treatment options decreases, as do the chances of long-term survival. Because it's diagnosed late, the disease kills three-in-10 women in the 12 months after diagnosis.

Further compounding the issue is that 40 per cent of UK women think that cervical screening (a smear test) detects ovarian cancer. Worryingly, this is up from 31 per cent in a 2016 survey. Confusion between cervical cancer and ovarian cancer can be fatal. Thinking that a smear test also helps prevent ovarian cancer stops people from looking out for the key symptoms of this deadly disease.

The new data comes as figures from the NHS show a shortfall in the number of people being diagnosed with cancer – risking an epidemic of late diagnosis and early death. Target Ovarian Cancer is urging the public to sign open letters to governments across the UK and tell them what is needed to combat the crisis: dedicated symptoms awareness campaigns across the UK so we can finally make progress in people's knowledge of the symptoms.

Anwen Jones OBE, Chief Executive of Target Ovarian Cancer, commented, 'These figures are incredibly disappointing. We know we've shifted the dial in the past 10 years, through the dedication of thousands of Target Ovarian Cancer campaigners. But it is not enough. Knowing the symptoms is crucial for everyone. We need to make sustained and large-scale government-backed symptoms campaigns a reality. Progress is possible. If we do

this, fewer people will be diagnosed late, fewer will need invasive treatment, and ultimately, fewer will die needlessly from ovarian cancer.'

## KATY'S EXPERIENCE

Katy Stephenson, 47, from Bury St Edmunds, was diagnosed with early-stage ovarian cancer in 2021.

She reflected, 'I had been experiencing symptoms like bloating and needing to wee more urgently for a few months, but I'd put it down to being peri-menopausal. I had a fluke diagnosis when I was admitted to hospital with appendicitis. If that hadn't happened, the cancer probably would have spread, and I hate to think about what would have happened. I was actually told that I wouldn't have symptoms in the early stages of ovarian cancer – but I did. I want everyone to know the symptoms of ovarian cancer. The only person that will catch them is you, so be aware of your own body, speak to a GP. And don't be afraid to mention ovarian cancer if you're worried.'

## WHAT ARE THE SYMPTOMS?

- Persistent bloating – not bloating that comes and goes
- Feeling full quickly and / or loss of appetite
- Pelvic or abdominal pain
- Urinary symptoms (needing to wee more urgently or more often than usual)

Occasionally there can be other symptoms:

- Changes in bowel habit (e.g. diarrhoea or constipation)
- Extreme fatigue (feeling very tired)
- Unexplained weight loss
- Any bleeding after the menopause should always be investigated by a GP

Symptoms will be:

- Frequent – they usually happen more than 12 times a month
- Persistent – they don't go away
- New – they are not normal for the patient

## THERE'S SOMETHING IN THE AIR

Despite the climbing temperature and clearer sky evoking a much-needed reprieve from winter's clasp, the warmer weather can be problematic for many asthmatic patients, particularly when it comes to the effects they encounter due to allergic rhinitis. Margaret Kelman, Specialist Allergy Nurse at Allergy UK, tells us more, and explores why patients' asthma treatment plans need to take into account the seasonal shift.

Asthma is a complex inflammatory condition of the airways. Allergic asthma is IgE-mediated and exposure to a trigger irritant or allergen releases a host of chemical mediators, causing swelling, inflammation and an increase in mucus production. This leads to increased hyper-reactivity in the airways, resulting in symptoms, including dyspnoea and wheezing.

When discussing an asthma management plan, especially during the spring / summer months, it is essential to ask about allergic rhinitis symptoms, as these symptoms are frequently overlooked by the patient. Poorly-controlled asthma can lead to unpredictable asthma attacks or worsening of asthma symptoms, especially when in contact with trigger allergens and irritants, as well as colds or infection. However, untreated or poorly-treated allergic rhinitis is also a risk factor for worsening or poorly-controlled asthma symptoms, as well as increasing the risk of developing asthma in both adults and children of any age.

Research suggests that around 90 per cent of people with asthma have allergic rhinitis and around 10-to-40 per cent of individuals with allergic rhinitis have symptoms of asthma. When allergic rhinitis and asthma symptoms are well-controlled and treated, individuals with asthma experience lower asthma flare-ups and fewer A&E / hospital admissions. Therefore, any treatment plan for asthma needs

to take into account any allergic rhinitis symptoms and treat them accordingly.

Seasonal allergic rhinitis is very common, affecting around 10-to-15 per cent of children and 26 per cent of adults in the UK, and is continuing to increase in prevalence. During the summer months, when grass pollen is particularly high, studies have shown that there is a significant impact on quality of life for sufferers. It has been shown to affect examination results for individuals with grass pollen allergy taking exams during grass pollen season. (Walker et al 2007) ARIA (2019) classifies allergic rhinitis as moderate-to-severe when one or more of the following are impacted; sleep disturbance, impairment of daily activities, and impairment of school / work.

