# Welsh Pharmacy Review

ISSUE 58 - 2023

## MIGRAINE

The complexities of the neurological condition

**WELSH PHARMACY AWARDS**

Who claimed the titles?

**ENDOMETRIOSIS**

Bridging the gap in care

**WELSH PHARMACEUTICAL STUDENTS' ASSOCIATION**

Meet the President

**INHALER TECHNIQUE**

How to optimise adherence


## ONE TREATMENT; TWO COLITIS INDICATIONS[1]

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- MILD TO MODERATE ULCERATIVE COLITIS FLARES WHEN 5-ASA IS INSUFFICIENT

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**Prescribing Information:** Cortiment® 9 mg, prolonged release tablets. **Please consult the full Summary of Product Characteristics before prescribing. Name of Product(s):** Cortiment® 9 mg, prolonged release tablets **Composition:** One tablet contains 9 mg of budesonide. **Indication:** Induction of remission in patients with mild to moderate active Ulcerative Colitis where 5-ASA treatment is not sufficient and induction of remission in patients with active Microscopic Colitis **Dosage:** *Adults:* The recommended daily dose for induction of remission for both Ulcerative and Microscopic Colitis is one 9 mg tablet in the morning, for up to 8 weeks. When treatment is discontinued, it may be useful to gradually reduce the dose. *Children:* No data are available, therefore the use in paediatric population is not recommended until further data become available. **Contraindications:** Hypersensitivity to the active substance, soya oil, peanut oil or to any of the excipients of the product. **Special Warnings and Precautions:** Caution is recommended in patients with infections, hypertension, diabetes mellitus, osteoporosis, peptic ulcer, glaucoma or cataracts or with a family history of diabetes or glaucoma or with any other condition where the use of glucocorticoids may have unwanted effects. Visual disturbance may be reported with systemic and topical corticosteroid use. If a patient presents with symptoms such as blurred vision or other visual disturbances, the patient should be considered for referral to an ophthalmologist for evaluation of possible causes which may include cataract, glaucoma or rare condition diseases such as Central serous chorioretinopathy (CSCR) which have been reported after use of systemic and topical corticosteroids. Reduced liver function may affect the elimination of glucocorticoids including budesonide, causing higher systemic exposure. Treatment with Cortiment tablets results in lower systemic steroid levels than conventional oral glucocorticoid therapy. As corticosteroids are known to have immunological effects the co-administration of Cortiment tablets is likely to reduce the immune response to vaccines. Concomitant administration of ketoconazole or other potent CYP3A4 inhibitors should be avoided. *Pregnancy:* Cortiment should only be used during pregnancy if the potential benefit justifies the potential risk to the foetus. **Side effects:** For the full list of side effects please consult the Summary of Product Characteristics. *Common:* nausea, abdominal pain upper, abdominal distension, abdominal pain, dry mouth, dyspepsia, headache, insomnia, acne, fatigue, myalgia, blood cortisol decreased. *Uncommon:* Flatulence, dizziness, mood altered, oedema peripheral, back pain, muscle spasms, influenza, leukocytosis. **Nature and Contents of Container:** The tablets are packaged in blister packs with aluminium push through foil, contained in a cardboard carton. **Marketing Authorisation Number:** *Tablets* 9 mg: 03194/0113 **Marketing Authorisation Holder:** Ferring Pharmaceuticals Ltd., Drayton Hall, Church Road, West Drayton, UB7 7PS, United Kingdom. **Legal Category:** POM. **Basic NHS Price:** £75.00 for 30 x 9 mg tablets. **Date of Preparation of Prescribing Information:** January 2021. Cortiment is a registered trademark. UK-COR-2100001:January 2021.

**Adverse events should be reported. Reporting forms and information can be found at www.mhra.gov.uk/yellowcard. Adverse events should also be reported to Ferring Pharmaceuticals Ltd. Tel: 0800 111 4126. Email: medical.uk@ferring.com**

**References: 1.** Cortiment 9 mg, Prolonged Release Tablets. SmPC. **2.** Entocort CR 3 mg Capsules. SmPC. **3.** Budenofalk 3 mg Gastro-resistant Capsules. SmPC. 4. Budenofalk 9 mg Gastro-resistant Granules. SmPC. **5.** Brunner M, *et al. Br J Clin Pharmacol.* 2006;61(1):31–38. **6.** Fiorino G, *et al. Curr Med Chem.* 2010;17(17):1851–1857. **7.** Travis SPL, *et al. Gut.* 2014;63:433–441. **8.** Sandborn WJ, *et al. Gastroenterology.* 2012;143:1218–1226. **9.** Danese S, *et al. J Crohns Colitis.* 2019;13 (supplement 1):296–297. **10.** Rubin D, *et al. J Crohns Colitis.* 2017;11(7):785–791.

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FERRING PHARMACEUTICALS

# WPR

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# WELCOME

## EDITOR'S LETTER

### Welcome to the latest edition of Welsh Pharmacy Review!

Two key revelations about my ageing process have unfolded over the last few months. One: my outdated pop culture references and limited TikTok knowledge will often be rewarded with disconcerting looks from my younger colleagues. Two: coming to collective agreement on a time to meet up with my friends grows increasingly difficult by the day, as more responsibilities surface.

Rather innovatively (well, to us, anyway), in a bid to tackle number two, everyone's burgeoning schedules, we recently downloaded a polling app to vote on the most convenient evening. True, it meant postponing the get-together an extra couple of weeks to accommodate everyone's priorities – and patience isn't a virtue I was lucky enough to be gifted – but I knew the end goal was more than worth the wait. It meant that we were all going to be able to be together at once.

Some waits are worth shouldering; the process helps absorb the excitement, may be unavoidable, and might not pose long-lasting effects. Other waits, however, warrant our impatience – they add more struggle to the experience and shouldn't be so easily accepted. In fact, it's often the mobilisers of change who have recognised the detriment of their delay and want to create a different, better, future for others.

Carla Cressy is a striking example of this. She has used her experiences of a long-awaited diagnosis of endometriosis as fuel for the formation of The Endometriosis Foundation, and to help establish a system that better supports other people. Read Carla's inspiring story on page 36. Those with Myalgic Encephalomyelitis have also been turning their pain into progress – helping inform clinical practice and bringing light to the frequently misunderstood disease (page eight). Also enlightened through his first-hand experience, Simon Lowe, retired GP, focuses on the important management questions surrounding facial palsy (page 21).

Elsewhere in this edition of WPR, we explore the role of disease-modifying drugs in MS (page 14), the different types and stages of migraine (page 34), and the relationship between the healthcare professional and patient in mastering asthma routines (page 10).

Also – Professor Elaine Cloutman-Green carves out the importance of sharing information in healthcare (page 24), Laura Humphrey Professional Engagement Lead for the Royal Pharmaceutical Society in Wales, reflects on the Pharmacy: Delivering A Healthier Wales Conference (page four), and Caitlin Edwards details the role of the Welsh Pharmaceutical Students' Association (page five).

Before you go, check out the reveal of this year's Welsh Pharmacy Awards winners (beginning on page 25).

Happy reading!

Sarah Nelson

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5mg/ml (100ml of infusion solution contains 500mg levetiracetam)


10mg/ml (100ml of infusion solution contains 1,000mg levetiracetam)


- Ready to Use
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**Name and active ingredients:** Kevesy® 5mg/ml solution for infusion and Kevesy® 10mg/ml solution for infusion. Active ingredient is levetiracetam. **Pharmaceutical form:** Clear, colourless to light yellow solution for infusion. pH: 5.3 – 6.0; osmolarity (mOsmol/Kg): 270 – 330. Kevesy® 5mg/ml solution for infusion contains 5mg of levetiracetam therefore each 100ml bag contains 500mg of levetiracetam. Kevesy® 10mg/ml solution for infusion contains 10mg of levetiracetam therefore each 100ml bag contains 1000mg of levetiracetam. **Indications:** As adjunctive therapy for the treatment of partial onset seizures with or without secondary generalisation in adults, adolescents and children from 4 years of age with epilepsy, treatment of myoclonic seizures in adults and adolescents from 12 years of age with Juvenile Myoclonic Epilepsy and treatment of primary generalised tonic-clonic seizures in adults and adolescents from 12 years of age with Idiopathic Generalised Epilepsy. **Posology and method of administration:** See SmPC section 4.2 for dosage, preparation, administration, duration and special populations. **Contraindications:** Hypersensitivity to the active substance or other pyrrolidone derivatives or to any of the excipients listed in section 6.1 of the SmPC. **Special warnings and precautions for use:** Precautions should be taken regarding: renal impairment, acute kidney injury, decrease in blood cell count, suicide, abnormal and aggressive behaviours, worsening of seizures, electrocardiogram QT interval prolongation, paediatric use and patients on a low sodium diet. **Interactions:** The list of products to avoid concomitant use of or to closely monitor the use of can be found in the SmPC section 4.5. **Adverse reactions:** The most commonly reported adverse reactions are: nasopharyngitis, anorexia, depression, hostility/aggression, anxiety, insomnia, nervousness/irritability, somnolence, headache, convulsion balance disorder, dizziness, lethargy, tremor, vertigo, cough, abdominal pain, diarrhoea, dyspepsia, vomiting, nausea, rash and asthenia/fatigue. For full details on adverse reactions, see SmPC section 4.8 **Presentations:** Both the 5mg/ml and 10mg/ml strengths are presented in a 100ml dual port bag with aluminium over wrap, equipped with two administration tubing ports (injection port and a twist off port with closure). NHS Cost: Kevesy® 5mg/ml solution for infusion: £127.30. Kevesy® 10mg/ml solution for infusion: £254.60. **Legal Classification:** POM **Marketing Authorisation Number:** 5mg/ml PL 21844/0027 10mg/ml PL 21844/0028. Distributed by Kent Pharma UK Ltd. Date of preparation: April 2022. UK22/001/SmPC Feb 2021.

**Adverse events should be reported.** Reporting forms and information can be found at: www.mhra.gov.uk/yellowcard or search for MHRA Yellow Card in the Google Play or Apple App Store. Adverse events should also be reported to Kent Pharma UK Ltd on 01233 506574 or medical@kent-athlone.com. For a copy of the SmPC or further medical information, please contact: medical@kent-athlone.com. Additional information available on request.

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# NEW BEGINNINGS

**From reflecting on the progress paved so far, to looking ahead to the profession's next moves towards fulfilling the 2030 vision, Laura Humphrey introduces her new role as Professional Engagement Lead for the Royal Pharmaceutical Society in Wales.**

Laura Humphrey

It's been an exciting time for me over the last few weeks as I've started a new job as Professional Engagement Lead for the Royal Pharmaceutical Society (RPS) in Wales and the West of England. For those of you who don't know me, I'm Laura and have moved to RPS after 16 years in the NHS. My background is in hospital pharmacy, particularly in paediatrics and in education and training. However, over the last decade I have worked closely with pharmacy professionals across all healthcare settings and walks of life.

My new role is focused around making sure that we at RPS are engaging as much as possible with all our members and the whole profession in Wales. Whatever your career stage, which ever sector you're working within, and wherever in Wales you're based; we want to engage with you.

This means listening to the concerns and opportunities you see for pharmacy, speaking on your behalf to NHS Wales bodies, government and other key groups that affect pharmacy, and providing networking opportunities for you with colleagues locally and nationally.

I will also be working closely with our three local ambassadors for East Wales, West Wales and North Wales as we now kickstart face-to-face RPS local events after the disruption of COVID-19. I hope to see you at a RPS local event soon!

## PHARMACY: DELIVERING A HEALTHIER WALES CONFERENCE

Speaking of face-to-face events, a few weeks ago RPS were delighted to be able to host the first Pharmacy: Delivering a Healthier Wales (PDaHW) Conference. This was the first national conference we've held since COVID and it was such a thrill to welcome a full house of nearly 200 pharmacist and pharmacy technician colleagues to the conference.

If you're not familiar with PDaHW, it's the 2030 vision for pharmacy in Wales that aims to make sure that our skills and knowledge are used to the full. Having led on engagement and drafting of the initial vision back in 2019 and the three-year update in 2022, we at RPS Wales are proud to have also this year been asked to take over responsibility for administration of the PDaHW Delivery Board and promotion and engagement work around the vision.

The conference proved to be a wonderful opportunity to reflect on progress made to date and to consider what more we as a profession need to do to reach our 2030 vision. But more than anything it proved to be a wonderful celebration of pharmacy in Wales. I think everyone in attendance would agree that as pharmacy in Wales, we have so much to be proud of.

Following a welcome from RPS Wales Chair Geraldine McCaffrey, the conference was expectedly chaired by community pharmacist, Chris Martin, who kept the energy high throughout the day. Speakers included:

- Baroness Finlay of Llandaff, a pioneer in palliative care who reflected on how we put our patients at the heart of what we do
- Welsh Government Minister for Health and Social Servies, Eluned Morgan MS, who outlined the government's priorities for pharmacy
- And BBC Wales Today's Lucy Owen who shared the story of her recent health scare and reminded us of the crucial role we as health professionals play in the lives of our patients

We also heard from the Chief Pharmaceutical Officer for Wales, Andrew Evans. For the team at RPS, this was a particular highlight as Andrew outlined the government's response to an independent review of the future of clinical pharmacy services in NHS hospitals in Wales conducted by RPS Wales. We're delighted that our recommendations have been accepted in full and look forward to supporting their implementation – a key part of the journey to our 2030 vision.

The afternoon also featured a pair of interactive workshops focused on pharmacy research and medicines safety. A big thank you must go to Pharmacy Research Wales and the All Wales Medicines Safety Pharmacy Group for supporting us with both workshops.

And finally, my personal highlight of the day were series 'TED talk' style presentations. During these quick-fire sessions, pharmacists and pharmacy technicians shared with us their trailblazing initiatives that are leading the way and putting PDaHW into practice. The feedback we've received for this session has been incredibly positive, so rest assured that next year's conference will also feature more of the these 'TED talks', showcasing the great work happening across pharmacy in Wales.

## NEXT YEAR'S CONFERENCE

Yes, I did say next year's conference! We're almost at the stage where we will be letting our members know the date and venue for the 2024 PDaHW Conference. So do keep an eye on RPS social media and on our website for details in the coming weeks. Looking forward to seeing you there!

***Stay up-to-date with us on Facebook: www.facebook.com/rpswales. Follow us on Twitter: @RPS_Wales. Find out more about Pharmacy's 2030 vision and join our Champions Network: rpharms.com/wales/pharmacy-delivering-a-healthier-wales.***

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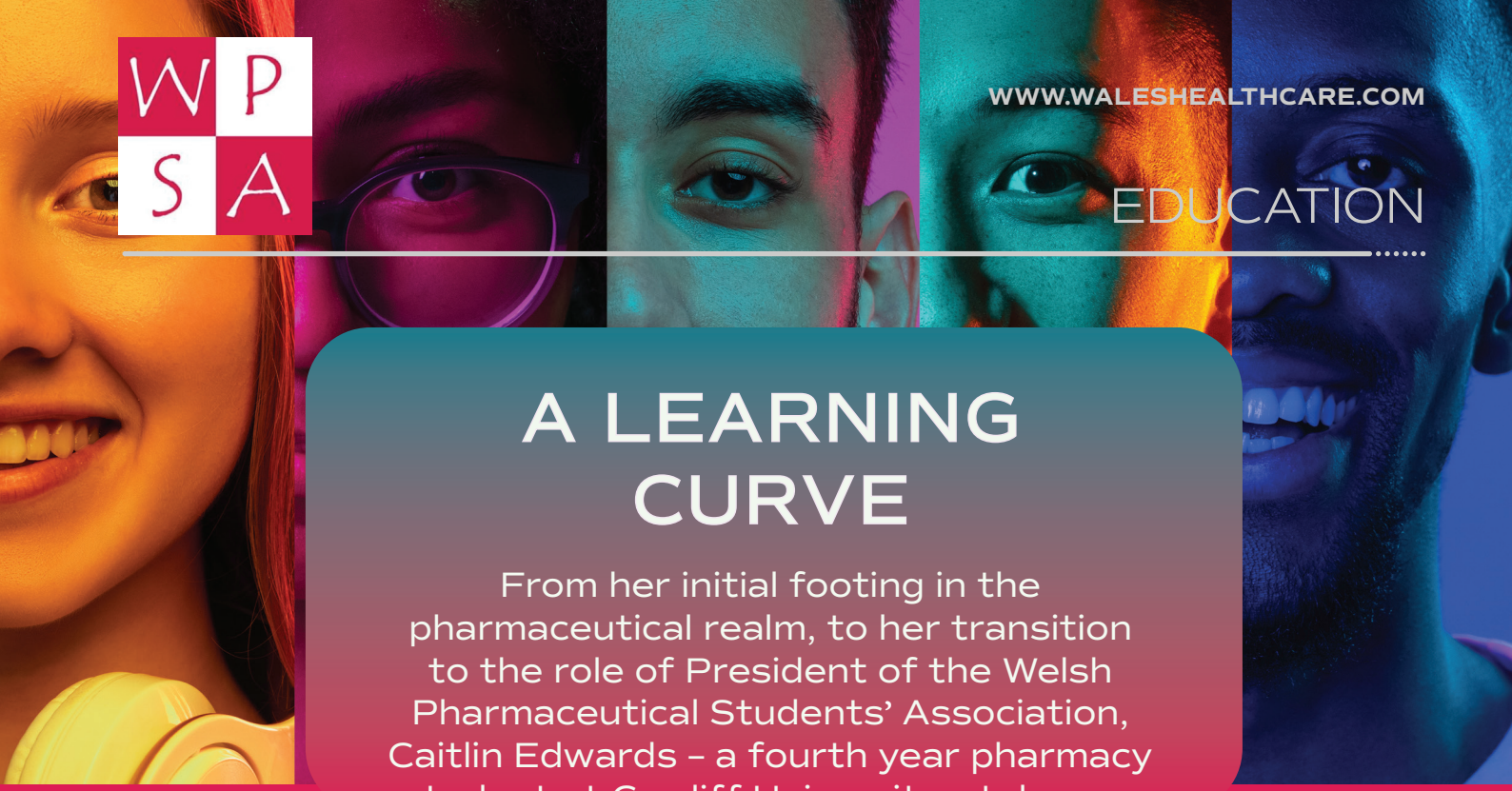


# A LEARNING CURVE

From her initial footing in the pharmaceutical realm, to her transition to the role of President of the Welsh Pharmaceutical Students' Association, Caitlin Edwards – a fourth year pharmacy student at Cardiff University – takes us along on her journey so far.