Allergic rhinitis occurs after exposure to an inhaled allergen in a sensitised individual, causing an immunoglobulin E (IgE)-mediated inflammatory response in the nasal lining, releasing chemical mediators in the nasal passages, eyes or airways. One of the key mediators, histamine, works quickly to cause the familiar sneezing, itching and runny nose and eyes. Other mediators work more slowly, causing an inflammatory reaction with symptoms, such as a blocked nose, reduced sense of smell and difficulty sleeping.

Symptoms of allergic rhinitis include itching of the nose, sneezing, rhinorrhoea and nasal congestion. Frequently, there is associated palate, throat, ear, and eye itching, as well as eye redness, puffiness, and watery discharge. Cough is also a common symptom and wheezing or difficulty breathing can also occur if the patient has allergic asthma.

A diagnosis of allergic rhinitis is usually confirmed through the patient's clinical history, without the need for diagnostic testing. However, where there is uncertainty over whether the rhinitis is driven by allergy, the trigger allergen is not obvious, or the exact identification of the allergen is needed for diagnosis or specialist treatments such as immunotherapy, then diagnostic testing, such as a skin prick test, specific IgE blood test or component testing, is useful to determine the allergen that is driving the symptoms.

### MANAGEMENT OF ALLERGIC RHINITIS AND ASTHMA

It is important to advise on avoidance of allergens where practical. In many cases the likely triggers can be identified by taking a careful history from the patient. However, many allergic individuals react to common aero allergens which are difficult to avoid.

Treating symptoms of allergic rhinitis can improve management of asthma symptoms. Mild allergic rhinitis symptoms, including itch and rhinorrhoea, can often be treated with an over-the-counter daily non-sedating antihistamine. Intranasal corticosteroids are very effective in relieving symptoms of nasal congestion, but it is essential to advise your patient that the treatment will only be effective if used regularly throughout the trigger season. Treatment options for more severe allergic rhinitis include intranasal antihistamines, Leukotriene

# ASTHMA

receptor agonist (LTRA) if asthmatic, and immunotherapy. (Scadding et al 2017, Scadding 2020 and Bousquet et al 2019)

Ensure that there is training provided for all medical devices for each patient, including intranasal spray and inhalers, to ensure that they are fully effective, and monitor asthma symptoms and response to treatment:

- How to use your inhaler – [www.asthma.org.uk/advice/inhalers-medicines-treatments/using-inhalers](http://www.asthma.org.uk/advice/inhalers-medicines-treatments/using-inhalers)
- How to apply a nasal spray – [www.bsaci.org/wp-content/uploads/2019/12/Howtouseanasalspray.pdf](http://www.bsaci.org/wp-content/uploads/2019/12/Howtouseanasalspray.pdf)

Also, observe for signs of poorly-managed allergic rhinitis, such as mouth breathing, persistent sniffing or nose-rubbing.

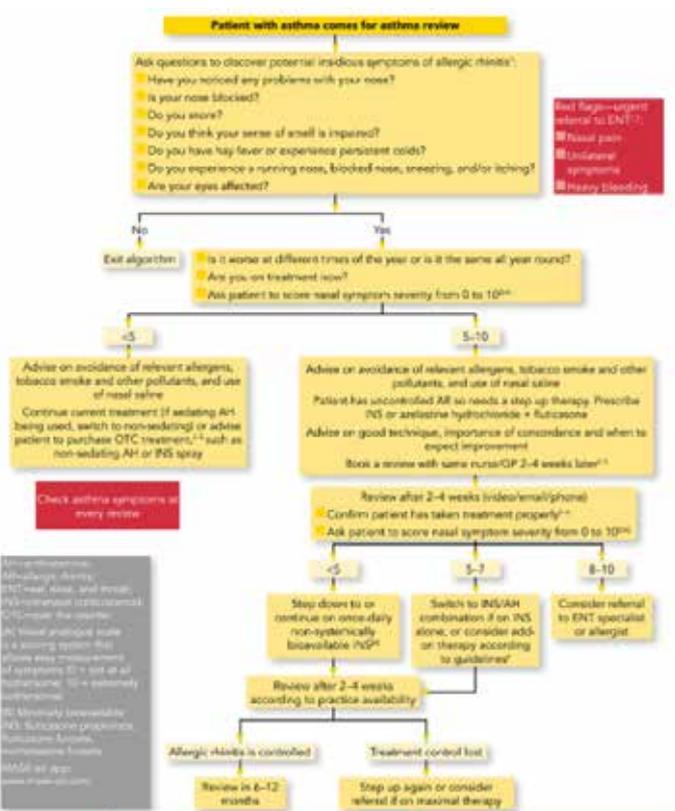
Treating symptoms of allergic rhinoconjunctivitis is important too. Eye drops can be very effective for eye symptoms, with these including antihistamine or mast cell stabilisers. Supportive measures during the pollen season can be very helpful in reducing the symptoms of allergic eye disease, including cold compresses, artificial tear preparations and wearing wraparound sunglasses when outside.

As well as pharmacotherapy, consider supportive measures, including wearing a face mask, wraparound sunglasses, and a hat with a brim to help keep pollen away from the face and hair; nasal douching, to flush out mucous, allergens and irritants; and barrier ointment applied around the base of the nostrils to help trap allergens before they enter the nose – very useful to aid symptom relief, and can be used as frequently as required and in conjunction with usual medication.