My initial exposure to the pharmaceutical field began when I was 15 years old. Back then, I needed to secure work experience for school, and it was my wonderful mother, who works at a GP surgery, who organised a week-long placement for me at our local pharmacy. That one week turned out to be a defining moment in my life; it provided me with all the insights I needed to determine my career path. However, in what feels like the blink of an eye, seven years have passed, and I now find myself in my final year of university, eager to venture into the incredible world of pharmacy that I've come to know and love.

Cardiff University has been my academic home for the past three years. Beyond just receiving an education, it has allowed me to be immersed in diverse communities, encounter valuable networking opportunities, and, most importantly, gain life-long friendships. The presence of a great pharmacy community in Cardiff, with the support of remarkable lecturers, is an honour to be a part of. Cardiff University has not only been a great university, but has nurtured my personal growth, giving me key opportunities to become independent, and supplying me with unforgettable opportunities, such as sharing my thoughts in this magazine, which is an honour.

Throughout my academic journey, both within and beyond Cardiff University walls, I've been fortunate to seize fantastic opportunities. A notable instance was my attendance at the Welsh Pharmacy Awards this year. There, I had the privilege of listening to inspiring stories about the transformative impact pharmacists are making every day which ignited thoughts and ideas on the positive changes I aspire to bring to my profession. Additionally, I feel honoured to have received the Pharmacists' Defence Association Student Leadership Award during this event. This recognition has opened another avenue for me to engage with the student community of the Pharmacists' Defence Association, allowing me to share insights on leadership skills and their benefits for us as students.

Among all these fantastic opportunities, my proudest endeavour would be being a committee member for the Welsh Pharmaceutical Students' Association, or WPSA, for the past two years. WPSA is primarily a pharmacy student-based group where our number one priority is to encourage our hardworking students to have some fun and make the most of their time at Cardiff University. I joined Cardiff University in 2020, during peak COVID-19, which meant that we couldn't easily make friends outside of our flats, leading to a sense of isolation. However, I used this loneliness as a source of motivation, to make the younger years below me have the best experience they possibly could at Cardiff.

WPSA's approach involves hosting social events, football, netball, and badminton teams with our unmissable annual ball. Giving students an opportunity to make friends on their course outside of work is paramount in the success of our students and thus as future pharmacists. Among all this fun, our secondary aim is raising money for our chosen charity, Papyrus, which aids in the prevention of suicide in young people. For example, during our November sports challenge this year, students and staff accumulatively ran 500km, with the hope of raising £500. Over the past two years, we have raised over £6,000 for this fantastic charity, and we hope this figure grows significantly.

Among all this amazing work, this year I was proudly nominated as WPSA president, which was an opportunity for me to build my leadership skills that I could not turn down. Instilling a supportive and inclusive environment for the committee was something I was adamant in creating, while communicating with external speakers to create opportunities for my fellow peers. Last year, I successfully launched a WPSA Instagram page also, allowing us to promote student engagement in social events.

All in all, I am grateful for the opportunities supplied to me by Cardiff University. As I come close to graduation and look on at the wider world of pharmacy to come, I am eager to see new opportunities that await me. My journey so far has been about self-growth and taking every opportunity that comes my way, and I can't wait to portray this in the working world of pharmacy.

Caitlin Edwards

AWTTC

# SETTING THE STAGE


**The All Wales Therapeutics and Toxicology Centre welcomed delegates from across Wales to the 2023 Best Practice Day at the Cardiff City Stadium. Here, they recap the pivotal event.**


The aim of the Best Practice Day (BDP) is to share learning related to the All Wales Medicines Strategy Group National Prescribing Indicators and guidelines, to improve prescribing practice across Wales. It was a welcome return to a face-to-face event, allowing plenty of opportunity for networking and discussion. Over 80 delegates were in attendance, including primary and secondary care pharmacists, pharmacy technicians, GPs, secondary care doctors, dentists, nurses and physiotherapists.

Swansea Bay University Health Board started off the presentations at the BPD July 2023 by sharing their experience of working to reduce the opioid burden and looked at ways to facilitate improvement in the prescribing of gabapentinoids. A whole-system and facilitatory approach worked well for them and, with improved dynamic communication between clinicians and patients. Along with the support of the medicines management team, help was given to people so that they could manage their pain better without the need for a pharmacological intervention.

Next on the agenda was the team from Betsi Cadwaladr University Health Board (BCUHB) who talked about the development of the Dental Antimicrobial Stewardship Programme. The team highlighted the negative effect that the COVID-19 pandemic had on dental antimicrobial prescribing, resulting in significant increases. The aim of the Dental Antimicrobial Stewardship Programme is to reduce dental prescribing and ensure that antibiotics are used appropriately. As a result, the team at BCUHB developed local guidelines based on national advice, and taking into account local resistance patterns, resulting in improved prescribing of antimicrobials by dentists.

Dr Adam Mackridge, Strategic Lead for Community Pharmacy at BCUHB, then talked about the national response to the Group A Strep demand surge in Wales following an outbreak of Scarlet Fever in the winter of 2022, when the demand for antibiotics exceeded usual levels and led to a depletion of stocks. He shared the lessons learned from this experience and told how a multi-agency approach helped steer healthcare through this crisis.

Dr Owen Seddon, Infectious Diseases Consultant at Cardiff & Vale University Health Board, was up next sharing his work on Outpatient Parenteral Antibiotic Therapy. He explained how this facilitates the administration of intravenous antibiotics in the community and fits the aims of the Welsh government to bring health closer to home. Dr Seddon highlighted the advantages – high patient satisfaction, saves money, reduces the risk to patients by keeping them away from the hospital setting and results in comparable or better outcomes. He showed how this model prevents admission to hospital and saves bed days.

Finally, Harriet Price and Sheridan Court from Swansea Bay University Health Board presented on the topical subject of polypharmacy in older people. People who are prescribed a higher number of medicines are at an increased risk of harm which could result in hospitalisation. The All Wales Medicines Strategy Group guidance was developed in order to help healthcare professionals address inappropriate polypharmacy, and includes practical guides for stopping certain medicines.

The team in Swansea use the guidelines to undertake polypharmacy reviews.

Some great conversations continued during the lunch break as we were joined by representatives of the Yellow Card Centre Wales, the National Poisons Information Service, the Royal Pharmaceutical Society and staff from the All Wales Therapeutics and Toxicology Centre who were on hand to exhibit and discuss various aspects of their work.

After lunch each health board and Velindre NHS Trust hosted informal sessions showcasing a variety of work, allowing delegates ask questions and discuss specific examples.

Feedback from the day demonstrated that the majority of delegates learned something new that they would share locally with their teams and be able to put into practice. Presentations from the day are available on the All Wales Therapeutics and Toxicology Centre website.

***We are looking forward to hosting the next Best Practice Day in 2024. Keep an eye on our website and Twitter (@AWTTCcomms) for more information on our educational activities, or if you would like to get involved, please get in touch.***


Ruth Lang

# LEVELLING THE PLAYING FIELD OF SUPPORT

**Welsh researchers are working to understand how early diagnosis and timely support for girls and women living with ADHD can be improved.**

Dr Joanna Martin

It has been a long-held observation that ADHD is more common in boys, and that girls are less likely to be diagnosed with it. However, research is showing that there are more girls and women with the condition than previously thought.

Delays in diagnosis can lead to differences in the care that people with ADHD receive; often, girls and women miss out on early support for an ADHD diagnosis, potentially leading to mental health issues and difficulties at school, in the workplace, and in other areas of life.

Dr Joanna Martin, Senior Research Fellow at the Division of Psychological Medicine and Clinical Neurosciences at Cardiff University, is working on research through a Health and Care Research Wales / National Institute for Health and Care Research (NIHR) Fellowship Award to better understand ADHD in young women in Wales, and to increase awareness and recognition of ADHD.

Dr Martin said, 'Many people believe that ADHD is more common in boys, and that girls are less likely to have the condition.

'ADHD is considered a neurodevelopmental condition. The symptoms may be slightly different in boys and girls, but may be more noticeable in boys.

'In epidemiological studies from Scandinavian countries, the peak age of ADHD diagnosis in boys is between six-and-nine years old; in girls, it's in adolescence when they are aged around 15-to-18.

'If left untreated and unsupported, women with ADHD are at increased risk of various mental health difficulties, including suicide. It's really heartbreaking.'

In her five-year study, Dr Martin hopes to better understand the experiences of young women in the healthcare system, and to find out what the impact of delayed diagnosis of ADHD means for them.

'We will look at existing data from the SAIL databank (Welsh healthcare records) and the Millennium Cohort Study (a longitudinal population sample of young people) and try to understand why young women are experiencing a delay in getting a diagnosis. This will help to identify factors that might be used by young women to cope with ADHD difficulties or mask those difficulties,' explained Dr Martin.

Dr Martin is also interested in studying a more gender diverse group of people with ADHD. As part of a recent qualitative study, her research team interviewed young adult women and non-binary people about their experiences of growing up with ADHD.

She added, 'We are also working with a variety of collaborators and partners (including the ADHD Foundation charity) to create a new gender-inclusive tool to assess ADHD behaviours that are more common in girls and young women. We hope that this new tool could be used to help recognise ADHD sooner in young children, as early intervention and support can help people to thrive.'

ADHD is linked to higher risks of different mental health conditions, including anxiety, depression, self-harm, suicide and substance misuse. Timely diagnosis, treatment and intervention can help to reduce these risks.

Dr Martin continued, 'People can experience a variety of health difficulties throughout their lives. If we're not helping young people as soon as they need it, there is a risk that they will develop additional problems.

'We want to make sure there's a level playing field for young women and non-binary people in terms of access to diagnosis and support. We need to get the message out there, raise awareness and improve earlier diagnosis.'

Health and Care Research Wales supports individuals on their journey to becoming future leaders in research, and takes on the funding and management of successful applications to the NIHR Fellowship Programme.

As a recipient of a Health and Care Research Wales / NIHR Fellowship Award, Dr Joanna Martin is a member of the Health and Care Research Wales Faculty.

***For further information and to find out about their funding schemes and opportunities, visit the Health and Care Research Wales Faculty website at www.healthandcareresearchwales.org.***

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

# KNOWLEDGE IS POWER

**Myalgic encephalomyelitis (ME) is a frequently misunderstood disease that affects around 13,070 children and adults in Wales. Often people with ME feel dismissed and not believed as others aren't able to understand the significant impact on all aspects of life that this neurological condition can bring, and how prevalent it is in the general population. Here, Action for ME bolster our learning and cast a light on ME informing professional practice.**

ME can affect anyone of any age and background, and research increasingly shows just how disabling and serious this disease is, lowering a person's quality of life and reducing their daily activities. See health-related quality of life for patients with ME / CFS (PLOS ONE, 2015); functional status and wellbeing in people with ME / CFS compared with people with Multiple Sclerosis (PharmacoEconomics, 2018); and impact of ME / CFS on the quality of life of people with ME / CFS and their partners and family members: an online cross-sectional survey' (BMJ Open, 2022).

In the early stages of the illness, fluctuation is characteristic but it's important to note that, for those patients most severely affected, symptoms are consistently present and extremely debilitating.

## GETTING THE GUIDANCE RIGHT

The 2021 National Institute of Health and Care Excellent (NICE) guideline on ME for England and Wales categorises the spectrum of severity experienced by people with ME as mild, moderate, severe and very severe, and offers advice on good practice in ensuring an early diagnosis and supporting effective symptom management.

Crucially, it makes it clear that active rehabilitation such as graded exercise therapy should not be offered to those with ME, while CBT should only be offered to help individuals manage symptoms, and not considered curative.

There are no specific guidance or services for children and young people with ME in Wales. Diagnosis, prognosis and management can be different for this group and needs to be addressed by all health boards in Wales.

## DIAGNOSING ME

NICE lists four features that should be present for a diagnosis of ME:

1. Debilitating fatigue that is not relieved by rest or sleep and is made worse by activity, even if that is minimal physical, cognitive, emotional, or social exertion
2. Post-exertional malaise after any type of activity. This results in the worsening of symptoms and its onset can be delayed by hours or days and be out of proportion to the level of activity. Recovery can be prolonged and take days, weeks or longer
3. Difficulties with sleep, such as sleep disturbance and sleep being unrefreshing. This can result in people feeling exhausted on waking, having altered sleep patterns and hypersomnia
4. Cognitive difficulties (brain fog), people may struggle to find words, communication may be slowed down due to difficulty in responsiveness and short-term memory. People may find it difficult to concentrate

People may also experience a range of other symptoms, such as general malaise, flu-like symptoms, recurrent sore throat with or without swollen glands, and pain in joints or muscles. Many experience other difficulties related to their nervous system and orthostatic intolerance; Postural Orthostatic Tachycardia Syndrome is frequently associated with ME.

Increased sensitives for those with ME also have implications for medication protocols. This may need to be started at a very low dose and increased gradually, and / or be scheduled around activities to ensure a new medication is not started at a time when there is increased activity and strain for the patient.

## ESSENTIAL MEDICAL EDUCATION

An exploratory study published in Medicina in 2021 showed that two-thirds of UK medical schools acknowledge the need to update medical knowledge on ME.

In its interim delivery plan on ME / CFS, the UK government has set out a number of actions relating to improving training and resources for health professionals.

This includes the Department for Health and Social Care requesting that 'the Medical Schools Council encourage shared learning and the NHS England e-learning package (in development) on ME / CFS to all UK medical schools and encourage medical schools to provide undergraduates with direct patient experience of ME / CFS, to raise awareness among medical students, by the end of March 2024.'

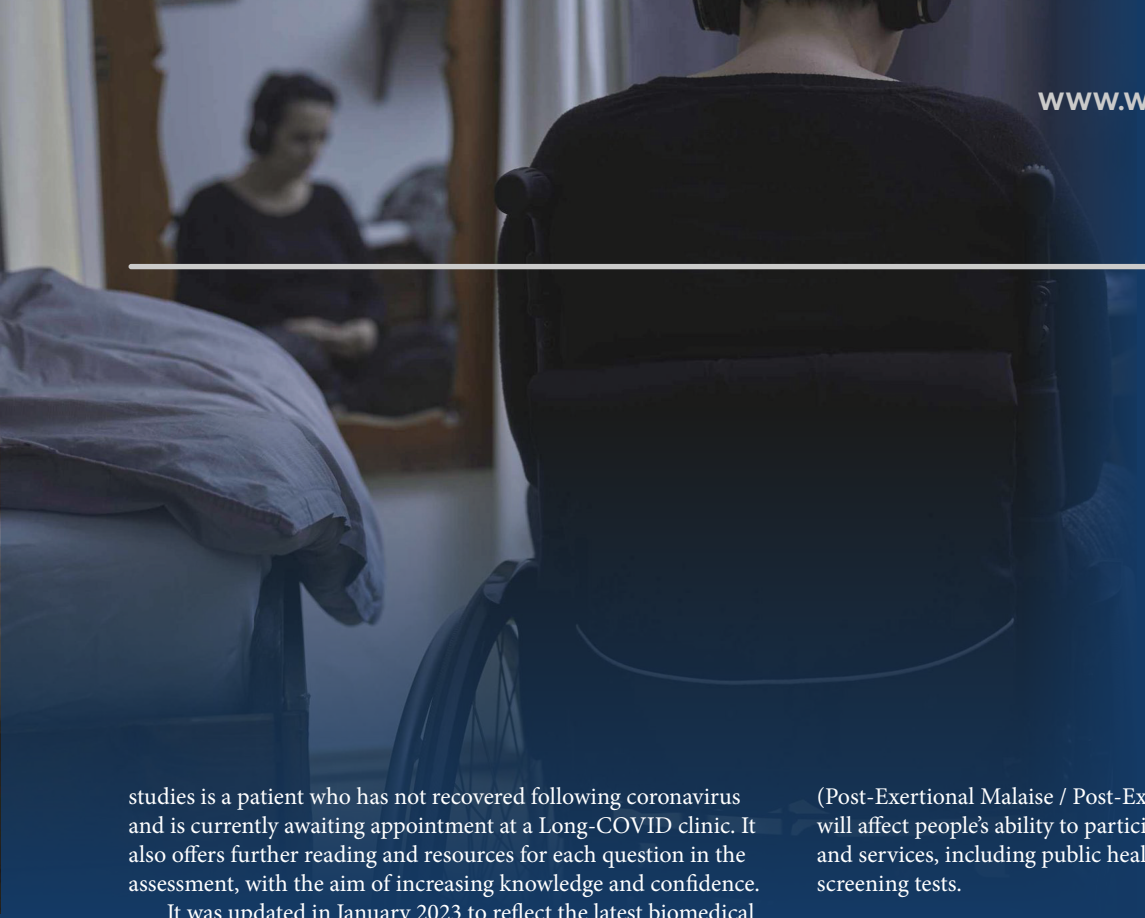
## CLINICAL CASE-BASED LEARNING

Learna's free accredited-CPD module on ME / CFS (produced in partnership with Cardiff University), based on 10 clinical case studies, was created by Cardiff University tutor and medical student supervisor, Dr Nina Muirhead. Core aims of the module include that healthcare professionals will be able to:

- Diagnose ME / CFS
- Consider relevant tests and investigations
- Prevent worsening of symptoms through advice on pacing and energy management

Dr Muirhead said, 'In writing this module I drew on the international peer-reviewed literature and emerging international ME / CFS educational resources, and have been fortunate to receive significant contributions from medical experts, scientists and patients.'

The module features the 2021 NICE Guideline on ME / CFS (NG206) and emerging parallels with Long-COVID; one of the case



studies is a patient who has not recovered following coronavirus and is currently awaiting appointment at a Long-COVID clinic. It also offers further reading and resources for each question in the assessment, with the aim of increasing knowledge and confidence.

It was updated in January 2023 to reflect the latest biomedical evidence.

'It has become evident that at least a subset of patients with Long-COVID have symptoms, and likely underlying pathophysiology, which significantly overlaps with those who have ME / CFS due to other causes,' said Dr Muirhead.

'This updated module has incorporated some of these relevant updates.'

## PODCAST SERIES

The Learna module is accompanied by a series of Learn about ME podcasts available on Buzzsprout, Apple and Spotify covering topics, such as GP prescribing, Long-COVID and the 2021 NICE guideline on ME / CFS, with the latest episode on paediatrics available from early October.

All feature health professionals and patients sharing their insight and experience, including Dr Aileen Billsdon-McGrane, a GP in Glasgow; and Professor Chris Ponting, University of Edinburgh, co-leading DecodeME, the world's largest genetics study of ME which published initial findings earlier this year.

With funding from the Scottish government's Neurological Framework, UK charities Action for ME, ME Association, #MEAction Scotland and 25% ME Group are working with Dr Muirhead to promote the module and podcasts through our Learn About ME project.

## WALES AND ME / CFS

In February 2023 the Health Minister Baroness Eluned Morgan announced funding to extend the Long-COVID Adferiad service to include other post-viral illnesses like ME / CFS. Each health board began to develop services during 2023 with Cwm Taf Morgannwg University Health Board launching the first service in October 2023. Health boards are aware that they are 'learning on the job' but are expecting to build up experience about healthcare for ME / CFS to share with colleagues in their own health boards and across Wales, aided by patient engagement and in some cases co-production.

Patient advocacy charity WAMES' #ImplementNICEmecfs campaign is asking for the NICE guideline to be used to shape the design of services. They are also calling for healthcare professionals to understand the potentially severe and often fluctuating nature of ME / CFS and how that and the key characteristic of PEM / PESE (Post-Exertional Malaise / Post-Exertional Symptom Exacerbation) will affect people's ability to participate in healthcare consultations and services, including public health and co-morbid conditions' screening tests.

## USEFUL CONTACTS

The Welsh Association of ME & CFS Support (WAMES)
Tel: 029 2051 5061
Email: helpline@wames.org.uk
For patients: www.wames.org.uk/cms-english/me-info
For professionals: www.wames.org.uk/cms-english/professionals

Action for ME
Tel: 0117 927 9551
Email: questions@actionforme.org.uk
For patients: www.actionforme.org.uk/info-support
For professionals: www.actionforme.org.uk/medical-professionals

The ME Association
Tel: 0344 576 5326
Email: meconnect@meassociation.org.uk
For patients: www.meassociation.org.uk/contact-me-association
For professionals: wwww.meassociation.org.uk/health-care-professionals

25% ME Group
Support for people with severe ME and professionals caring for them: 01292 318 611
Email: enquiry@25megroup.org
For patients: www.25megroup.org/me/living-with-severe-me
For professionals: www.25megroup.org/me/for-professionals-2

Professor Chris Ponting

Dr Aileen Billsdon-McGrane



Banner image credit: fotocredits_lea_aring_f2 and German Association for ME / CFS

# CHECK, PLEASE

**The significance of inhaler adherence among asthma patients can't be overstated – granting them the confidence and knowledge to lead a safe and independent life. Asthma and Lung UK Wales break down the basics of correct inhaler usage, in addition to how healthcare professionals can help individuals sharpen their technique and maximise their quality of life as a result.**

## INHALER ERRORS AND ASTHMA OUTCOMES

We don't have exact statistics on this. The closest we have is stats on inhaler technique check – survey data on whether people with a lung condition had one or not:

| | England | Northern Ireland | Scotland | Wales | UK |
|---|---|---|---|---|---|
| I don't use inhalers | 5.7% | 6.4% | 5.7% | 6.1% | 5.7% |
| No | 45.2% | 42.9% | 52.3% | 49.5% | 46.1% |
| Not sure | 1.6% | 0.9% | 0.7% | 1.5% | 1.5% |
| Yes | 47.5% | 49.7% | 41.2% | 42.8% | 46.7% |
| Grand Total | 100.0% | 100.0% | 100.0% | 100.0% | 100.0% |

There's also been plenty of research on this. A 2018 systematic review of the issue found that published data from studies in asthma and COPD demonstrate the presence of an association between inhalation errors and outcomes, with an apparent relationship between a reduction in errors and improvement in outcomes, irrespective of endpoint. There's another similar paper here: www.respiratory-research.biomedcentral.com/articles/10.1186/s12931-017-0710-y. There's also other research looking at which people in particular are at risk of poor inhaler technique and these poor outcomes, examples can be found at www.tandfonline.com/doi/abs/10.1080/02770903.2020.1742353 and www.bmjopenrespres.bmj.com/content/8/1/e000823.

## COMMON INHALER-RELATED MISTAKES

Common inhaler mistakes include:

### NOT USING THE RIGHT TECHNIQUE FOR THE INHALER

It can take time for the individual to practice and master the right technique for their inhaler. There are two main types of inhalers – dry powder inhalers (DPIs) and metred dose inhalers (MDIs).

Depending on which type the individual uses, they'll need to use a different inhaler technique. If they're not sure what type of inhaler to have, they should ask their GP, asthma nurse or pharmacist.

Asthma and Lung UK have fantastic videos on their website: www.asthmaandlung.org.uk/living-with/inhaler-videos.

### NOT USING A SPACER

A lot of people don't realise that using a spacer is the best way to take their MDI inhaler. Spacers help the right amount of medicine get to their lungs and reduce side-effects.

### NOT BREATHING OUT FULLY BEFORE USING THE INHALER

People often don't breathe out as fully as they need to before using their inhaler. When they breathe out as fully as they can just before taking their inhaler, they create more space in their lungs for their next breath in. This means that the individual can breathe in deeper and for longer when they inhale their asthma medicine – giving it the best chance of reaching the small airways deep inside their lungs.

### FORGETTING TO SHAKE THE INHALER BEFORE USING IT

Some people forget to shake their inhaler before using it. Inhalers, such as MDIs, need shaking before using to ensure that the medicine and propellant mix properly, but other inhalers may not need shaking.

### NOT LIFTING THEIR CHIN SLIGHTLY BEFORE BREATHING IN

Lifting their chin helps the medicine go down into the lungs more efficiently.

### BREATHING IN TOO EARLY OR LATE

When an individual breathes in too early, they won't have enough time to finish breathing in all the medicine because their lungs will already be full. Breathing in too early will mean some of the medicine will end up sticking to their mouth or the back of their throat, instead of being carried to the lungs where it's needed.

If the individual breathes in too late, especially if they're not using a spacer, the medicine can stick to their mouth or the back of their throat, instead of getting to their lungs. This is because it takes a very short amount of time for the medicine to be released once the canister is pressed.

### NOT WAITING BETWEEN PUFFS

With some inhalers, such as MDIs, you need to wait at least 30-to-60 seconds before taking the next puff. This gives the medicine and propellant enough time to mix.

### NOT HAVING A TIGHT LIP SEAL

When an individual breathes in, they should make sure their lips are tightly sealed around their inhaler. If the seal is not tight, medicine will escape, and they won't get the full dose.

### NOT HOLDING THEIR BREATH AFTER TAKING THE INHALER

If the individual's GP, asthma nurse, or pharmacist has told them to hold their breath after using their inhaler, it's important to do this. Holding their breath gives the medicine more time to settle into their lungs. 10 seconds is ideal, but if this isn't possible, they'll still benefit by holding their breath for as long as they feel comfortable.

### NOT RINSING THEIR MOUTH AFTER USING A STEROID INHALER

It's important for the individual to rinse their mouth out after using a steroid inhaler, such as their preventer inhaler. This is so that any medicine that is stuck in their mouth or throat is cleaned away. This will prevent side-effects, such as oral thrush.

## OPTIMISING ADHERENCE AND ABILITY

The key to optimising adherence to inhalers is to make sure that the patient understands why they need to use it and how it is going to help them. So, healthcare professionals need to ensure that they have explained this thoroughly, using language that the patient understands. Providing written information, a personalised asthma action plan, and links to useful websites, such as Asthma and Lung UK, helps to reinforce this. It's really important that healthcare professionals demonstrate how to use inhalers, because incorrect technique will make the inhaler less effective, and this will mean that the patient is less likely to use it.

Healthcare professionals also need to explore if the patient has got any lifestyle issues which make sticking to a regular routine challenging. For example, people with mental health difficulties, or conditions that affect their organisational skills, such as ADHD, might not manage a twice-daily routine and would find a once-a-day inhaler easier to adhere to. Other psychosocial factors include embarrassment or self-consciousness about using an inhaler in public, which can impact their willingness to use it as prescribed.

Healthcare professionals also need to consider cost-of-living implications and advise, where applicable, the use of pre-paid prescription certificates: www.nhsbsa.nhs.uk/help-nhs-prescription-costs/nhs-prescription-prepayment-certificate-ppc (not in Scotland, of course, where prescriptions are free).

Factors that affect an individual's ability to use inhalers are wide-ranging. Cognitive impairments or conditions, such as dementia, can make it challenging for patients to remember and perform the steps required for inhaler use. Patients with physical disabilities affecting their hands or fingers, such as arthritis, may have difficulty manipulating the inhaler device. Patients with visual impairments may struggle to see the dose counter or other important markings on the inhaler.

## THE IMPACT OF POOR INHALER TECHNIQUE

Poor inhaler technique may lead to insufficient medication delivery to the lungs. As a result, the individual may experience inadequate symptom control, including shortness of breath, coughing, and wheezing. This can, in turn, lead to increased exacerbations of asthma, resulting in hospitalisations, missed work or school days, and reduced quality of life. Poorly-managed respiratory conditions can disrupt sleep patterns, leading to poor sleep quality and fatigue during the day. Living with asthma symptoms can cause anxiety, depression, and emotional distress.

Individuals with poor inhaler technique may rely heavily on rescue medications (e.g., short-acting bronchodilators) to relieve symptoms, rather than using maintenance medications as prescribed.

## THE IMPORTANCE OF HEALTHCARE PROFESSIONALS

Healthcare professionals play a critical role in educating patients about inhaler technique and ensuring that they maintain proper technique over time. Their guidance, monitoring, and support are essential for effective disease management, symptom control, and overall wellbeing of individuals with respiratory conditions. Yearly asthma reviews allow healthcare professionals to assess the patient's inhaler technique and provide feedback. This ongoing monitoring ensures that patients are using their inhalers correctly and the healthcare professionals can make adjustments if needed. These reviews should take place face-to-face to observe the inhaler technique adequately.

The relationship between the healthcare professional and patient is key in helping patients maintain their inhaler routines. Making sure that they understand how and why to take their inhalers, tailoring the inhaler device to suit their needs, that they have a written asthma action plan, and that they are actively engaged with their asthma, will enable patients to recognise the role of inhaler adherence in managing their asthma. Healthcare professionals can also signpost patients to use apps to support inhaler adherence.

## WIDER ADVANTAGES WHICH MAY BE ACHIEVED IF INHALATION COMPETENCE IS IMPROVED

- This is outlined in our paper: www.asthmaandlung.org.uk/sites/default/files/Levelling%20up%20lung%20health_what%20needs%20to%20be%20done.pdf
- There are some useful stats in this paper: www.demos.co.uk/wp-content/uploads/2023/02/Potential-Limited-Updated-03.21.pdf

***For more information, visit www.asthmaandlung.org.uk.***

ASTHMA+ LUNG UK CYMRU

CARBON FOOTPRINT

# A BRIGHTER FUTURE

The Upper Valley Cluster, along with Swansea Bay University Health Board, committed in 2021 to look at the responsible disposal of inhalers as part of a decarbonisation action plan. As the Interim Cluster Lead and Pharmacy Collaborative Lead for the Upper Valley Cluster, Mr Niki Watts led the project with help from colleagues from Swansea Bay University Health Board. Here, he explains further.

We decided to focus our attention on inhalers as it's estimated that Metered Dose Inhalers (MDIs) currently contribute to 3.5 per cent of the carbon footprint of the NHS. (All Wales Therapeutics and Toxicology Centre, 2021) The project was split into three different phases: patient education, inhaler returns, and then the final part of recycling the inhalers. The targets for the project are to reach 100 per cent of patients receiving inhalers and provide them with a brief education on safe disposal and to recycle 80 per cent of inhalers prescribed by 2025.

## PHASE ONE

- Took place between October 2021-and-November 2022
- We wanted baseline figures of patients' knowledge and current inhaler disposal methods
- We set up a survey monkey questionnaire which asked three simple questions:

- How do you currently dispose of your inhaler?
1. General household waste
2. Curb-side recycling
3. Return to pharmacy

- Do you know that disposing of your inhaler inappropriately has a negative impact on the environment?
1. Yes
2. No

- Would you consider returning your inhaler to the pharmacy for appropriate disposal in future?
1. Yes
2. No

Responses from 40 participants revealed that at this time only 10 per cent of the respondents returned their inhalers to the pharmacy for safe disposal. Almost 68 per cent of the respondents revealed they didn't know that disposing of the inhaler incorrectly negatively affects the environment and almost 98 per cent said they would be happy to return their inhalers to the pharmacy in the future.

## PHASE TWO – PATIENT EDUCATION

During this phase we had a concentrated effort to educate patients on correct disposal of used and unwanted inhalers. Staff members used stickers to identify patients who were prescribed inhalers and then staff members provided a brief intervention. Staff members explained that the majority of MDIs contain a propellant HFA 134a which is a potent greenhouse gas, and when these inhalers are sent to landfill the HFAs can slowly leak out of the inhalers and contribute to global warming. Most patients were surprised that any inhalers which were disposed of in household recycling were sent directly to landfill as they are classed as hazardous waste.

At this stage of the project all inhalers returned were sent for incineration with the rest of pharmaceutical waste. This method of disposal is better than being sent to landfill, as during the incineration process the HFAs are destroyed. The only downside with incineration is that we lose the useful parts of the inhaler which could be recycled.

## PHASE THREE – RECYCLING

It was identified early on in the project that we needed to look into a recycling scheme so the useful aluminium, plastic and HFAs could be recovered and recycled. From research it became clear that there were not many options available for recycling. Some manufacturers had closed or were in the process of reviewing their recycling schemes so were not accepting any new returns. There was a recycling scheme identified which delivered by Chiesi, but this was a pilot scheme and restricted to the Leicester area. It was decided that we would need to set up our own recycling scheme and the work in finding a waste management company who could process the inhalers started. The only company who had the facilities to process the inhalers and recycle as much of the inhaler as possible was Grundon.

Grundon has a recycling plant in Gloucester and they had the facilities to process the inhalers. During this process 99 per cent of the propellant could be recovered and recycled for use in cooling equipment like fridges. They are able to recover 100 per cent of the metal, 95 per cent of liquid and 100 per cent of the plastic is recovered and recycled. If the plastic could not be recycled it would be incinerated and the heat generated could be used for energy production. There are eight pharmacies taking part in the pilot and each pharmacy has a 800L container so store the returned inhalers. Grundon has made the first collection, and to date 8,427 have been processed and recycled.

## ABOUT THE AUTHOR

Mr Niki Watts MRPharmS IP is Upper Valley Cluster Lead and Upper Valley Pharmacy Collaborative Lead.

# Teva is investing in both original biologic medicines and in **biosimilars** to help patients around the world[1]

**Teva is investing in biopharmaceuticals as part of our long term strategy for the future, and to help patients around the world.[1]**

A biosimilar medicine is a biological medicine which has been shown, not to have any clinically meaningful differences compared to the originator medicine in terms of quality, safety and efficacy.

Biosimilar medicines are not the same as generic medicines, which contain simpler chemical structures and whose active ingredients are identical in terms of molecular structure to their reference medicines.[2]

Biosimilars could provide accessibility benefits to patients, healthcare professionals and the wider healthcare system, so why, when and how would you consider a biosimilar treatment?

Your first priority will be to ensure that the safety profile for your patients isn't compromised. You may also need information in terms of administration of the biosimilar as well as support materials for your patients. Once this is in place, then you may feel more confident to recommend, prescribe or switch to a biosimilar.

Biosimilars typically also offer cost savings in terms of health economics with any cost-efficiencies potentially leading to reinvestment in services, further benefiting patients and healthcare professionals alike.

If you would like to speak to someone at Teva, please contact Teva UK Medical Information on 0207 540 7117 or medinfo@tevauk.com.

For further information please visit: **https://www.tevauk.com**


**References:**

1. https://www.tevauk.com/our-medicines/biopharmaceuticals/ Accessed February 2023
2. https://www.england.nhs.uk/medicines-2/biosimilar-medicines/ Accessed February 2023




**www.tevauk.com**


**Date of Preparation: February 2023 Job Code: BIO-GB-00002 Teva UK Limited, Ridings Point, Whistler Drive, Castleford WF10 5HX**

MS

# ON THE RIGHT PATH

**Just what role do disease-modifying drugs represent in the care of MS – and how can we equip ourselves with the necessary information to empower our patients throughout their journey? The MS Trust explores.**

Most disease-modifying drugs (DMDs) are for people with relapsing-remitting MS, but there are some that are licenced for use by people with progressive MS. For people with relapsing-remitting MS, DMDs reduce the number of relapses they might experience, as well as reducing the severity of any relapses they do have.