Consider onward referral for severe symptoms / symptoms not responding to standard treatments / insufficient response to optimised medical treatment.

- Red flags: consider differential diagnosis and refer to ENT if there are unilateral symptoms only, anosmia, pain, pus or heavy bleeding

## PROFESSIONAL RESOURCES



Box One: Taking a patient history for asthma and allergic rhinitis

Reference – Taking a patient history for allergic rhinitis and asthma [www.guidelinesinpractice.co.uk/respiratory/treating-allergic-rhinitis-helps-improve-asthma-symptoms/455636.article](http://www.guidelinesinpractice.co.uk/respiratory/treating-allergic-rhinitis-helps-improve-asthma-symptoms/455636.article)

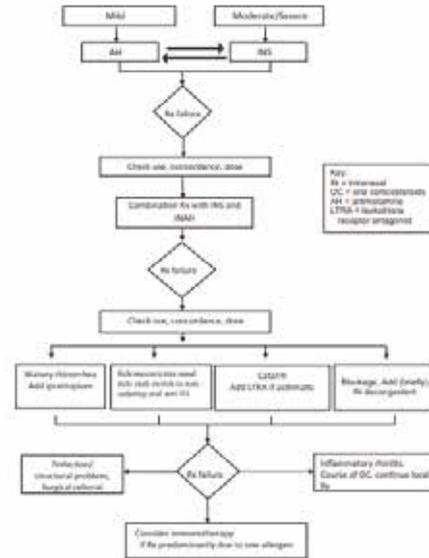


FIGURE 3 Rhinitis treatment algorithm. Additional therapies can be accomplished using two different medications, or a combination treatment in one device. There is, as yet, no comparative evidence on which to base this choice; however, concordance appears more likely when the regime is simple.

## Box Two: BSACI rhinitis treatment algorithm

Reference – Scadding G et al. BSACI guideline for the management of allergic and non-allergic rhinitis (revised edition 2017 first edition 2007) *Clinical & Experimental Allergy*. 2017;47:856–889

## PATIENT RESOURCES

- Asthma – [www.allergyuk.org/types-of-allergies/asthma-respiratory](http://www.allergyuk.org/types-of-allergies/asthma-respiratory)
- Hay fever – [www.allergyuk.org/types-of-allergies/hayfever](http://www.allergyuk.org/types-of-allergies/hayfever)
- Allergic eye disease – [www.allergyuk.org/resources/allergic-eye-disease-factsheet](http://www.allergyuk.org/resources/allergic-eye-disease-factsheet)
- Four seasons booklet – [www.allergyuk.org/resources/four-seasons-managing-your-asthma-and-your-allergic-rhinitis-throughout-the-seasons](http://www.allergyuk.org/resources/four-seasons-managing-your-asthma-and-your-allergic-rhinitis-throughout-the-seasons)
- Asthma UK – how to use your inhaler – [www.asthma.org.uk/advice/inhalers-medicines-treatments/using-inhalers](http://www.asthma.org.uk/advice/inhalers-medicines-treatments/using-inhalers)
- BSACI – standard operating procedure – how to apply a nasal spray – [www.bsaci.org/wp-content/uploads/2019/12/Howtouseanasalspray.pdf](http://www.bsaci.org/wp-content/uploads/2019/12/Howtouseanasalspray.pdf)

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**Prescribing Information: Luforbec<sup>®</sup> 100 micrograms/6 micrograms/actuation (beclometasone dipropionate/ formoterol fumarate dihydrate) pressurised inhalation solution. Consult the full Summary of Product Characteristics (SmPC) before prescribing. Presentation:** Luforbec 100/6 pMDI: Pressurised inhalation solution. Each metered dose (ex-valve) contains beclometasone dipropionate (BDP) 100 mcg and formoterol fumarate dihydrate 6 mcg. This is equivalent to a delivered dose (ex-actuator) of beclometasone dipropionate 84.6 mcg and formoterol 5.0 mcg. **Indications: Asthma:** Regular treatment of asthma where use of an inhaled corticosteroid/long-acting beta<sub>2</sub>-agonist (ICS/LABA) combination is appropriate; patients not adequately controlled on ICS and as needed short-acting beta<sub>2</sub>-agonist, or patients already adequately controlled on both ICS and LABA. **COPD:** Symptomatic treatment of patients with severe COPD (FEV<sub>1</sub> <50% predicted normal) and a history of repeated exacerbations, who have significant symptoms despite regular therapy with long-acting bronchodilators. **Dosage and administration:** For inhalation in adult patients (≥18 years). Luforbec is not recommended for children and adolescents under 18 years. **Asthma: Maintenance therapy:** Luforbec 100/6 pMDI: 1-2 inhalations twice daily. The maximum daily dose is 4 inhalations. Luforbec may be used as maintenance therapy, together with a separate short-acting bronchodilator available for rescue at all times. Patients should receive the lowest dose that effectively controls their symptoms. **Maintenance and reliever therapy:** Luforbec can be taken as a regular maintenance treatment and as needed in response to asthma symptoms: 1 inhalation twice daily (morning and evening) plus 1 additional inhalation as needed in response to symptoms. If symptoms persist after a few minutes, an additional inhalation is recommended. The maximum daily dose is 8 inhalations. Patients should be advised to always have Luforbec available for rescue use. Close monitoring for dose-related adverse effects is needed in patients who frequently take high numbers of Luforbec as-needed inhalations. **COPD:** 2 inhalations twice daily. Luforbec pMDI can be used with the AeroChamber Plus<sup>®</sup> spacer device. BDP in Luforbec is characterised by an extrafine particle size distribution which results in a more potent effect than formulations of BDP with a non-extrafine particle size distribution (100mcg of BDP extrafine in Luforbec are equivalent to 250mcg of BDP in a non-extrafine formulation). When switching patients from previous treatments, it should be considered that the recommended total daily dose of BDP for Luforbec is lower than that for non-extrafine BDP containing products and should be adjusted to the needs of the individual patient. **Contraindications:** Hypersensitivity to the active substances or to any of the excipients. **Warnings and precautions:** Not intended for the initial management of asthma. Treatment should not be initiated during an exacerbation, or if they have significantly worsening or acutely deteriorating asthma. Treatment should not be stopped abruptly. Medical attention should be sought if treatment is ineffective. Patients should be advised to take Luforbec every day even when asymptomatic. Treatment should be discontinued immediately if the patient experiences a paradoxical bronchospasm. Use with

caution (which may include monitoring) in patients with cardiac arrhythmias, especially third degree atrioventricular block and tachyarrhythmias (accelerated and/or irregular heart beat), idiopathic subvalvular aortic stenosis, hypertrophic obstructive cardiomyopathy, severe heart disease, particularly acute myocardial infarction, ischaemic heart disease, congestive heart failure, occlusive vascular diseases, particularly arteriosclerosis, arterial hypertension, aneurysm, thyrotoxicosis, diabetes mellitus, pheochromocytoma and untreated hypokalaemia. Caution should be used when treating patients with known or suspected prolongation of the QTc interval (QTc > 0.44 seconds). Formoterol itself may induce QTc prolongation. Potentially serious hypokalaemia may result from beta<sub>2</sub>-agonist therapy and may also be potentiated by concomitant treatments (e.g. xanthine derivatives, steroids and diuretics). Particular caution is advised in severe asthma as this effect may be potentiated by hypoxia. Formoterol may cause a rise in blood glucose levels. Luforbec should not be administered for at least 12 hours before the start of anaesthesia if halogenated anaesthetics are planned as there is risk of arrhythmias. Use with caution in patients with pulmonary tuberculosis or fungal/viral airway infections. An increase in pneumonia and pneumonia hospitalisation in COPD patients receiving ICS has been observed. Clinical features of pneumonia may overlap with symptoms of COPD exacerbations. Systemic effects of ICS may occur, particularly at high doses for long periods e.g. Cushing's syndrome, Cushingoid features, adrenal suppression, decrease in bone mineral density, cataract and glaucoma and more rarely, a range of psychological or behavioural effects including psychomotor hyperactivity, sleep disorders, anxiety, depression and aggression. Consider referral of patients reporting blurred vision or visual disturbances to an ophthalmologist as causes may include cataract, glaucoma or rare diseases such as central serous chorioretinopathy. Prolonged treatment with high doses of ICS may result in adrenal suppression and acute adrenal crisis. **Interactions:** Possibility of systemic effects with concomitant use of strong CYP3A inhibitors (e.g. ritonavir, cobicistat) cannot be excluded and therefore caution and appropriate monitoring is advised. Beta-blockers should be avoided in asthma patients. Concomitant administration of other beta-adrenergic drugs and theophylline may have potentially additive effects, therefore exercise caution. Concomitant treatment with quinidine, disopyramide, procainamide, phenothiazines, antihistamines, monoamine oxidase inhibitors (MAOIs) and tricyclic antidepressants can prolong the QTc interval and increase the risk of ventricular arrhythmias. L-dopa, L-thyroxine, oxytocin and alcohol can impair cardiac tolerance towards beta<sub>2</sub>-sympathomimetics. Concomitant treatment with MAOIs including agents with similar properties (e.g. furazolidone, procarbazine) may precipitate hypertensive reactions. Concomitant treatment with xanthine derivatives, steroids, or diuretics may potentiate a possible hypokalaemic effect of beta<sub>2</sub>-agonists. Hypokalaemia may increase the likelihood of arrhythmias in patients receiving digitalis glycosides. There is a small amount of ethanol in Luforbec pMDI. There is theoretical potential for interaction in particularly sensitive patients taking disulfiram or