There is a wide range of drugs approved for use by the NHS in the UK. Each drug offers a different combination of benefits and risks.

Our MS Decisions guide is here to help individuals find out more about the DMDs for relapsing-remitting MS, explore their options, and discuss starting or switching between one of the drugs with their MS team.

Other treatments are available:

- To reduce the severity of MS symptoms
- To speed up recovery from relapses

## WHAT ARE THE BENEFITS OF DMDS?

The main benefits of taking one of the DMDs are:

- Fewer relapses
- Less severe relapses
- Reducing the build-up of disability which can occur if the individual doesn't recover completely from relapses

DMDs work with different parts of the immune system to reduce the inflammation caused by MS to nerve cells in the brain and spinal cord. This helps reduce the number and severity of relapses.

Inflammation does not always result in a relapse or visible symptoms. This silent activity may mean that although they are feeling well, there may still be changes caused by the MS that can only be seen on a brain scan. MRI scans show that taking a DMD can lead to fewer, smaller, or no new areas of damage (lesions) in the brain and spinal cord. Treating the visibly active (relapses), as well as the silently active, aspects of MS, is a new goal that is emerging in MS treatment. This goal is often called no evidence of disease activity. The aim is to reach a point where the patient is free of visible (relapses) and invisible (changes seen only on brain scans) MS disease activity.

On average, people with relapsing-remitting MS have one or two relapses a year. In the NHS, DMDs are approved for prescription according to how frequently the individual has been having relapses. The NHS describes relapsing-remitting MS as being either active or very active:

### ACTIVE RELAPSING-REMITTING MS

The individual's MS may be described as active if they have had two relapses in the previous two years.

### VERY ACTIVE RELAPSING-REMITTING MS

The individual's MS may be described as very active if it has been either:

- Highly active despite treatment – if the individual continues to have relapses even though they have been taking a DMD for a year OR
- Rapidly evolving severe – if they have had two or more severe, or disabling, relapses in the previous year and show areas of new damage (lesions) on two consecutive MRI scans

Some research suggests that DMDs work best when they are started as soon as possible after diagnosis, effectively before there is any sign of disability, to reduce the build-up of damage to nerve cells.

Most people will continue to have a background of symptoms. DMDs are not able to repair nerve damage already caused by MS so they can't reverse existing symptoms.

When used to treat clinically-isolated syndrome, some of the DMDs have been shown to delay further episodes that would lead to a definite diagnosis of MS.

Although most DMDs are prescribed for people with relapsing-remitting MS, some of the DMDs can be prescribed for people with secondary progressive MS or primary progressive MS.

## DO DMDS REDUCE LONG-TERM DISABILITY?

For most DMDs, clinical trials are conducted over two-to-four years, which means that the evidence on long-term disability and disease progression is limited at the time when the drug is licensed. After licensing, longer-term data on safety and efficacy is collected, analysed and reported.

For the injectable DMDs, this data comes from the UK Department of Health Risk Sharing Scheme. This study followed 5,000 people taking one of the injectable DMDs over 10 years, and compared them to an untreated historical group.

The researchers found that the treated group developed lower levels of disability compared to the untreated group, and that the DMDs did slow the progress of the disease. However, the treatment effect wanes over the longer-term. This implies that a person gets more long-term benefit from a DMD if they start treatment when they are relatively younger and less affected by disability.

In 2019, research showed that people who received early treatment with a highly effective DMD did better over five years than those who started on a less effective DMD. Even though the group who started on a less effective DMD were closely monitored and switched to a highly effective DMD if their MS remained active, they still experienced worsening disability and a faster increase in their EDSS than those who started on a highly effective DMD at the outset.

## WHAT ARE THE RISKS OF TAKING DMDS?

All the DMDs can potentially cause side-effects. Some people do not experience any side-effects at all, some find they ease after the first month or two as their body adapts to the drug, and others may find that side-effects persist. The individual's MS team will give them advice on how to reduce the impact of side-effects. A few people find that side-effects cause problems or are intolerable and have to change or stop treatment.

Some of the DMDs are associated with less common but potentially serious and life-changing side-effects. There are mechanisms in place to minimise the risks for people taking one of these drugs, such as advice on warning signs, additional tests and regular check-ups. The MS team will step in quickly if there is any cause for concern. However, some people may feel that, despite regular monitoring, they are unwilling to take the risk of developing serious side-effects. Others may feel that the benefits of the drugs outweigh the risks.

## HOW DO WE KNOW THE DMDS WORK?

Phase III clinical trials provide the main evidence for the effectiveness of DMDs.

DMD clinical trials recruit hundreds of people and last for about two years. The main aim of these trials is to compare the number of relapses in people taking the new drug with those taking the standard treatment or placebo. Trials can include other measures, such as the number of lesions seen on MRI scans and changes in disability which last for three months or more. Any side-effects the participants report are recorded and monitored.

### COMPARING ONE DRUG WITH ANOTHER

Relatively few clinical trials have directly compared one DMD with another.

Comparing the results of one clinical trial with another may not give an accurate picture of which DMD is more effective than another. One of the main problems is that the groups of people recruited for each of the trials will be different, in terms of average age, gender mix, where they live and how long they have been diagnosed with MS. For example, the earliest large-scale DMD trials were carried out 25 years ago; it's likely that, on average, participants in the early studies will have had MS for a longer time than those recruited for more recent clinical trials.

Statistical techniques have been developed which take account of differences in the groups of participants in trials; this approach has been used to compare results from separate clinical trials and provide an indirect comparison of how effective the drugs are at reducing relapse rates.

For MS Decisions we have grouped the DMDs according to how effectively they reduce relapse rates, based on broad categories recommended in guidelines published by the Association of British Neurologists:

- Category 1.1: moderately effective – reduces relapses by one-third (30 per cent)
- Category 1.2: more effective – reduces relapses by one half (50 per cent)
- Category 2.0: highly effective – reduces relapses by two-thirds (70 per cent)

## HOW ARE DMDS APPROVED FOR USE BY THE NHS?

Before a DMD is approved for use by the NHS it will have been thoroughly investigated in clinical trials to establish its effectiveness and safety.

### NHS APPRAISAL

NICE appraises new medicines for England and Wales. They look at the evidence on how well a new DMD works, any drawbacks or limitations the drug may have, and the cost-effectiveness of treatment. In Scotland, appraisal is carried out by the Scottish Medicines Consortium. NICE guidance is reviewed and adapted for use in Northern Ireland.

Other organisations may also influence a drug's availability within the NHS. To guide prescribing, NHS England has published a commissioning policy and a treatment algorithm for the DMDs and requires neurologists to enter details of each prescription into Blueteq, an online system for managing high-cost drugs. The All Wales Medicines Strategy Group may appraise a new drug if NICE is not expected to carry out an assessment within the next 12 months. The Association of British Neurologists has published guidelines for prescribing DMDs in the UK.

***For more information, visit www.mstrust.org.uk.***

# PHARMACIST RACIALLY HARASSED BY PHARMACY TEAM MEMBERS

**Following a five-day hearing earlier this year, an Employment Tribunal has upheld seven allegations of harassment related to race occurring during a shift on 18th July 2020 in a claim issued against Boots and one of its pharmacy technicians.**

The tribunal concluded that the treatment of the pharmacist by the pharmacy technician, a pharmacy advisor and the store manager was significantly influenced by the pharmacist's race. The pharmacist was represented throughout the internal grievance processes and at the Employment Tribunal hearing by the Pharmacists' Defence Association (PDA).

In a detailed written judgment, the pharmacy team members and company managers were heavily criticised by the tribunal, who found the pharmacy technician and a pharmacy advisor working with the pharmacist during the shift had undermined the pharmacist in his professional role as the Responsible Pharmacist (RP) and insulted him.

## EVENTS OF 18TH JULY 2020

The experienced relief pharmacist of many years standing was working with two pharmacy-trained members of staff during a time of COVID-19 restrictions. The pharmacist asked the staff to assist him in filing prescriptions and putting bagged items on the shelves which they refused to do, saying it was not their job. The pharmacy advisor refused to help the pharmacist resolve a problem for an Asian customer whose prescription had been sent to another store. This behaviour, in front of the customer, was described as being disrespectful and insubordinate.

The pharmacist later asked the pharmacy advisor to leave the pharmacy because of the way she was behaving and her refusal to assist an Asian customer earlier. The pharmacist reminded the staff that he was the RP and responsible for the safe and effective running of the pharmacy, to which the pharmacy technician said, 'I am the technician'. By this stage, both staff members shouted at the pharmacist, and he was told that he would have to leave and that they were not prepared to work with him any longer.

While the pharmacist was on the phone with his line manager seeking advice, the pharmacy technician tried to interrupt the conversation and shouted that he was lying about what he was saying to his manager.

The two members of staff also phoned their own line manager who then proceeded to shout down the telephone at the pharmacist saying that he was an 'utter disgrace' and told him to leave the store without hearing his account of events.

Insults from the pharmacy staff included saying he had a bad reputation in the area and when the pharmacist disagreed and mentioned that he had been offered cakes by the staff in other stores, the pharmacy technician said, 'I hope they are poisoned.'

The pharmacy technician also alleged the pharmacist was acting aggressively towards her and her colleague and threatened to call the police.

After further discussions with his line manager, the PDA member decided it was no longer safe for him to remain in the store and left after signing out as the RP. The pharmacy technician asked him to stay until the pharmacy closing time, even though she had threatened to call the police earlier.

## CONCLUSIONS

The pharmacist, who is black and of Nigerian national origin, complained to Boots about his experience, however, the subsequent investigation was described by the Judge as 'simply not fit for purpose' and lacking a basic level of competence. The grievance manager was 'not equipped' for an enquiry of this nature with no specific training on conducting grievances into serious allegations of discrimination. There were unacceptable delays in dealing with the complaints. The tribunal concluded that the actions of Boots had seriously damaged the relationship of mutual trust and confidence, meaning that the pharmacist's resignation in response to the numerous issues was a constructive unfair dismissal.

The pharmacist supported by the PDA brought multiple claims against the employer and the pharmacy technician. The tribunal heard evidence over the course of the five-day hearing from the pharmacist, the pharmacy technician, the pharmacy advisor and the grievance and appeal managers.

In a detailed decision running to 33 pages, the tribunal upheld seven claims of harassment related to race brought by the pharmacist against Boots and the pharmacy technician. These allegations all related to events on 18th July 2020. The tribunal also upheld his claim of constructive unfair dismissal.

## SUPPORT FROM THE PDA

The PDA supports all members that experience discrimination. Unlawful discrimination related to race is unacceptable and the PDA encourages members who encounter discrimination at work to seek advice from the PDA Member Support Centre by emailing enquiries@the-pda.org.

***For further information and to read the full tribunal decision, visit www.the-pda.org/pharmacist-racially-harassed-by-pharmacy-team-members-with-tribunal-decision.***

# PDA Member Networks

The PDA Equality, Diversity & Inclusion (EDI) Networks provide a structure through which pharmacists, pharmacy students and trainees can work together to proactively address and campaign around various forms of discrimination and its causes and consequences.

pda national association of women pharmacists

pda BAME pharmacists' network

pda ability network

pda

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**#PDAnawp - #PDAbame - #PDAlgbt - #PDAability**

# TO B OR NOT TO B?

Despite eliciting extensive symptoms – including extreme fatigue, weakness, shortness of breath, and brain fog – much about pernicious anaemia remains unknown. Katrina Burchell, Chief Executive Officer, the Pernicious Anaemia Society, helps WPR to determine the condition's impact, as well as dismantle some of the barriers to treatment.

Katrina Burchell

In the middle of the 19th Century, patients were dying of a disease which became known as pernicious anaemia (PA). Some amazing doctors and scientists, six of whom won Nobel Prizes for their work specifically in this area, found that certain people could not absorb vitamin B12, which resulted in vitamin deficiency symptoms affecting all parts of the body and led to a long and painful death often by way of the asylum. You will be able to read about the history of PA in our blog post on our website: www.pernicious-anaemia-society.org.

We now know that PA is an autoimmune disease and, like other autoimmune diseases, patients usually have more than one. Most commonly people with PA also have Hashimoto's and / or vitiligo. Others have iron or folate deficiencies alongside their PA, and the truth is that even after all this Nobel Prize-winning, there is still much that is unknown, and which needs further research.

It is important to mention here that we have been left with something of a misnomer in 'PA', coined by Michael Biermer in 1871. In other countries they call it Biermer's disease or sometimes Addison-Biermers. It might be thought of as autoimmune atrophic gastritis, but there are problems with calling it that too! The word anaemia suggests haematology, but many patients are never actually anaemic. The condition comes from a failing in the stomach, but many patients never describe gastric symptoms before diagnosis. Many symptoms are neurological and neuropsychiatric symptoms are often the first manifestation. However, PA is what it is currently called in patient records and research papers, so that is what we will stick with for now, especially as it is the name of our charity too!

People with PA can't absorb B12 in the 'normal' way and this leads to B12 deficiency symptoms and a higher risk of stomach cancer. A normal healthy person will produce intrinsic factor and hydrochloric acid from their parietal cells. Intrinsic factor is essential for B12 absorption while hydrochloric acid allows B12 to be released from food. Parietal cells may fail due to infection (e.g. H.pylori) or because the body produces antibodies that kill off the parietal cells. Hydrochloric acid reduces with age. Reduced intake of B12 through diet can be a factor in B12 deficiency but vegans and vegetarians can have malabsorption issues too. The world is seeing an increase in dietary B12 deficiency due to lifestyle choices but having PA is not a choice.

Regardless of the reason why B12 is not absorbed properly, the Pernicious Anaemia Society believes that improving diagnosis and treatment for people with this condition is vital. PA or malabsorption of B12 can't be cured by dietary changes or oral supplementation and is a lifelong condition.

## THE SURVEY SHOWS

A survey we carried out of our members showed:

- One-third of patients experienced symptoms for up to one year before diagnosis
- 22 per cent had to wait two years
- 19 per cent for five years
- Four per cent for 10 years for an accurate diagnosis
- 14 per cent of individuals experienced symptoms for more than 10 years before arriving at their diagnosis

Patients were also asked if they were satisfied with their treatment – 64 per cent said 'No'! Nearly two-thirds of respondents were dissatisfied with current treatment, with 50 per cent saying that their treatment was inadequate, poor, very poor, or unreasonable.

Without adequate supplies of vitamin B12 a person will not be able to build healthy red blood cells and the symptoms of B12 deficiency are debilitating and life-changing for many of our members.

# TESTS AND TREATMENT

The treatment for PA is IM hydroxocobalamin, a relatively inexpensive and non-toxic vitamin that can't be overdosed. Sadly, we hear so many patient stories where treatment is refused, stopped, or reduced due to a lack of knowledge or awareness about the condition.

As a patient advocacy and support group we have conducted and funded research into this area, including working with the James Lind Alliance on a priority-setting partnership which outlined the top 10 uncertainties which need further research.

Most notable among these in my opinion are that we need a more accurate test for B12 deficiency and PA. Current tests for serum B12 are woefully inadequate to determine if a patient is B12-deficient and do not explain the reason why. Ranges vary considerably throughout the UK and symptoms can occur even within range. GPs should focus more on symptoms and risk factors rather than exact numbers. The test for PA is only accurate in around 40-to-60 per cent of cases, and a negative test result does not rule out PA.

It's not one-size-fits-all! Some people need more frequent injections than others, some find that symptoms return at certain life events, pregnancy, menopause, with exercise, heat, age. People with PA will see a return of symptoms if injections are reduced or stopped. Oral supplementation is rarely sufficient for PA patients, although in some cases a few manage on high dose oral supplementation because a small amount of B12 can be absorbed in the Ileum.

# DIAGNOSIS

There are clear indications that should point a healthcare professional in the direction of diagnosing PA, not least a family history, other autoimmune diseases, B12 serum under 300 and raised homocysteine or MMA etc. Most important, however, is the patient's symptoms.

As was for the case for me, the symptoms often develop slowly over many years. This means that doctors and patients might attribute the symptoms to advancing age or a busy modern lifestyle. PA is more common in women than in men and we believe that factor also contributes to the late diagnosis for many of our members. Persistent myths abound, including that PA is only found in the elderly and in those of North European descent. Both are categorically untrue. We have heard that some GPs try to ration B12 injections or believe that a patient can become addicted to a vitamin. Most of our members report only being addicted to feeling better when they receive their injection and worse towards when their injection is due. It's unfair to put the PA patient on a rollercoaster ride of returning symptoms and low functioning social and work life by not treating according to the resolution of symptoms.

We accept that diagnosing PA can be a challenge. The symptoms vary in severity from patient-to-patient and can overlap with other conditions. Some patients will report nearly all the symptoms on our check list, others will have just a few.

Breathless, lethargic, forgetting words, pins and needles, numbness, mood changes, vertigo, tinnitus, profound fatigue, anxious, delusional, psychotic, nerve damage – no-one wants to live like that! Medicine has moved on from treating people with liquidised raw liver but sometimes I feel that people with PA were more empathetically treated in the 1930s. A regular B12 injection and adequate co-factors like folate and iron through supplements where necessary and magnesium and potassium through diet can literally turn life around for a person with PA.

I can see no logical reason why IM injections in the GP surgery remains the only licensed way to treat PA in the UK, sub-cutaneous self-administered injections work in other countries and a willing patient should be supported if they want to regain freedom and control over their life and condition with more frequent injections. NICE is currently working on guidelines for B12 deficiency in the over-16s – www.nice.org.uk/guidance/indevelopment/gid-ng10176 – and as stakeholders we sincerely hope that the submissions from patient advocacy groups, research organisations like Club-12 and universities will be listened to and incorporated in the final draft.