metronidazole. **Pregnancy and lactation:** Use only during pregnancy or lactation if the expected benefits outweigh the potential risks. A risk/benefit decision should be taken to discontinue/abstain from therapy in the mother or discontinue breastfeeding. **Effects on driving and operating machinery:** Unlikely to have any effect on the ability to drive and use machines. **Side effects: Common:** Pharyngitis, oral candidiasis, pneumonia (in COPD patients), headache, dysphonia. **Uncommon:** Influenza, oral fungal infection, oropharyngeal candidiasis, oesophageal candidiasis, vulvovaginal candidiasis, gastroenteritis, sinusitis, rhinitis, granulocytopenia, allergic dermatitis, hypokalaemia, hyperglycaemia, restlessness, tremor, dizziness, otosalginitis, palpitations, electrocardiogram prolonged QTc interval, ECG change, tachycardia, tachyarrhythmia, atrial fibrillation (in COPD patients), hyperaemia, flushing, cough, productive cough, throat irritation, asthmatic crisis, diarrhoea, dry mouth, dyspepsia, dysphagia, burning sensation of the lips, nausea, dysgeusia, pruritus, rash, hyperhidrosis, urticaria, muscle spasms, myalgia, C-reactive protein increased, platelet count increased, free fatty acids increased, blood insulin increased, blood ketone body increased, blood cortisol decrease (in COPD patients). **Rare:** Ventricular extrasystoles, angina pectoris, paradoxical bronchospasm, angioedema, nephritis, increased blood pressure, decreased blood pressure. **Very rare:** Thrombocytopenia, hypersensitivity reactions, including erythema, lips, face, eye and pharyngeal oedema, adrenal suppression, glaucoma, cataract, dyspnoea, exacerbation of asthma, growth retardation in children and adolescents, peripheral oedema, decreased bone density. **Unknown frequency:** Psychomotor hyperactivity, sleep disorders, anxiety, depression, aggression, behavioural changes (predominantly in children), blurred vision. Refer to SmPC for full list of side effects. **Legal category: POM Price and Pack:** E20.52 1x120 actuations **Marketing authorisation (MA) No:** PL 35507/0204 **MA holder:** Lupin Healthcare UK Ltd, The Urban Building, Second Floor, 3-9 Albert Street, Slough, Berkshire, SL1 2BE, United Kingdom. **PI Last Revised:** August 2021. AeroChamber Plus<sup>®</sup> is a registered trademark of Trudell Medical International.

Adverse events should be reported. Reporting forms and information can be found at <https://yellowcard.mhra.gov.uk> or search for MHRA Yellowcard in the Google Play or Apple App store. Adverse events should also be reported to the Lupin Healthcare Limited on +44 (0)1565 751 378 or email us at EU-PV@lupin.com

**Ref: 1.** Certifications of carbon neutrality for Luforbec pMDI. 2. Carbon Footprint Limited, Carbon Assessment Report 2022. Data on File. 3. MIMS: Inhaler Carbon Emissions. <https://www.mims.co.uk/inhaler-carbon-emissions/respiratory-system/article/1739635>. Accessed: May 2022. 4. NHS BSA. Drug Tariff. <https://www.nhsbsa.nhs.uk/pharmacies-gp-practices-and-appliance-contractors/drug-tariff>. Accessed: May 2022. Fostair<sup>®</sup> is a registered trademark of Chiesi Ltd

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# CROSSING THE LINE

## Have you checked in on the latest updates on newly-licensed medicines for use by NHS Scotland?

Advice on three new medicines for use in conditions, including a rare and fatal genetic condition affecting young children and a form of leukaemia, has been published by the Scottish Medicines Consortium.

An initial assessment report has been published for atidarsagene autotemcel which can be used to treat children with a rare genetic condition called metachromatic leukodystrophy (MLD). This medicine has been assessed through the ultra-orphan pathway for medicines that treat extremely rare conditions. MLD causes damage to the nervous system and children with the condition rapidly become unable to walk, talk, swallow, see and hear. The condition is fatal, and children usually only live for five-to-eight years. MLD impacts on the patient but also has a devastating impact on their families and carers.

Atidarsagene autotemcel is a highly specialised stem cell treatment that is given as a single dose and could potentially allow children to develop physically to fully participate in everyday life and attend school. The available clinical evidence for atidarsagene autotemcel is, however, limited, and despite a confidential discount provided by the company, the cost in relation to the health benefits remains high. The company is now required to provide a plan detailing how further data on the effects of the medicine, including those on the patient and carer lived experience, will be collected. Atidarsagene autotemcel will then be available for three years while the information is gathered. Following this, the Scottish Medicines Consortium will review the evidence and make a decision on routine availability in NHS Scotland.

Venetoclax was accepted for the treatment of acute myeloid leukaemia (AML), a cancer of the white blood cells. Used in conjunction with a chemotherapy medicine, venetoclax can be used in patients newly-diagnosed with AML who are unable to have

intensive chemotherapy. Venetoclax was considered through the Scottish Medicines Consortium Patient and Clinician Engagement (PACE) process, which is used for medicines for end-of-life and rare conditions. In the PACE meeting, participants explained the symptoms of the condition which can include fatigue, feeling weak, bleeding and bruising, as well as pain and difficulty moving. The addition of venetoclax to current treatment may increase overall survival and reduce symptoms, therefore improving a patient's wellbeing and quality of life.

Upadacitinib was accepted for the treatment of adults and adolescents with moderate-to-severe atopic dermatitis, a chronic inflammatory skin condition. The itch can be intense, relentless and unbearable and constant scratching causes the skin to split and bleed, leaving it open to infection. Upadacitinib is an additional treatment option that can improve symptoms and allow patients a better quality of life. This treatment is taken orally and may help patients better manage their care.

Mark MacGregor, Chairman of the Scottish Medicines Consortium, reflected on the latest advice, saying, 'MLD is a devastating hereditary disorder. The patient group representatives shared powerful personal testimony with the committee, describing the extent of disability the condition causes and its life-changing impact on patients and families. Atidarsagene autotemcel will be available in NHS Scotland through the ultra-orphan pathway. This will allow patients with MLD to access treatment while more information on its clinical-effectiveness is gained. The Scottish government will announce when this medicine will be available for prescribing. The cost is, however, extremely high. It is essential that the pharmaceutical industry works to improve its efficiency in developing these life-changing therapies if the costs are to be sustainable for health systems around the world.'

'From the evidence given by patients and clinicians in the PACE meeting, we know that AML can cause a range of distressing symptoms. Adding venetoclax to current treatment may have benefits for some patients and we know this decision will be welcomed.'

'Our decision on upadacitinib provides another treatment option for atopic dermatitis which may improve symptoms and provide patients with a better quality of life.'



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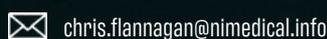
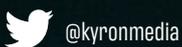


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## INFLAMMATORY BOWEL DISEASE

# A MATTER OF URGENCY

**SHR sweeps the healthcare landscape to discover which recent inflammatory bowel disease-related updates present potential advancements for both the provision and receipt of patient care.**

### **NEW THERAPEUTIC OPTIONS FOR CHILDHOOD INFLAMMATORY BOWEL DISEASE**

Did you know that globally the prevalence for inflammatory bowel disease (IBD) is 396 cases per 100,000 persons annually? And that although the symptoms include abdominal pain, persistent diarrhoea, weight loss and fatigue, the exact cause of the disease remains unknown?

Researchers from the School of Medicine, Trinity College, working closely with paediatric gastroenterologists at CHI-Crumlin, have previously shown that small proteins known as IL-36 cytokines are 'switched on' in the inflamed intestines of children with newly-diagnosed IBD. However, it's still not fully understood how IL-36 cytokines drive disease.

Now, new research from the team addresses this by demonstrating how IL-36 can instruct proinflammatory CD4+ T cells to accumulate in the inflamed intestine and worsen disease. Identifying how these proteins promote disease progression will be invaluable in advancing efforts to target their activity among IBD patients as a new therapeutic option. The study is published in the journal, *Mucosal Immunology*.

IL-36 acts as an instructive signal to drive inflammation in different tissue sites. Its activity is perhaps best characterised in the skin where it is thought to play an important role in driving chronic inflammation in diseases, such as psoriasis. Normally the activity of IL-36 is tightly regulated in healthy tissues to ensure that inappropriate activity does not result in chronic inflammation. For ill-defined reasons this regulation appears to be lost in IBD.

The key finding of the study identifies how IL-36 can cause the accumulation of the damaging CD4+ T cell in the inflamed intestine, where they play a central role in driving the inflammation observed in IBD. These findings build upon the team's earlier work which identified that IL-36 cytokines were elevated among children with IBD and was associated with worsening disease outcomes.

Identifying how these proteins promote disease progression offers fresh insights and will advance efforts to target their activity among IBD patients as a new therapeutic option.

Patrick Walsh, Associate Professor in Paediatric Immunology, Department of Clinical Medicine at Trinity's School of Medicine, explained, 'These results shed new light on how a potential new therapeutic target can promote the early pathogenesis of IBD. Gaining a deeper understanding of how IBD develops during its earliest stages, in childhood and adolescence, is critically important in efforts to design new and improved treatment options for these patients as they transition to adulthood.'

### **COVID-19 VACCINE PROTECTS SUFFERERS OF IBD**

COVID-19 vaccines taken by people with IBD, which affects millions worldwide, safely and effectively protects them from the SARS-Cov-2 virus, a Rutgers study has found.

The comprehensive review, published in the journal, *Alimentary Pharmacology & Therapeutics*, focused on all studies describing the response of patients with IBD who were administered a COVID-19 vaccine. People with IBD are commonly treated with drugs that suppress the immune system and have reported concerns over whether such treatments might weaken their response to the vaccine.

'We wanted to demonstrate in a systematic way that the vaccines will safely protect our IBD patients from COVID-19,' explained study author Abhishek Bhurwal, an Advanced IBD Fellow in the Division of Gastroenterology and Hepatology at the Rutgers Robert Wood Johnson Medical School.

'Our systematic review and meta-analysis confirmed that the vaccines are safe and work well in our patients.'

The disease, which includes Crohn's disease and ulcerative colitis, causes chronic inflammation of the gastrointestinal tract. The numbers of such patients, Bhurwal said, are growing.