The society is less willing to accept the way patients diagnosed with PA are currently treated within the healthcare system in the UK. This needs a thorough overhaul and needs to be more patient-led. Primary care is responsible for the ongoing treatment of patients with PA and GPs need to work closely with their patient, addressing symptoms and the improvement of these with sufficient injections. The focus needs to move away from serum B12 levels. GPs should also ensure a regular follow-up and periodic gastro referral, especially if the patient reports their symptoms have changed. If a patient has been diagnosed with PA and is responding to treatment, there is no need to re-test B12 serum or intrinsic factor and surgeries writing letters to patients suggesting these tests fills our helpline inbox daily with anxious calls for help and support.

***A helpful list of facts for professionals is available on our website and we offer free membership and access to our seminars and training for healthcare professionals so please sign up and follow us on LinkedIn or social media for more information on current research: www.pernicious-anaemia-society.org/professionals.***

# ABOUT THE PERNICIOUS ANAEMIA SOCIETY

The Pernicious Anaemia Society is a registered charity and the only organisation worldwide solely dedicated to improving the diagnosis and treatment of PA. Established in 2005 we have members from all over the world. The society is run by volunteers and relies on membership subscriptions, donations and grants. The society provides a credible bank of patients for research organisations, we are stakeholders and lobbyists for change, and we provide practical online, written and in-person support for our members and potential members. Membership is open worldwide to people with or without a formal diagnosis of PA, their family or carers, and people with B12 deficiency malabsorption issues and symptoms. We also have membership and support and training services for healthcare professionals who are interested to learn more about this condition and support their patients.

***For more information, visit www. pernicious-anaemia-society.org.***

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# FACIAL PALSY: A NEGLECTED CONDITION?

**In this article, Simon Lowe, retired GP and member of the Facial Palsy UK Medical Advisory Board, focuses on the important management questions surrounding facial palsy and aims to improve clinical awareness of optimal treatment.**

In May 2020, during the first COVID lockdown, I woke with a painful left ear and paralysis of the left side of my face. As a recently-retired GP I was able to self-diagnose Ramsay Hunt syndrome and persuade my medical colleagues that high dose steroids (despite their reluctance, given the uncertainty about their safety in the early days of COVID) and antivirals represented my best chance of full recovery. The next four weeks were distressing. I was unable to speak or chew properly and drinking was only possible with a straw. I had severe otalgia, fatigue, vertigo and, worst of all, the anxiety that I wouldn't get better.

I was lucky and whether due to correct, prompt treatment or not, I made a full recovery. Sadly, this is frequently not the case as my (now) colleagues at Facial Palsy UK will testify.

Since that event it has been interesting talking to clinical colleagues around their knowledge of treatment options for facial palsy. Many express anxiety that they are not aware what forms optimal management of acute or chronic facial palsy. Both undergraduate and postgraduate training on the subject was minimal and haphazard. 'Go to' clinical websites are rarely up-to-date. A significant percentage of patients with facial palsy are being let down.

It is not surprising therefore that at Facial Palsy UK we have a constant flow of patients with ongoing symptoms, distressed by what they perceive as not being treated appropriately or taken seriously.

So, 'is facial palsy a neglected condition?'

There are about 50 different causes of facial palsy covering all medical specialities. Chronic facial palsy is a life-changing condition whether it is congenital, chronic or acute. This article will aim to focus on the important management questions and to improve clinical awareness of optimal treatment.

## WHAT IS FACIAL PALSY?

My Ramsay Hunt syndrome

Facial nerve palsy (FNP) is most commonly a unilateral paralysis of the facial nerve, resulting in a patient partially, or completely, losing the ability to voluntarily move facial muscles on the affected side of the face. It causes significant functional and psychological morbidity, including anxiety and depression. As clinicians we are most likely to encounter acute onset facial palsy. Strokes typically cause upper motor neurone facial weakness that involves the mouth and spares the eye and forehead. Facial palsy of lower motor origin affects the whole face, including the forehead. Strokes involving the brainstem can sometimes mimic a peripheral lesion although one would expect other focal neurologic deficits.

**TABLE ONE: MOST COMMON CAUSES OF ACUTE ONSET FACIAL PALSY**

| Diagnosis | Distinguishing Features |
|---|---|
| Bell's palsy | Gradual onset over a few hours |
| Stroke (main differential diagnosis) | Additional neurological signs |
| Ramsay Hunt syndrome (shingles affecting geniculate ganglion) | Shingles rash, more severe symptoms, pain and vertigo |
| Surgical causes e.g. removal vestibular schwannoma | Usually obvious |
| Neurological conditions e.g. neurofibromatosis, MS | Additional neurological signs |
| Tumours affecting the facial nerve, primary and secondary | Gradual onset over >two weeks |
| Lyme disease | Commonest cause in children (1) |

There are over 50 different causes of facial palsy. Many have a range of additional symptoms depending on the aetiology.

***A comprehensive list can be found at www.facialpalsy.org.uk/causesanddiagnoses.***

## WHY IS IT IMPORTANT TO DIAGNOSE FACIAL PALSY ACCURATELY AT THE EARLIEST OPPORTUNITY?

### CORRECT INITIAL DIAGNOSIS IMPROVES PROGNOSIS

Clearly prompt diagnosis of stroke is critical.

With regard to lower motor neurone facial palsy, it is not uncommon for patients to be diagnosed with Bell's palsy, then subsequently be re-diagnosed with Ramsay Hunt syndrome as new symptoms and signs evolve. Delayed treatment (>72 hours) increases the likelihood of long-term sequelae like prolonged facial weakness, development of synkinesis, pain, deafness and vertigo. Red flags are easily ignored in the rush to diagnose Bell's palsy. Early diagnosis with safety netting is key.

### RED FLAGS, TUMOURS OR OTHER NEUROLOGICAL DIAGNOSES ARE EASY TO MISS

A patient presenting with gradual onset facial palsy may be misdiagnosed as Bell's palsy, prescribed steroids with some improvement, only to reattend later. A high index of clinical suspicion is required at initial presentation. See Table One.

### RESIDUAL SYMPTOMS FROM FACIAL PALSY ARE DISTRESSING AND LIFE-CHANGING

Imagine having to live your life, unable to close your eye, chew or speak properly. Having to drink with a straw. Experiencing reduced quality of life, psychological distress, depression, and social alienation, in social situations around your appearance. Suffering from chronic otalgia, fatigue, vertigo while knowing that a prompt diagnosis at the outset and early treatment may have altered these life-changing events. Residual deficits result in a long-term disability. (2-6)

## WHAT IS BELL'S PALSY?

Bell's palsy is the commonest cause of acute peripheral facial nerve palsy, accounting for approximately 80 per cent of all cases and causing rapid onset of facial weakness.

Inflammation or damage to the facial nerve causes a range of symptoms due to dysfunction of the structures affected as indicated in Table Two. Deficits accumulate over hours to days and reach maximum severity within three weeks. The symptoms may also develop at night while the patient is sleeping, making them seem more acute. It affects between 20 to 30 per 100,000 people per year. The average GP will see a case every two years.

People in the last trimester of pregnancy or during the days after giving birth are a high-risk group.

Although normal facial function is completely restored in approximately 70 per cent of cases, 30 per cent will have a poor

# FACIAL PALSY

recovery (7, 8) with facial disfigurement and sometimes facial pain (2,3), and up to 16 per cent of those affected will have residual involuntary movements known as synkinesis. (2)

Although the exact cause of Bell's palsy is often unknown, it is widely believed that the most common cause is reactivation of herpes simplex virus.

The main initial differential diagnosis, as previously mentioned, is acute stroke. Once this had been excluded then it is important to perform a thorough assessment to distinguish between the various conditions presenting with facial palsy. The commonest symptoms are listed in Table Two.

A full neurological assessment is required to narrow differential diagnosis. Accurate diagnosis and prompt treatment where possible will improve prognosis.

**TABLE TWO**

| Common Symptoms Facial Palsy |
|---|
| Disordered movement of the muscles that control facial expressions, such as smiling, blinking, frowning or closing the eyelid |
| Drooling and / or dryness of the mouth |
| Headache |
| Tearing or dryness of the eye |
| Loss of the sense of taste on the front two-thirds of the tongue |
| Hypersensitivity to sound in the affected ear (hyperacusis) |

## BELL'S PALSY OR RAMSAY HUNT SYNDROME?

Ramsay Hunt syndrome (caused by Herpes Zoster (shingles) affecting the geniculate ganglion) causes a broader range of symptoms. There is frequently an erythematous vesicular shingles rash involving the skin of the ear canal/aurical (also termed Herpes Zoster Oticus) and/or the mucous membrane of the oropharynx. In addition, the proximity of the facial nerve to the vestibulocochlear nerve can result in hearing loss (43 per cent), tinnitus (20 per cent), and vertigo (51 per cent) in Coulson's series.

**TABLE THREE**

| ADDITIONAL SYMPTOMS COMMONER IN RAMSAY HUNT SYNDROME |
|---|
| Pain in or around ear on affected side |
| Shingles rash ipsilateral |
| Vertigo |
| Deafness |
| Tinnitus |
| Fatigue |

A study by Facial Palsy UK in 2018 found that only 32 per cent of patients with Ramsay Hunt syndrome are diagnosed at first visit, 42 per cent later and 27 per cent believe they had it, but it was never diagnosed.

The largest retrospective Ramsay Hunt syndrome treatment study (8) showed a statistically significant improvement in patients treated with prednisone and acyclovir within three days of onset. 80 patients were separated into groups based on the time treatment was started – that is, less than three days, three-to-seven days, and after seven days. Complete recovery was seen in 21 (75 per cent) patients treated within the first three days ($p<0.05$), 14 (48 per cent) patients treated at four-to-seven days, and seven (30 per cent) when treatment was not started until after seven days.

Sadly, patients with FNP continue to have relatively low public visibility, unless a high-profile international star reveals their own diagnosis. (9)

## SHOULD DRUGS BE PRESCRIBED FOR BELL'S PALSY AND RAMSAY HUNT SYNDROME?

As a clinician we are always keen to follow evidence-based treatment. Systematic reviews will often end by stating the need for a prospective trial. However, we all realise that this will not happen without major investment which is all too often sadly lacking.

This applies to both Bell's palsy and Ramsay Hunt syndrome.

Most studies that have reached a conclusion, have suggested that evidence points to the fact that prompt (within 72 hours) treatment with high dose steroids for 10-to-14 days, with the addition of antivirals in the case of Ramsay Hunt, will optimise outcome.

NICE guidelines for treatment of Bell's palsy (10) are as follows:

- For people presenting within 72 hours of the onset of symptoms, consider prescribing prednisolone. There is no consensus regarding the optimum dosing regimen, but options include:
  - o Giving 50 mg daily for 10 days or
  - o Giving 60 mg daily for five days followed by a daily reduction in dose of 10 mg (for a total treatment time of 10 days) if a reducing dose is preferred
- Antiviral treatments alone are not recommended
  - o Antiviral treatment in combination with a corticosteroid may be of small benefit, but seek specialist advice if this is being considered

- NICE guidelines for treatment of Ramsay Hunt syndrome:
  - o THERE ARE NONE!

Rather disappointingly, in my opinion, there are no NICE guidelines for Ramsay Hunt syndrome. While Ramsay Hunt syndrome is less common than Bell's palsy, misdiagnosis is more common and long-term sequelae more likely and more severe.

NICE does recommend prescribing antivirals for shingles as follows:

### WHEN SHOULD I PRESCRIBE ORAL ANTIVIRAL TREATMENT FOR SHINGLES?

If admission or immediate specialist advice is not indicated, consider the need for oral antiviral treatment (aciclovir, valaciclovir, or famciclovir).

Prescribe an oral antiviral treatment within 72 hours of rash onset for people with any of the following criteria: immunocompromise, non-truncal involvement, moderate or severe pain or rash.

### NICE GUIDELINES FOR FACIAL PALSY MANAGEMENT AND THERAPY

o THERE ARE NONE

Despite the high number of patients living with residual facial palsy there are no NICE guidelines on optimal management / therapy for patients suffering the sequelae of facial palsy either!

## THE IMPORTANCE OF EYE CARE IN FACIAL PALSY

### WHY IS THIS IMPORTANT?

It is critical to appropriately manage the eye if it is not closing fully, to avoid long-term avoidable damage.

Patients with facial palsy are at risk of severe dry eye due to both reduced or absent tear production, combined with evaporative dry eye due to inability to close the eye or blink. The cornea can become dry and easily damaged.

### IS THIS SERIOUS?

Drying or damage to the eye can affect vision. The eye may become red, sore and sensitive to light. An ulcer can form on the surface of the eye which may cause permanent damage if not treated. This is a

serious condition and if not treated promptly, can cause permanent scarring and loss of sight.

Treatment: In most cases, topical ocular lubrication (with preservative-free artificial tears during the day and lubricating ophthalmic ointment at night, or occasionally ointment day and night) is sufficient to prevent exposure keratopathy. Occluding the eyelids with tape is important. This provides advice for people with acute facial paralysis: www.facial-rehabilitation-centre.rjmdigital.net/wp-content/uploads/2022/08/The-Facial-Rehabilitation-Centre-Advice-for-people-with-acute-facial-paralysis.pdf

## WHEN TO SEEK REFERRAL AFTER FACIAL PALSY

### EYE HEALTH

If the eye does not close properly after two-to-three weeks a patient should be referred to ophthalmology as prolonged drying of the eye can lead to permanent damage.

In the later stages of recovery some people develop 'crocodile tears' where the eye waters involuntarily, particularly while eating. This is due to faulty 're-wiring' of the nerves during the recovery phase and is a separate complication that you would discuss with a facial palsy specialist consultant or ophthalmic consultant.

### GENERAL FACIAL RECOVERY

Consider referral to a facial nerve specialist if:

- There is any doubt about the diagnosis
- No improvement at all after three weeks
- Incomplete recovery three months after onset of initial symptoms

Many people assume that the specialist they need to see is a neurologist when in fact a facial nerve specialist could be a plastic surgeon, ENT consultant or neurologist. In some cases, you might be referred directly to a specialist facial therapist. There are very few facial nerve specialists in the UK, if your GP is unsure where to refer, they can contact Facial Palsy UK.

## SUBOPTIMAL THERAPY FOR CHRONIC FACIAL PALSY IS COMMONPLACE

### THE ROLE OF FACIAL THERAPY

We are frequently contacted at Facial Palsy UK by patients who have accessed our website and realised that their therapy does not follow the established guidelines. We work in partnership with Facial Therapy Specialists International (FTSI), an organisation which provides support, research and education on specialist facial therapy internationally. FTSI was founded having established that many people receiving therapy for Bell's palsy and other similar conditions (for example, Ramsay Hunt syndrome, Lyme disease and post-surgical conditions), were receiving non-specialist treatment from general therapists who had little experience in the specific needs of this patient group. Inappropriate treatments, such as gross facial exercise, strength training and electrical treatments, are recognised to do more harm than good in this patient population and were excluded by consensus in a recent treatment guideline research study of international facial therapy experts. There is a need for change in undergraduate therapy training programmes to educate physiotherapists, speech and language therapists or occupational therapists in this specialist field.

## IN SUMMARY

Facial palsy is not a homogenous condition but represents a symptom of more than 50 different conditions, covering many medical specialities. Experience at Facial Palsy UK indicates that misdiagnosis and inadequate treatment are commonplace in patients with acute facial palsy. It's clear that a thorough assessment, prompt diagnosis with regular review are essential to optimise recovery and reduce the numbers of patients who are misdiagnosed or have to live with life-changing and physically and emotionally life-altering symptoms. For patients with chronic symptoms there is a lack of awareness of the need to refer to specialist services for advice on facial therapy and nerve-related interventions. There is a need for improved resources to improve awareness among healthcare professionals of optimal treatment pathways. We shouldn't have to rely on Justin Bieber.

**Take home learning points.**

- **Accurate diagnosis and early treatment** are important for optimal prognosis in acute onset facial palsy
- **Medication is indicated for** Bell's palsy and Ramsay Hunt syndrome
- **Specialist Facial Therapy by a FTSI qualified therapist** will maximise recovery
- **Significant psychological morbidity** is common in chronic facial palsy and requires proactive support
- **Facial Palsy UK** is an excellent resource for patients and clinicians

Recovered (four weeks later)

## ABOUT FACIAL PALSY UK

Facial Palsy UK is a charity that supports people affected by facial paralysis, provides information for health professionals and aims to fund new research. Its website www.facialpalsy.org.uk contains information covering all aspects of facial palsy, including advice on various treatment options, support groups and answers to commonly-asked questions. Every patient presenting with facial palsy should be given information about their condition. The Facial Palsy UK website represents an extensive resource. Please recommend it.

Facial Palsy UK is launching a dedicated website and book aimed at health professionals in early 2024. The charity is also launching an app which will provide patients with some self-care tips while they are waiting to see a specialist.

***Join Facial Palsy UK's community and opt-in to health professional website updates to receive an alert when they are ready. This is the join link: www.facialpalsy.org.uk/support/join-our-community.***

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# ‘WHERE’S THE EVIDENCE FOR THAT?’

In the Microbiology Society’s latest expert instalment, Professor Elaine Cloutman-Green carves out the importance of sharing information in healthcare.

It’s a Friday night, it’s kicking off. It’s 5.30pm and everyone’s gone home so I’m up against it trying to find anything that will help me decide on treatment for a patient. I need to be able to take into account all the evidence and make a decision. I’m not going to have time to read 40 papers to inform that decision, so I look to a recently-published review.