The study focused on four key aspects of COVID-19 vaccination of IBD patients: the strength of their immune response to the vaccine; the occurrence of breakthrough infections after taking the vaccine; the occurrence of adverse events to the vaccine; and whether differing IBD treatments affected vaccine effectiveness.

The analysis found that vaccinated IBD patients showed high levels of antibody response, known as seroconversion, two weeks after the first vaccine, indicating a strong, positive response to the vaccine. The response was even higher after two doses, as compared with one dose.

Vaccinated IBD patients did not experience a higher or lower rate of breakthrough infections than the control group in studies. However, the studies analysed were likely not designed to allow for more subtle distinctions. Additionally, further studies regarding effectiveness for variants and booster doses are needed.

Vaccinated IBD patients experienced a low rate of adverse events, and the most common events have also been seen in the general population: reactions at the injection site; headaches; backache; and joint pain.

Vaccinated IBD patients on different immunosuppressive treatments had a similar response to the vaccine. Further studies are needed for assessing patients on corticosteroids for IBD.

Because of their treatment with immunosuppressive drugs, IBD patients are more susceptible to infectious disease than the general population. As a result, they have been encouraged to receive COVID-19 vaccines.

'Because members of the IBD population are immunocompromised, it was important to document that the SARS-CoV-2 vaccines work for them,' Bhurwal continued.

'With this analysis, we can say that two doses of the SARS-CoV-2 vaccines are safe and effective in the IBD population. But we need further studies regarding booster doses and COVID variants.'

# FRONT AND CENTRE

How important is personomics and precision medicine? The Prescribing and Research in Medicines Management team shed light.



The importance of knowing patients as individuals has been highlighted throughout the history of medicine. However, with shorter visits, electronic documentation, reliance on technology, and increasing linguistic and cultural differences between patients and physicians, plus the added challenges of COVID-19, the importance of effective communication is more vital than ever before.

Perhaps more concerning is the greater emphasis on aspects of care considered more precisely measurable and quantifiable, the sum of which is sometimes felt to represent the patient better, than knowledge of the patient himself. While genomics, proteomics, pharmacogenomics, metabolomics, and epigenomics promise enhanced diagnostics and therapeutics, understanding the unique circumstances of the person – what may be called personomics – is at least as critical to patient care. Such an understanding can only be developed when the relevant psychological, social, cultural, behavioural, and economic factors are obtained. Personomics determines how a disease reveals itself phenotypically and the way that disease and the individual with the disease respond to treatment.

Prescribing and Research in Medicines Management (PRIMM) (UK & Ireland) is a multidisciplinary organisation devoted to the study of medicine use in society: research, education, outcomes, interventions, consumption and administration. PRIMM was founded in 1989 by a multidisciplinary group of about 30 people, who were working in drug utilisation research and who noted a lack of awareness of their work among pharmacologists. They recognised a great need to do research in drug utilisation / patient adherence and related issues. The organisation rapidly grew from 30-to-150, attracting hospital

pharmacists, prescribing advisers and academic researchers.

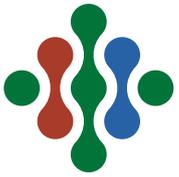
By 1993 an International Conference on Drug Utilisation at the University of Oxford attracted an audience of 380 delegates. PRIMM has flourished particularly in the quality of research. Members of PRIMM made substantial input into the Royal Pharmaceutical Society Working Party entitled, 'Partnership in Medicine Taking'. Since PRIMM's inception, we have seen the subject mature from 'soft science' to one with its own methodology, encompassing qualitative research, precise statistical design and analyses of quantitative research and pharmacoeconomics.

Professor Hugh McGavock, a General Practitioner by background, was a founder member of DURG UK & Ireland (Drug Utilisation Research Group – now known as PRIMM UK & Ireland). Among his other professional activities throughout his long and distinguished career, Hugh was very keen to encourage and support more junior drug utilisation researchers in their careers, hence the Hugh McGavock Award for the best abstract submitted for presentation at the PRIMM Annual Scientific Meeting.

Hugh McGavock sadly died in 2018 aged 79 years. True to form, at the time of his death, he was in the midst of planning a new medical school with the University of Ulster. PRIMM continues to award the Hugh McGavock Bursary at the Annual Scientific Meetings. This year will be PRIMM's 33rd meeting and will be held on 10th June 2022. The title this year is 'Personomics: Putting the Patient at the Centre of Prescribing and Medicines Use'. Globally, it is now recognised that a personalised approach to patient care improves quality and experience of care and can be delivered in an economical way. This is an exciting area for medicines as we see advances in genomics and a move to more personalised prescribing. At our 2022 scientific symposium we will explore the key issues, barriers and enablers to personomics. It promises to be another exciting and innovative event.

*For more information, visit [www.primm.eu.com](http://www.primm.eu.com).*

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Naloxone can help reverse an opioid overdose. So if you use opioids or know someone at risk of an overdose, don't wait. Speak to your local drug service centre about getting a free kit.

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It could help  
save a life.