The review provides me with not just all of the evidence I need, but the thinking associated with it. It’s incredibly valuable: to have evidence that is all in one place and to understand the thought processes of a diverse range of contributors. I’m able to go back to my patient with a clear plan of how to proceed.

If I make a decision as a healthcare professional, people will always come back and, quite rightly, ask ‘where’s the evidence for that?’. Evidence-based decision-making, the backbone of healthcare, and academia and clinical practice are closely linked, but academics perhaps don’t realise how much healthcare professionals appreciate the work that is getting published. It really enables them to have the key evidence base for any conversations about decisions so that they can pitch treatment choices appropriately.

It can’t be under-estimated how important collaborative working is, both within and between clinical and academic settings. It’s all about valuing those different perspectives and understanding that you’re bringing your specific lens to a conversation, but somebody else will have a different lens. My job is to make sure that patients don’t get an infection. So, when I go into a conversation with colleagues, I am thinking about the safest thing we could do. That could mean that effectively I put each patient in a bubble. No-one goes in to see them. Nothing ever touches them. However, my patients are also kids who are learning everything for the first time. I’m going to impact their development in their formative years, and possibly the rest of their lives. But where is the patient quality of life when someone is staying with me for a year? It’s therefore vital to have that openness to a conversation where I balance risk, opinions of my colleagues and the evidence to agree a plan of action.

That situation reflects the importance of collaboration in my ‘day-to-day’, but it’s also essential for the bigger picture. It’s easy for academic pathways to be developed and really valuable academic innovations to come to me that will never work in my clinical situation. It may be brilliant and interesting but it’s not going to change what I do in practice. It’s therefore important for collaboration to be fostered from the onset so that my response changes from ‘it’s too late’ or ‘none of that enables me to change my management decisions’ to ‘let’s not do it for that virus, let’s do it for this virus’ and that could completely revolutionise how I manage a patient.

Having that joint conversation about where my clinical challenges are and where there are opportunities in academic research changes things. Then academics and clinicians can work together to answer the real problems that are out there. We can also create opportunities to test those innovations in practice, to pull from research as well as push from academia, and create translational tools that can ultimately save lives.

***This article was created from a podcast recorded with Professor Elaine Cloutman-Green by the Microbiology Society. You can listen to the full podcast by searching for Microbe Talk wherever you get your podcasts.***

## ABOUT THE AUTHOR

Professor Elaine Cloutman-Green is a Microbiology Society member whose work spans clinical, lab and patient-facing roles. She holds positions as a Consultant Clinical Scientist (Infection Control Doctor), Deputy Director of Infection Prevention and Control and Joint Trust Lead Healthcare Scientist at Great Ormond Street Hospital. She is also an Honorary Professor, Department of Civil, Environmental and Geomatic Engineering at University College London.

Welsh Pharmacy Awards 2023

# Shining Examples

## The talent and triumphs of Wales' pharmacists once again took centre stage at the 2023 Welsh Pharmacy Awards.

The Welsh Pharmacy Awards celebrated the extraordinary healthcare initiatives being spearheaded throughout the last 12 months and beyond, from business development, to female health.

The event, hosted by publishing company Kyron Media, provided a much-needed opportunity to unite the sector at the Vale Resort, Glamorgan, in a ceremony which was to both resonate and encourage.

This year, presenter Andrea Byrne hosted a turnout of 300-plus industry experts and students, who gathered for the reveal of the 11 competitive category winners.

In the closing moments, the 2023 Special Recognition Award was presented to Berwyn Owen for his passionate and impactful pursuit of profession improvement over the years, including as Chief Pharmacist at Betsi Cadwaladr University Health Board.

Funds were also raised throughout the ceremony for Pharmacist Support – a well-established, independent and trusted charity supporting pharmacists and their families, former pharmacists, trainee pharmacists and pharmacy students.

***All the winners and their reactions will be featured over the following pages. Congratulations again!***

Kyron Media

# HOSPITAL PHARMACY TEAM OF THE YEAR **WINNER**

## SPONSORED BY ETHYPHARM UK

'We are absolutely thrilled to be the recipient of this award, what a proud and well-deserved moment for the team! Winning this award recognises our commitment and outstanding achievements this past year and a big thank you to the Welsh Pharmacy Awards and its sponsors for creating the opportunity to celebrate such a success.'

**The Education and Training Team**
**Swansea Bay University Health Board**

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**Bruno Ultra Barcelos**
**Ethypharm UK**


Hospital Pharmacy Team of the Year Award winner, the Education and Training Team, Swansea Bay University Health Board, with Bruno Ultra Barcelos, Ethypharm UK, and Bethan Tranter, Chief Pharmacist, Velindre Cancer Centre

# COMMUNITY PHARMACY PATIENT INITIATIVE **WINNER**

## SPONSORED BY KYRON MEDIA

'We are incredibly pleased and proud of Matthew being recognised with this award. Since the introduction of this IP-led service over 2,000 patients have been supported by Matthew. The award is a reflection of the hard work and dedication Matthew puts into his patient care and great network locally with healthcare professionals.'

**Matthew Lizakowski and the Boots Cardiff Queen Street Team**

'Well done Matthew and the Boots Cardiff Queen Street Team! His steadfast work ethic and passion for patient care puts him firmly at the heart of the community – a very worthy winner!'

**Chris Flannagan**
**Kyron Media**


Community Pharmacy Patient Initiative Award winner, the Boots Cardiff Queen Street Team, with Chris Flannagan, Kyron Media, and Elen Jones, Director for Wales, Royal Pharmaceutical Society

# FEMALE HEALTH INITIATIVE OF THE YEAR **WINNER**

## SPONSORED BY KENT PHARMA

'We were delighted to receive this award, and gain recognition for our developments in women's heath. The post-menopausal bleeding service was developed to expedite and streamline the investigation and management of post-menopausal bleeding on an urgent suspected cancer pathway. The time from first consultation to definitive treatment or discharge was reduced, and has had a positive effect on patient care. We are extremely grateful for this award and thankful to everyone who made it possible.'

**Caryl Thomas, Anna Denereaz and the Outpatient Gynaecology Team**
**University Hospital of Wales**

'Kent Pharma are delighted to sponsor the award for Female Health Initiative of the Year. We understand the many challenges women face both physically and mentally, throughout their lives and the importance placed on access to appropriate healthcare. We recognise the dedication and commitment shown by everyone working in this area and the significant impact that your hard work has on the lives of your patients. We would like to congratulate all finalists who have been nominated in this category and we wish each and every one of you, the very best of luck.'

**Nikki Jessop**
**Kent Pharma**


Female Health Initiative of the Year Award winner, Caryl Thomas, Anna Denereaz and the Outpatient Gynaecology Team, University Hospital of Wales, with Nikki Jessop, Kent Pharma, and Liz Bruen, Endometriosis and Pelvic Pain Clinical Nurse Specialist

# BUSINESS DEVELOPMENT OF THE YEAR **WINNER**

## SPONSORED BY AAH PHARMACEUTICALS

'It has been a great honour to receive the award for Business Development of the Year. We have worked extremely hard to offer both NHS and private clinical services for our local community. With the integration of technology, it has allowed us to build a great platform for patients to access the healthcare they need and deserve. We are always striving to expand and improve the services that we provide.'

**The Hopwoods Pharmacy Team**
**Llanedeyrn**

'At AAH we are proud sponsors of the Business Development of the Year category at the Welsh Pharmacy Awards. It is a fantastic opportunity to recognise the outstanding work community pharmacy teams do every day to support patients.'

**Roddy McEwan**
**AAH Pharmaceuticals**


Business Development of the Year Award winner, the Hopwoods Pharmacy Team, Llanedeyrn, with Roddy McEwan, AAH Pharmaceuticals, and Rhodri Thomas, Community Pharmacy Wales

# PATIENT SAFETY DEVELOPMENT IN SECONDARY CARE **WINNER**

## SPONSORED BY CAREFLOW MEDICINES MANAGEMENT

'The Grange University Hospital Pharmacy Team feel extremely privileged to have won the award for Patient Safety Development in Secondary Care. Our staff across the hospital have endured a difficult couple of years. Through the COVID pandemic, opening of the new hospital and high vacancy rates, the majority of our staff are feeling that they will always be under significant pressure to deliver high-quality patient care. Patients are our main priority and to be able to work together within a multidisciplinary team, developing new ideas and working practices to ensure patient safety is at the forefront, is a fabulous achievement. To be recognised for this achievement is of great significance to all the staff involved. We look forward to progressing the patient safety agenda over the coming year.'

**The Grange University Hospital Pharmacy Team**

'The standard of this year's applications was higher than ever before. It's a privilege to have witnessed the work of the exceptional teams. Congratulations to the Grange University Hospital Pharmacy Team on their innovative pursuits and unfaltering commitment to patient safety.'

**Chris Flannagan**
**Kyron Media**


Patient Safety Development in Secondary Care Award winner, the Grange University Hospital Pharmacy Team, with Chris Flannagan, Kyron Media

# INDEPENDENT COMMUNITY PHARMACY PRACTICE OF THE YEAR **WINNER**

## SPONSORED BY CAMBRIAN ALLIANCE GROUP

'We are so thrilled to have been recognised as a team in this year's Welsh Pharmacy Awards. Greater use of pharmacy services has allowed us to offer more to the local community and this offer has been taken up and appreciated in our area. It's been great working in this environment! We are lucky to have such a fantastic team and great support from other colleagues across primary care locally.'

**The Caerau Pharmacy Team**
**Maesteg**

'It was inspiring to be alongside so many dedicated pharmacy teams from the breadth of Wales. With the demands on their time – providing services as well as scripts, and battling the complexities of the market – it's important to celebrate and recognise the particular achievements of community pharmacies. We don't need reminding how dedicated and adaptable our pharmacists continue to be. All the nominees play a vital role on the frontline of healthcare in their communities and talking to them, their passion was clear. We were proud to present the award for Independent Community Pharmacy Practice of the Year to Caerau Pharmacy – congratulations from everyone at Cambrian Alliance to them and all the winners and nominees.'

**Leon Vincent**
**Cambrian Alliance Group**


Independent Community Pharmacy Practice of the Year Award winner, the Caerau Pharmacy Team, Maesteg, with Leon Vincent, Cambrian Alliance Group, and Raj Aggarwal, the Aggarwal Group

# MANAGEMENT OF SUBSTANCE DEPENDENCY **WINNER**

## SPONSORED BY ETHYPHARM UK

'We would like to say a huge thank you, for not only being shortlisted, but being recognised as individual services working in partnership, changing the way substance services work alongside GPs in making a difference to people's lives. We were very humbled to receive such a prestigious award. We want to thank everyone involved for such a memorable evening. We will forever be grateful.'

**The Pencoed Medical Centre and Brynawel House Partnership Team**

'It's great to see such a dedicated team winning this award. Well done and keep up the good work within the community to further the healthcare needs of those individuals who need it.'

**Ken Sutherland**
**Ethypharm UK**


Management of Substance Dependency Award winner, the Pencoed Medical Centre and Brynawel House Partnership Team, with Ken Sutherland, Ethypharm UK, and Amy Jayham, Head of Pharmacy Operations (Swansea Bay University Health Board)

# INNOVATIONS IN SERVICE DELIVERY IN COMMUNITY PHARMACY (INDEPENDENT) **WINNER**

## SPONSORED BY NUMARK

'We're so glad for the team on winning the award – it's a reflection of the hard work they put in.'

**HOW Pharm Ltd – The Llanidloes Pharmacy Team**
**Powys**

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**John Pignone**
**Numark**


Innovations in Service Delivery in Community Pharmacy (Independent) Award winner, HOW Pharm Ltd – The Llanidloes Pharmacy Team, Powys, with John Pignone, Numark, and Dave Thomas, Managing Director, Thomas Group (Newport) Ltd

# PHARMACY STUDENT LEADERSHIP **WINNER**

## SPONSORED BY THE PHARMACISTS' DEFENCE ASSOCIATION

'I'm still in shock at the award! I want to say congratulations to all the winners and nominees. I would also like to say a massive thank you to my parents and grandparents for constantly supporting me, and for being the best role-models I could ever have.'

**Caitlin Edwards**
**Cardiff University**

'The Welsh Pharmacy Awards are a great way to recognise and celebrate the dedication and outstanding work of pharmacists in all sectors. It's lovely to be able to shine a light on the pharmacists of the future with the Pharmacists' Defence Association proudly sponsoring the Student Leadership Award. It's a shame that there can only be one winner.'

**Helen Lewis**
**The Pharmacists' Defence Association**


Pharmacy Student Leadership Award winner, Caitlin Edwards, Cardiff University, with Helen Lewis, The Pharmacists' Defence Association, and Professor Andrew Morris, Swansea University

# SUSTAINABILITY IN HEALTHCARE **WINNER**

## SPONSORED BY TEVA UK

'We are delighted with the award. Sustainability in healthcare is something that I care passionately about and this is recognition of all the hard work that the pharmacy team has put in over the last couple of years to achieve carbon neutrality.'

**The JDS Evans Pharmacy Team**
**Newport**

'Today, Teva aims to be a new kind of pharmaceutical company. One liberated from the traditional definition of a generic medicines company. A company with a category-defying portfolio, harnessing our generics expertise and stepping up innovation, continuing the momentum behind the discovery, delivery and expanded development of modern medicine. To healthcare professionals, patients, caregivers and families, we commit to push the boundaries to help deliver quality medicine wherever it is needed, discover life-changing treatments, and strive forward through scientific innovation. Because when it comes to health, good is not enough for us. THIS is the Teva legacy – to be stronger, bolder and simpler in the way we operate and relentless in our growth by understanding what's next – in science, for patients, people and society.'

**Alasdair Mercer**
**Teva UK**


Sustainability in Healthcare Award winner, the JDS Evans Pharmacy Team, Newport, with Alasdair Mercer, Teva UK, and Paul Gimson, Assistant Director of Improvement (Cwm Taf Morgannwg University Health Board)

# PRIMARY CARE TEAM OF THE YEAR **WINNER**

## SPONSORED BY BOOTS

'The Primary Care Team in Hywel Dda University Health Board were delighted to win the award for Primary Care Team of the Year 2023. This was particularly important for us as we are a team working across a number of departments to achieve a common goal. This award was the affirmation that joined up working, listening to and learning from different departments can bring about a shared vision which beneficially impacts not only patients, but the NHS as a whole.'

**The Medicines Management Team**
**Hywel Dda University Health Board**

'Sponsoring the Primary Care Team of the Year Award has been a great honour for Boots UK. We are delighted to recognise how working in partnership with community pharmacies across Wales, primary care teams help to deliver great care and ensure patients can be looked after closer to home.'

**Jenny Rose**
**Boot UK**


Primary Care Team of the Year Award winner, the Medicines Management Team (Hywel Dda University Health Board), with Jenny Rose, Boots, and Lloyd Hambridge, Divisional Director Primary Care and Community Services, NHS Wales

# SPECIAL RECOGNITION **WINNER**

## IN ASSOCIATION WITH ROYAL PHARMACEUTICAL SOCIETY

'I'm very grateful to the Royal Pharmaceutical Society for bestowing this award which I dedicate to the entire pharmacy workforce across Wales who deliver the best care day in day out. To all pharmacists, pharmacy technicians, pharmacy assistants and our administrative teams who are the glue that holds the NHS together.'

**Berwyn Owen**
**Former Chief Pharmacist at Betsi Cadwaladr University Health Board**

'We are delighted to have awarded this year's Special Recognition Award to Berwyn Owen. Berwyn has had huge impact on pharmacy in Wales as well as the wider healthcare team during his role as chief pharmacist in Betsi Cadwaladr University Health Board – he is a true leader that's never afraid to speak up on behalf of the profession and patients. We wish Berwyn every success in his next chapter in pharmacy, as a community pharmacy contractor.'

**Elen Jones**
**Royal Pharmaceutical Society for Wales**


Special Recognition Award winner, Berwyn Owen, former Chief Pharmacist at Betsi Cadwaladr University Health Board, with Geraldine McCaffrey and Elen Jones, Royal Pharmaceutical Society Wales

**Photos: Henry Bird – www.hbev.uk**

# Welsh Pharmacy Awards 2023

# Welsh Pharmacy Awards 2023

MIGRAINE

# A HEADS UP

Migraine is a complex neurological condition affecting one-in-seven people in the UK. From its all-encompassing symptoms and advancement through stages, to understanding the route of effective management, Andrea Quinn, Senior Communications Officer at The Migraine Trust, explains why migraine is so much more than a headache.

Andrea Quinn

For many, migraine attacks are full-body experiences which head pain forms just one part of. In fact, there are distinct stages of a migraine attack, and it is these stages and their symptoms that distinguish a migraine from a headache. However, not everyone will experience all of the symptoms of each stage and the stages can overlap. In adults, we can divide a migraine attack into four or five stages that lead on from each other:


It can be useful to understand the different symptoms that may present in each of these stages.

## PREMONITORY STAGE

- Feeling tired
- Excessive yawning
- Food cravings
- Changes in the mood, such as feeling down or irritable (high or low)
- Feeling thirsty
- Neck stiffness
- Passing more urine (wee)

These feelings can last up to 24 hours.

## AURA STAGE

Around a quarter of people with migraine have aura. Migraine without aura doesn't include this stage. The aura of migraine includes a wide range of neurological symptoms. These symptoms include:

- Changes in sight (visual disturbances), such as dark spots, coloured spots, sparkles or 'stars', and zigzag lines
- Numbness or pins and needles
- Weakness
- Dizziness or vertigo (sensation of spinning and poor balance)
- Speech and hearing changes
- Some people experience memory changes, feelings of fear and confusion, and more rarely, partial paralysis or fainting

This stage can last from five-to-60 minutes, and usually happens before the headache.

It's possible to have the aura symptoms without the headache – this is often referred to as 'silent migraine'.

### HEADACHE STAGE

- Moderate-to-severe head pain, usually on one side of the head, especially at the start of an attack. However, an individual can get pain on both sides, or all over the head
- Nausea (sickness) and vomiting (being sick) can happen at this stage, and they may feel sensitive to light, sound, smell and movement

### RESOLUTION OR POSTDROME STAGE

- Fatigue
- A 'hangover' type feeling
- Symptoms similar to, or mirroring, those in the premonitory phase

## DIFFERENT TYPES OF MIGRAINE

In addition to the 'classic' symptoms just mentioned, others may experience these and additional symptoms depending on the type of migraine they have. These may include:

### VESTIBULAR MIGRAINE

A type of migraine where people experience a combination of vertigo, dizziness or balance problems with other migraine symptoms.

### HEMIPLEGIC MIGRAINE

A rare type of migraine involving temporary weakness on one side of the body.

### ABDOMINAL MIGRAINE

A common condition that affects four-in-100 children and also some adults. Symptoms include: regular attacks of moderate-to-severe stomach pain that last from two-to-72 hours, feeling sick and vomiting during attacks and no headache during attacks.

*'For me it's usually the non-headache aspects of migraine that can be the most debilitating; in the prodrome phase I experience a range of disconcerting symptoms, including fatigue, depression, anxiety, visual and auditory hallucinations, visual disturbances, insatiable hunger, pins and needles, light-headedness, facial pain and cognitive impairment. The aura phase renders me temporarily blind and disorientated, and the postdrome phase is marked by extreme fatigue and brain fog.'*
***Person who lives with migraine***

Some symptoms in each of these stages and types can occur either accompanied by, or without, pain. It's important to remember that symptoms associated with migraine are diverse, impact people in different ways and to varying degrees, and affect much more than just the head. Despite this, migraine care is often primarily focused on management of head pain.

## PREVENTIVES THAT GO BEYOND PAIN MANAGEMENT

Typically, for those struggling with frequent migraine attacks, a migraine preventive will be required for a period of time to control how frequent and severe the symptoms are. Preventive medicines (also known as prophylactics) for migraine are taken to prevent migraine attacks. They are taken every day and are aimed at preventing migraine attacks altogether, or at least reducing their frequency and severity.

If an individual is having at least four migraine attacks per month, they may wish to discuss preventive medication with their doctor. There are a range of different preventive migraine medicines that can be taken, including several that are just becoming available in the UK, such as calcitonin gene-related peptide antibodies (CGRP) and monoclonal antibodies (mAbs).

The treatment needs to be tolerated and, if not, consideration should be given to switching to another. After three preventives are tried without benefit or adequate benefit, or if they have a rare type of migraine, a referral to a specialist for a different type of treatment will be appropriate.

Acute and preventive treatments should be selected by healthcare professionals according to the types and severity of symptoms that patients report. It's useful for people with migraine to keep a migraine diary to note symptoms, their severity, and the areas of their life impacted, to allow clinicians and GPs to best assess treatment options.

## PHARMACISTS HAVE AN IMPORTANT ROLE IN MIGRAINE CARE

Pharmacists should be able to advise patients on how to use acute treatments, what combinations work well and, crucially, how to avoid overuse of acute medications, particularly opiates. They can check the doses of preventive treatments patients are on, advise them on side-effects, and signpost back to GPs for review when needed.

## MIGRAINE AWARENESS WEEK 2023

This year, for Migraine Awareness Week, we wanted to highlight that people with migraine deserve better. You can help us do this by downloading and sharing some of our migraine resources with colleagues, or downloading and displaying our Migraine Awareness Week poster in areas patients frequent. By being better informed about migraine and understanding that its impact extends far beyond head pain, healthcare professionals can be integral to ensuring that people with migraine get the care they deserve.

***For more information, visit www.migrainetrust.org.***

ENDOMETRIOSIS

# WHY THE WAIT?

Here, Carla Cressy, founder and CEO of The Endometriosis Foundation, discusses the necessity of bridging the gap in healthcare for endometriosis, in addition to the first-hand experience which sparked her formation of the integral charity.

Carla Cressy

My personal experiences of a long-awaited diagnosis of endometriosis led to over a decade battling with healthcare professionals to believe the severity of my pain.

Despite being under the care of gynaecology aged 14, presenting with all the common signs of endometriosis, I was continuously told what I was experiencing was 'normal'.

Eventually, in 2016, I was diagnosed with stage four endometriosis through a laparotomy (open surgery), which by this time had led to frozen pelvis disease and infertility, following an unnecessary appendectomy, aged just 25.

Eventually, aged 29, I had no other choice than to undergo a total hysterectomy, forcing me into surgical menopause. This was following multiple – eight – operations to try to fix the irreversible damage caused by endometriosis.

My surgeries included bladder and ureter reconstruction surgery and bowel surgery, leaving me with an ileostomy (stoma) which I was lucky to have reversed 18 months later. To this very day, I have never been offered any kind of support outside of my family and friends, or so much as an information leaflet about the condition throughout my entire journey.

Like most people living with endometriosis, I had never heard of the condition. Once diagnosed, I was continuously told it was 'just a period issue' and to quite simply 'just get on with it'.

I knew I had my work cut out when I discovered there was space for a charity. Since founding The Endometriosis Foundation, a charity dedicated to awareness, education and support, I've realised that over the years sadly not a lot has changed.

With this in mind, I knew I needed to create a charity that has endometriosis patients' best interests at heart, a charity I wish existed all those years ago, everything that I never had.

The current state of the healthcare system presents several challenges, particularly in addressing the unique needs of people suffering with endometriosis – a chronic and often debilitating condition affecting millions of people assigned female at birth worldwide.

It occurs when endometrial-like tissue is found growing and functioning elsewhere in the body, leading to inflammation, pain, organ dysfunction, and, in some cases, organ failure, and infertility.

Despite being common, affecting more than 10 per cent of the female population, a similar number to those affected by asthma and diabetes, it currently takes on average eight years from the onset of symptoms to achieving a diagnosis of endometriosis in the UK. This is despite the condition being listed by NHS England among the most painful conditions to have.

Endometriosis remains significantly underdiagnosed, under-funded, and often misunderstood. This highlights a fundamental issue within the current healthcare system – insufficient awareness, research, funding, and understanding of the condition.

In my opinion, the ideal healthcare system for people with endometriosis would first and foremost address the glaring gaps in the current system.

One of the primary deficiencies is the lack of awareness and understanding about the condition. Currently, many individuals, including healthcare professionals, hugely underestimate the severity of endometriosis, which understandably leads to a delay in diagnosis and inadequate treatment. Raising awareness should consequently be a central pillar of the ideal system.

This would involve comprehensive public health campaigns, inclusion of endometriosis education in the school curriculum, and targeted awareness efforts within the medical community. By breaking down the stigma and misinformation surrounding the condition, we can promote early recognition and understanding, reducing the suffering that many endure.

In addition to awareness, the ideal healthcare system must offer more tailored and multidisciplinary care. Specialised centres staffed with experts in gynaecology, colorectal and urology, and for those who need it, respiratory.

Pain management, holistic therapies, such as dietary advice and acupuncture, and fertility services, should be established to provide comprehensive care under one roof, tailoring treatment plans to each patient's unique needs. These centres would streamline the diagnostic process, ensuring that people with endometriosis, of all stages, receive accurate diagnoses promptly.

Furthermore, personalised treatment plans that may involve a combination of medical, surgical, and complementary therapies, accounting for factors like pain levels, fertility wishes, and mental health, should be the norm rather than exception.

Ultimately, I believe mental health services should be integrated into endometriosis care, offering counselling and support to help patients cope with the emotional toll of the condition.

Implementing guidelines for early and accurate diagnosis is essential, and healthcare professionals should be educated on recognising symptoms of endometriosis, and diagnostic tools, such as ultrasound, MRI, and minimally-invasive laparoscopic surgery, should be more readily accessible.

By prioritising awareness and comprehensive, patient-centred care, we can create a healthcare system that better supports people suffering with endometriosis.*

***For more information and to support The Endometriosis Foundation, visit www.theendometriosisfoundation.enthuse.com/donate.***

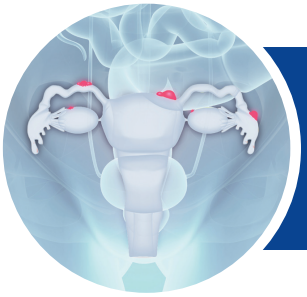
***This story was first published on femtechworld.co.uk. Check out the latest news with in-depth comment and analysis @ femtechworld.***

The Endometriosis Foundation

# Zalkya® 2 mg

film-coated tablets

*dienogest*



## A significant progress in the **treatment of endometriosis**[1]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**Dienogest is a 4th generation selective progestin having anovulatory and anti-proliferative effect in endometrial cells, as well as anti-inflammatory and anti-angiogenic actions.**[2]

- Reduces endometrioma volume[3]
- Preserves the ovarian reserve[4]
- As effective as GnRH agonists in relieving pain associated with endometriosis[5]
- Presents a favourable adverse events profile vs GnRH agonists[5]

In addition to a significant pain reduction, **women treated with Zalkya® 2mg experienced hypoestrogenic symptoms less frequently** than women treated with Leuprolide acetate.[5]

### References

**1.** Vercellini et al., Fertility and Sterility Vol. 105, No. 3, March 2016. **2.** Sasagawa S et al, Steroids 2008; 73: 222-231. **3.** Angioni et al. Gynecological Endocrinology 2019. **4.** Muzii et al., Gynecological Endocrinology 2019. **5.** Strowitzki T. et al, Human Reproduction, Vol.25, No.3 pp. 633–641, 2010.

### Prescribing information

Please refer to the Summary of Product Characteristics (SmPC) before prescribing.
**Name and active ingredient:** Zalkya® 2mg film-coated tablets. Each tablet contains 2mg of dienogest. **Indications:** Treatment of endometriosis. **Posology and method of administration:** One tablet daily without any break, taken preferably at the same time each day with some liquid as needed. The tablet can be taken with or without food. For oral use. **Contraindications:** Zalkya® should not be used in the presence of any of the conditions listed and should any of the conditions appear with first use of Zalkya® treatment must be discontinued: active venous thromboembolic disorder, arterial and cardiovascular disease, past or present (e.g. myocardial infarction, cerebrovascular accident, ischemic heart disease), diabetes mellitus with vascular involvement, presence or history of severe hepatic disease as long as liver function values have not returned to normal, presence or history of liver tumours (benign or malignant), known or suspected sex hormone-dependent malignancies, undiagnosed vaginal bleeding or hypersensitivity to the active substance or to any of the excipients listed (see section 6.1 of the SmPC). **Special warnings and precaution for use:** Precautions should be taken regarding serious uterine bleeding, changes in bleeding pattern, circulatory disorders, tumours and osteoporosis (see SmPC section 4.4). **Interactions:** Inducers or inhibitors of CYP3A4 may affect the progestogen drug metabolism. An increased clearance of sex hormones due to enzyme induction may reduce the therapeutic effect of Zalkya® and may result in undesirable effects e.g. changes in the uterine bleeding profile. Substances increasing the clearance of sex hormones (diminished efficacy by enzyme-induction), e.g.: phenytoin, barbiturates, primidone, carbamazepine, rifampicin, and possibly also oxcarbazepine, topiramate, felbamate, griseofulvin, and products containing St. John's wort (Hypericum perforatum). See section 4.5 of the SmPC for full information. **Adverse reactions:** The most commonly reported adverse reactions of Zalkya® are: weight increase, depressed mood, sleep disorder, nervousness, loss of libido, altered mood, headache, migraine, nausea, abdominal pain, flatulence, abdominal distension, vomiting, acne, alopecia, back pain, breast discomfort, ovarian cyst, hot flushes, uterine / vaginal bleeding including spotting, asthenic conditions, irritability. See section 4.8 of SmPC for full information. **Presentation:** 2 x 14 white film-coated tablets packed in PVC (250 µm)-Aluminium (20 µm) push-through-blister. Pack Size: 28 film-coated tablets. NHS Cost: £20.68. **Legal Classification:** POM. **MA Number:** PL 21844/0037. Distributed by Kent Pharma UK Ltd. Date of preparation: June 2021. UK21/007/SmPC Sept 2019.

**Adverse events should be reported:** Reporting forms and information can be found at: www.mhra.gov.uk/yellowcard or search for MHRA Yellow Card in the Google Play or Apple App Store. Adverse events should also be reported to Kent Pharma UK Ltd on 01233 506574 or medical@kent-athlone.com. For a copy of the SmPC or further medical information, please contact: medical@kent-athlone.com. Additional information available on request.

For further information on this product, please contact your Kent Pharma Hospital Key Account Manager or our customer service team.

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Date of Preparation: April 2022 Ref: UK22/17/00

LEUKAEMIA

# GIVING NOTICE

People in Wales are being urged to adopt increased vigilance when it comes to symptoms of leukaemia as staggering figures show limited awareness of bruising, fatigue and infections as signs of the blood cancer. How can meaningful recognition be harnessed among the population?

Leukaemia is a form of blood cancer that affects people of all ages and 27 people receive a leukaemia diagnosis every day in the UK – that's just under 10,000 every year. Overall survival for leukaemia stands at just over 50 per cent – making it one of the most deadly forms of cancer.

Early diagnosis could saves lives, yet the recent public survey by leukaemia charities Leukaemia Care and Leukaemia UK, found that 45 per cent of respondents from Wales could not recognise any among the four most widely-reported symptoms of the disease, which kills nearly 5,000 people a year in the UK, and which is often diagnosed too late.

The two charities are collaborating on an important campaign, #SpotLeukaemia, to raise awareness of the symptoms ahead of Blood Cancer Awareness Month. Blood cancer is the fifth most common cancer and third deadliest.

In a recently-released film Leukaemia Care and Leukaemia UK have called on five-year-old children to try to make the symptoms of leukaemia memorable. The advert sees youngsters asking a range of questions to encourage people to ask 'why' am I feeling this way – channel your inner five-year-old and question your symptoms which could be leukaemia.

People who are concerned about any of these symptoms – fatigue, bruising, unusual bleeding and repeated infections – are being strongly urged by the charities to contact their GP and request a blood test. More information is available on the Spot Leukaemia website at www.spotleukaemia.org.uk.

The advert focuses on the four most widely-reported symptoms. Other symptoms of leukaemia include fever or night sweats, bone or joint pain and swollen lymph nodes.

The charities are now calling on people to start 'asking why' about leukaemia and its symptoms, share the video with friends and family, and visit the Spot Leukaemia website for more help and advice.

## AWARENESS OF THE SYMPTOMS OF LEUKAEMIA IS LOW IN WALES

Only nine per cent of respondents across Wales recognised infections as one of the most common symptoms, of leukaemia, only 26 per cent said unusual bruising is a most common symptom and just 16 per cent said unusual bleeding is a most common symptom. Only 34 per cent of respondents were able to recognise fatigue as a symptom – which is often the most likely symptom to be identified by those later diagnosed with leukaemia.

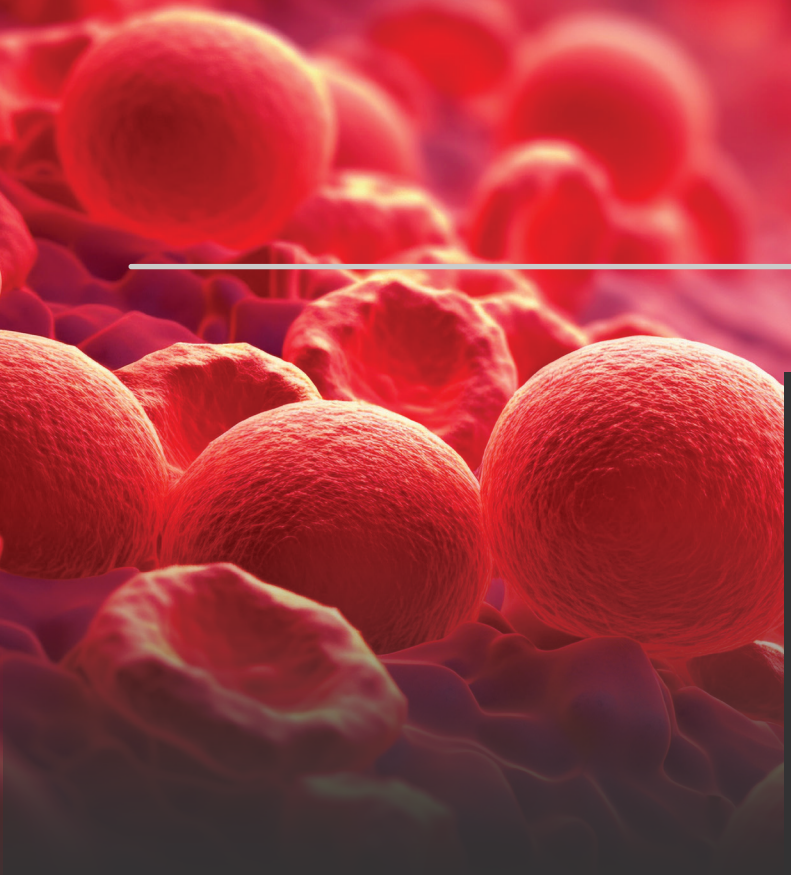
## JULES' STORY

Jules' first symptom of leukaemia was unusual bleeding at the age of 39. She visited her GP when a period lasted six weeks. She went to the appointment knowing that a six-week duration really needed investigating, having already put it off.

Typically, Jules' bleeding stopped when her appointment arrived but feels grateful that she mentioned it to colleagues who encouraged her to still attend. At the time, Jules was also feeling fatigued, and she also experienced unexplained bruising – something she had brushed off as a busy Mum.