Opioid overdoses kill thousands every year in the UK. But those deaths could have been prevented – with naloxone. It's a drug that can help reverse an opioid overdose and help save lives. Signs of an opioid overdose include pinpoint pupils, unconsciousness, or breathing problems. Always call an ambulance first if you think someone is having an opioid overdose. For more information, go to [naloxone.org.uk](http://naloxone.org.uk). This campaign is sponsored by Ethypharm and made in conjunction with real naloxone carriers.

# Alkindi® for the Individual

Individualised, accurate and flexible dosing—  
without the need for compounding<sup>1</sup>



hydrocortisone granules  
in capsules for opening



In the long term follow-up study for Alkindi, there were no trends for accelerated or reduced growth and no adrenal crises were observed<sup>2</sup>

## Abbreviated Prescribing Information for Alkindi® 0.5 mg, 1 mg, 2 mg, and 5 mg granules in capsules for opening (Hydrocortisone)

Capsules for opening containing 0.5 mg, 1 mg, 2 mg or 5 mg of hydrocortisone respectively. **Indication** Replacement therapy of adrenal insufficiency in infants, children and adolescents (from birth to < 18 years old). **Dosage** Dosage must be individualised according to the response of the patient: the lowest possible dosage should be used. Recommended replacement doses are 8-15 mg/m<sup>2</sup>/day, in three or four divided doses. In minor illness or trauma, the total daily dose of Alkindi may need to be doubled or tripled. In more severe situations particularly with vomiting/diarrhoea, high fever or trauma/surgery parenteral administration of hydrocortisone and transfer to a facility with resuscitation facilities are necessary. **Administration** The capsule shell must not be swallowed but carefully opened. The granules are either poured directly onto the child's tongue, or a spoon, with or without soft food, can be used to place the granules in the child's mouth. Immediately after administration fluid should be given orally. **Contraindications** Hypersensitivity to the active substance or to any of the excipients. Patients with dysphagia or premature infants where oral feeding has not been established. **Warnings and precautions** Where a child is vomiting or acutely unwell parenteral hydrocortisone should be started immediately. Sudden discontinuation of therapy risks adrenal crisis and death. Relative adrenal insufficiency may persist after discontinuation and in any stress situation therapy should be reinstated. Any signs of infection should be treated seriously, with an increased dose of Alkindi being started promptly. Inaccuracy in dosing possible with conventional oral hydrocortisone crushed or

compounded formulations can lead to adrenal crisis when switching from these to Alkindi. Close monitoring of patients is recommended for a week after switch, and extra doses of Alkindi should be given if symptoms of adrenal insufficiency are seen. If this is required, an increase in the dose of Alkindi should be considered and immediate medical advice should be sought. Growth and/or bone mineral density may be retarded during infancy, childhood and adolescence. Psychiatric disturbances have been observed in adult patients taking replacement doses of hydrocortisone. If this occurs parents should seek medical advice immediately. Rarely anaphylactoid reactions have occurred in patients receiving corticosteroids. Visual disturbances of various types have been reported in patients receiving oral corticosteroids. Should this occur, consult an ophthalmologist. Granule cores may sometimes be seen in stools, no additional dose is required. Alkindi must not be administered through nasogastric tubes. **Interactions** Hydrocortisone is metabolised by cytochrome P450 3A4 (CYP3A4). Concomitant administration of medicinal products inhibiting or inducing CYP3A4 may require dose adjustment of Alkindi and close monitoring. **Pregnancy and lactation** Hydrocortisone for replacement therapy can be used during pregnancy and breast feeding. **Adverse events** A total of 30 healthy adult male subjects in two phase 1 studies and 24 paediatric patients with adrenal insufficiency in two phase 3 studies have been treated with Alkindi. There were no adverse reactions seen in any of the studies. In adult patients receiving hydrocortisone replacement therapy adverse events have been reported with unknown frequency: psychosis with hallucinations and delirium, mania, euphoria, gastritis, nausea, and hypokalaemic alkalosis.

## Legal classification: POM

Product (50 capsule bottle)	Basic NHS Cost	MA Number
Alkindi 0.5 mg granules in capsules for opening	£33.75	PLGB 50616/0007 (UKNI) EU/1/17/1260/001
Alkindi 1 mg granules in capsules for opening	£67.50	PLGB 50616/0008 (UKNI) EU/1/17/1260/002
Alkindi 2 mg granules in capsules for opening	£135.00	PLGB 50616/0009 (UKNI) EU/1/17/1260/003
Alkindi 5 mg granules in capsules for opening	£337.50	PLGB 50616/0010 (UKNI) EU/1/17/1260/004

## Marketing Authorisation Holder

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Tel. +31 (0)20 6615 072. Email: info@diurnal.co.uk

## Prescribers should refer to summary of product characteristics for full prescribing information.

**Approval Code:** Inf EU-GB-0169

**Date of Preparation:** January 2022

**References:** 1. Diurnal. Alkindi® Summary of Product Characteristics. Available from <https://diurnal.co.uk/UkResidents/HCP/alkindi-r-hydrocortisone-granules-in-capsules-for-opening>. Last accessed 18/01/22;

2. Neumann et al. *JCEM* 2021; 106(3):e1433-e40.

**Date of Preparation:** January 2022 **Code:** Inf EU-GB-0174

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