Jules had blood tests which flagged her white blood cell count, and the GP re-did the bloods a couple of times more to ensure it wasn't a fluke. Next, Jules was referred to the hospital's gynaecology department to rule out ovarian cancer as this was the primary concern. These tests weren't showing anything else apart from what the bloods were already showing. Jules was then referred to the rapid diagnosis centre, who also couldn't find anything specific, so she was referred back to her GP.

Fortunately, investigating what was wrong didn't stop there and Jules was referred to the haematology department at her local hospital. Jules attended Morriston Hospital and recalls going on her own as she was yet to get an answer for her symptoms from previous appointments.



It was on this occasion that Jules was told, because of tests that were previously carried out, they had ruled out everything other than chronic myeloid leukaemia (CML). It was necessary for Jules to have more blood tests, which would be sent to Cardiff for analysis to confirm her suspected diagnosis.

It was on 14th February 2020 that Jules received her official CML diagnosis. It was four weeks from meeting the consultant to receiving the unexpected news – a time Jules describes as her 'worst time'. A time of so many what-ifs and that Googling any information just made everything scary.

After meeting the consultant, Jules was sent to have a bone marrow extraction to enable them to see how advanced the cancer was and what treatment would be needed. Jules was lucky – it was very early days.

Jules also received the news that her CML was incurable – something that freaked her out, she says. She learned it was liveable, but they couldn't cut this illness out. For Jules it was a time when she felt she'd lost control of her life which was further affected by COVID-19.

In late March, Jules started treatment. Support groups and information pages helped Jules find out more to help deal with her situation, especially from others who were further into their treatments. She said it was surprising how many other women in the group also experienced changes in their menstrual cycles.

Jules found her treatment very hard; she gained weight, her mobility suffered greatly, and a weakened immune system meant she picked up a lot of bugs. Jules says though that she would do everything she could to work through it. She began to meditate, do gentle exercise when possible and followed a vegan diet. She also credits keeping a positive mindset.

It was on 28th May 2022 that Jules received a call from her consultant to say her latest bloods had come back as undetectable. She must continue treatment, as there is a risk of it coming back without it, while she still deals with the side-effects.

Jules says that knowing the signs and symptoms of leukaemia is so important. Many women in their late-30s put down a change in their periods to early menopause or ignore it altogether, but early detection is invaluable to people's lives.

# AWARENESS AMONG DIFFERENT AGE GROUPS

Nationally of those surveyed, 16 per cent of those over the age of 55 believed leukaemia is a childhood disease (most common in ages 0-to-15 years) – this drops slightly to 13 per cent in Wales. Whereas in reality, cases rise sharply after the age of 55 and 38 per cent of all new cases occur in the over-75s.

Zack Pemberton-Whiteley, Chief Executive of Leukaemia Care, said, 'To hear that less than half a percent of those surveyed in the UK are able to identify the four most common symptoms of leukaemia is extremely worrying. Early diagnosis of leukaemia can improve survival. With just under 10,000 people being diagnosed every year with leukaemia, this shows just how important it is to continue to raise awareness of the signs and symptoms and how much work needs to be done.

'We know that our new Spot Leukaemia video may make some people laugh but in order to raise awareness of this serious subject we needed to channel our inner five-year-old and ask 'why'. It's crucial that if you think you have fatigue, bruising or bleeding or repeated infections you contact your GP and ask for a blood test. It's that straightforward and we will keep pushing people to ask why and get what could be a crucial diagnosis.'

Fiona Hazell, Chief Executive of Leukaemia UK, said, 'It's concerning to learn that so few UK adults can correctly identify the four most common symptoms of leukaemia, or even any symptoms at all. Each day in the UK 27 people are diagnosed with leukaemia, and despite decades of progress, only half of leukaemia patients will live longer than five years after diagnosis. Spotting the signs of leukaemia and asking for that all-important blood test can make a meaningful difference in treating this disease.

'That's why it's even more concerning to learn that most people would not visit their GP if experiencing one or more of the four most common symptoms. We would encourage anyone who is concerned about leukaemia to make an appointment to request a blood test as soon as possible.'

When asked why they would not contact their GP if experiencing any unusual symptoms, 26 per cent of UK adults who said they would not do this selected "don't want to put additional pressure on the NHS" as their main reason, from a given list. Long waiting times were also listed as an off-putting factor, with 23 per cent of UK adults who said they would not visit a medical professional, citing this as their main reason, from a given list, for not getting in touch.

Leukaemia is a form of blood cancer which affects people of all ages but is most common in the over-65s. Other symptoms of leukaemia can include fever or night sweats, bone or joint pain and swollen lymph nodes.

***For more information visit the Spot Leukaemia website at www.spotleukaemia.org.uk.***

# IT'S NO PICNIC: LIVING AS A YOUNG PERSON WITH TYPE 1 DIABETES

**Type 1 diabetes can seem daunting at the best of times, but its reach extends further than initially expected – in fact, the condition is experienced by approximately 400,000 people in the UK, including 29,000 children. In this article, 17-year-old Eve Wilson illuminates the journey which young people with type 1 diabetes may encounter, particularly in light of the influx of diagnoses following COVID-19, and in the context of mental health issues surrounding teenagers.**

Eve Wilson

Type 1 diabetes (T1D) is an autoimmune disease by which the pancreas is prevented from producing insulin. Without intervention, this can cause blood sugar levels to skyrocket.

The condition is diagnosed often in young people and can add stress to everyday life, ranging from causing food to have to be monitored intently, to causing anxiety around glucose monitors being visible under short sleeves.

Nine years ago I was diagnosed with T1D at the age of eight. Such a massive change was a difficult adjustment, not to mention the onslaught of responsibility – suddenly, every meal seemed like a matter of life and death. Suffice to say, it was a challenging time for me and my family.

As a 17-year-old now, diabetes seems a lot less daunting. I am lucky in the fact that my peers seeing my insulin pump or glucose monitor doesn't bother me – in fact, I appreciate any opportunity to answer questions or clear up misconceptions.

For example: firstly, I am not a 'diabetes sufferer'. 90 per cent of the time, it's really not that bad. Secondly, sometimes I need to sit down, even when it is inconvenient. This isn't for my own comfort; this is because my legs are shaking, and my brain doesn't have enough glucose available to think straight. Thirdly, there is no cure yet, no matter how I change my diet. I can eat anything, no matter how sugary or unhealthy, and if I take my insulin, I'll be as okay as anyone else. Finally, I can do anything – I just need to take a little extra care.

As a teenager, it has been difficult to maintain the responsibility needed to stay safe. What I have found most helpful are classmates, family and friends who do what they need to accommodate me when hypoglycaemia strikes, not to mention being able to rely on an insulin pump and continuous glucose monitor, which help me stay healthy in a far more convenient way than finger pricks and injections.

## INNOVATIVE ADVANCEMENTS

Speaking of such devices, new developments in technology are making strides in making life easier for type 1 diabetics everywhere.

Continuous glucose monitors display blood sugar levels in real time and can be linked to a phone or handset, which can have alarms for low or high blood sugar, for convenience. They are small devices attached to the skin and must be routinely replaced. They can display trends, or let parents or caregivers monitor blood sugar levels at the same time as a child. While blood checks may be needed for calibration, the need for them is greatly decreased!

Insulin pumps are wearable devices attached to the body via tubing (tethered), or stuck directly on the skin (patch). They continuously deliver small doses of insulin in the background, which can be edited for flexibility, as well as doses for food. Insulin for meals can be taken over a prolonged period as needed. The set of the pump must be replaced every few days (usually three). They can allow for a tighter control over blood sugar levels, along with reducing the need for needles. However, they can be difficult to learn to use, can cause blood sugars to rise if they are damaged or disconnected, or could get infected if the set site isn't replaced as recommended.

A newer treatment is Islet Transplants. Here, islets (cells which produce insulin in the pancreas) are donated from a donor to a diabetic. These can benefit diabetics with low blood sugar unawareness, but are usually temporary, as the body destroys the new islets. This treatment is only rarely used, due to the shortage of donors and the risk arising from the need for immunosuppressants so the islets aren't rejected. More research is being conducted to improve this treatment, though!

## DISPELLING THE STIGMA

However, these developments do not negate the struggles faced by diabetics, particularly those around my age. There is a lot of shame attached to T1D. There are a lot of uncomfortable questions to be asked about its cause and care. I have known many people who preferred to hide their glucose monitors or opted out of using an insulin pump for the sake of the condition being less obvious. Even worse, there is not one type 1 diabetic out there who has not seen or heard of another who has hidden snacks from their parents and avoided taking their insulin or left precautionary sweets at home while hanging out with friends, all in an attempt to ignore the existence of their condition. In all honesty, I can't blame these people – some are apprehensive to even reveal that they are a diabetic to close friends.

I am passionate about dispelling the stigma around the condition. Diabetes can make life more difficult, but it does not define life. The care needed may be unusual, but health will always be more important than reputation. I find that the best way to explain things to friends is to tell them that I'm a cyborg. You can't go wrong with that!

However, with the poor mental health rampant among teenagers, the addition of T1D can lead to a dangerous outcome.

## FURTHER HEALTH STRUGGLES

T1DE (previously known as diabulimia) is an eating disorder that exclusively affects diabetics. The act of eating without taking insulin has a very specific impact on the body; when the body can't sustain itself on glucose, it turns to fat. When the body can't sustain itself on fat, it turns to protein. This can lead to a dangerous loss of weight.

Among type 1 diabetics, particularly young people who already struggle with the epidemic of body image issues, eating without taking insulin can be used to lose weight, morphing into T1DE. T1DE, in addition to causing unsustainable weight loss, can also cause health issues, such as damage to the eyes or liver, or even, in severe cases, a hyperglycaemic coma.

This disorder causes a threat to young diabetics on an everyday basis – it is vital that both young people and caregivers are educated on its causes, and what it can lead to. Even as a young diabetic myself, while I have never struggled with T1DE, I have heard the stories from support groups – time after time, there are tales of young people in crisis, worsened by a condition most are entirely unfamiliar with.

Such conditions are prime examples of why support structures for young diabetics are so vital. For me, the work of paediatric diabetic nurses was invaluable to feeling independent and secure after my diagnosis. I don't think it's possible to thank diabetic nurses enough for what they do!

So, in conclusion, living as a young person with diabetes isn't easy, but it is nowhere near impossible. Hopefully, reading this will have provided a bit more insight on what it is like to live with T1D. It's just part of life!

## MY ADVICE FOR NEW DIABETICS

I can still remember my own diagnosis, sitting on a hospital bed that was far too big, facing a condition that seemed far too imposing. As clear as day, I can remember saying to my mum, 'I don't want it to be normal, I want it to go away.'

I know that other new diabetics might feel this way, too. The number of new diagnoses of T1D is increasing by four per cent per year; five per cent per year in children under five. Since the COVID-19 pandemic, the amount of type 1 diabetics in my year at school has doubled. Most of the time, just the same as me, individuals may not want it to be normal. They just want it to go away.

However, diabetes does become normal. There's no point pretending it's easy, and there's no point pretending there won't be scary days, but it isn't the end of the world. In the spirit of living with T1D instead of despite it, here is the advice I wish I had heard at eight years old:

- I promise; people have seen odder than a glucose monitor or an insulin pump
- I know the possible side-effects are terrifying, but be careful, and you will be fine
- You are not alone in diabetes. There are hundreds of thousands of us out here, and we know what it's like
- Carbohydrate-counting will become second nature. You can adapt
- The inconvenience is worth it for your health
- Be wary of pasta. There are so many slow-acting carbs in pasta (it is 100 per cent worth it, though)
- Speaking of which – learn the difference between types of carbohydrates. Pasta and pizza will affect you differently than sugar and sweets, and it's best to get on top of that early
- Things will get easier. In eight years, I went from a finger-pricker blood-checker to a glucose monitor that was linked to my pump and operated by my phone. Work like that will make all the difference, so don't be afraid to embrace it
- Celebrate your diaversary (the anniversary of the day you were diagnosed). You more than deserve it
- Your life will still be as rich and fulfilling as it would have been otherwise. Work with T1D, not against it, and it won't stand in your way. You can still do anything

# OUT OF HARM'S WAY

**In light of the recent NICE guidance surrounding the potential threshold lowering for patients eligible for statin treatment, WPR considers the key questions which may be expressed by your patients prior to commencing their statin treatment journey.**

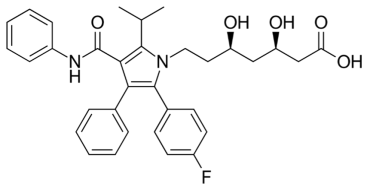
Patients, it seems, are more eager than ever before to understand their medication, particularly why they are taking it, and any effects it may have on their daily lives. This, in many ways, can be seen as a positive step in the diagnosis and treatment process as, when a patient feels as though they are part of the decision-making process, their compliance is likely to be greater. An increase in compliance leads to better outcomes, less wastage and, in general, fewer appointments, leaving clinicians with more time to concentrate on other areas of work.

## WHAT ARE STATINS?

Statins (HMG CoA reductase inhibitors) are prescription medicines that can help lower the levels of low-density lipoprotein (LDL) cholesterol in the patient's blood.

Type II statins all contain a fluorophenyl group and a series of hydrophobic ring structures that are covalently attached to an HMG-CoA-like moiety.

Below is the chemical structure for atorvastatin, one of the most popular statins currently on the market today:




## WHY MIGHT AN INDIVIDUAL NEED STATINS?

Having a high level of LDL in the bloodstream can cause a hardening and narrowing of the arteries i.e. atherosclerosis. This can lead to an increase in the risk of a patient developing cardiovascular disease (CVD) which, if left untreated, could eventually result in a serious cardiovascular event. Examples of CVD most commonly experienced by patients in the UK include coronary heart disease, angina, and also heart attack and stroke. These CVD events are the most common cause of death in the UK and reducing this risk is thus crucial. That is where statins in particular come into play.

## ARE STATINS SAFE?

Statins are one of the most investigated drug groups presently available and recent data from the British Heart Foundation shows that they are very effective at what they do but also very safe.

The European Society of Cardiology released a paper entitled, 'Cardiovascular Protection from Statins Greatly Outweighs the Risk of Muscle Symptoms' within which it stated, 'Statin therapy is effective for the prevention of cardiovascular disease, the world's largest killer, and is widely prescribed. However, there have been concerns that statins may cause muscle pain or weakness, leading some patients to stop taking their treatment. This analysis was conducted to resolve uncertainties around the possible effects of statins on muscle symptoms.

'This was an individual participant data meta-analysis of all recorded muscle symptoms in large-scale randomised blinded double-blind trials of statin therapy, led by researchers from Oxford Population Health. The researchers compiled data from 23 trials from the Cholesterol Treatment Trialists' Collaboration, with information on nearly 155,000 patients.'

Professor Baigent concluded, 'Muscle symptoms, such as pain or weakness, were experienced by similar numbers of people in the statin and placebo groups.'

The European Society of Cardiology also published the following statistics:

- Each year CVD causes 3.9 million deaths in Europe and over 1.8 million deaths in the European Union (EU)
- CVD causes 45 per cent of all deaths in Europe and 37 per cent in the EU
- CVD is the main cause of death in men in all but 12 countries of Europe and is the main cause of death in women in all but two countries
- CVD by itself is the leading cause of mortality under 65 years in Europe
- Overall CVD is estimated to cost the EU economy 210€ billion a year
- Of the total cost of CVD in the EU, around 53 per cent (111€ billion) is due to healthcare costs, 26 per cent (€54 billion) due to productivity losses and 21 per cent (€45 billion) due to informal care of people with CVD
- CVD mortality is now falling in most European countries, including Central and Eastern European countries, which saw considerable increases until the beginning of the 21st Century
- Smoking remains a key public health issue in Europe. Smoking rates have decreased across much of Europe, although the pace of decline has slowed and rates remain stable or are rising in some countries, particularly among women
- Women are now smoking nearly as much as men in several Northern and Western European countries and girls often smoke more than boys
- Few adults in European countries participate in adequate levels of physical activity, with inactivity more common among women than men
- Levels of obesity are high across Europe and in the EU in both adults and children, although rates vary substantially between countries
- Cholesterol, particularly LDL cholesterol, is a major determinant of CVD risk which increases linearly as blood concentrations increase
- CVD remains the most common cause of death within ESC member countries, accounting for 2.2 million deaths in females and 1.9 million deaths in males

Harvard Medical School recently published information surrounding statin drugs and dosage intensity. The choice of statin and dose is dependent on a patient's risk. For example, a dose of 10mg-to-20mg daily of atorvastatin is classified as 'moderate intensity' (lowers LDL by 30-to-49 per cent) but a daily dose of 40mg-to-80mg daily is considered 'high intensity' (lowers LDL by 50 per cent or more).

NICE defines this even further by stating that a 'medium intensity' dose of atorvastatin at 10mg daily reduces LDL cholesterol by 37 per cent but 'high intensity' doses of 20mg, 40mg or 80mg daily reduces LDL cholesterol by 43 per cent, 49 per cent, and 55 per cent respectively.

NICE guidance states, 'A high-intensity statin, defined as the dose at which a reduction in LDL-cholesterol of greater than 40 per cent is achieved, is recommended as first-line therapy in all patients with familial hypercholesterolaemia. The dose of the statin should be titrated to achieve a reduction in LDL-cholesterol concentration of greater than 50 per cent from baseline.'

This shows that when it comes to prescribing statins, the dose can be very patient-specific and care needs to be put into each decision.

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**Abbreviated Prescribing Information:** Atorvastatin 4mg /ml Oral Suspension **Consult Summary of Product Characteristics before prescribing. Presentation:** White to brownish white oral Suspension, each 1 ml contains 4mg of Atorvastatin (as 4.14 mg atorvastatin calcium trihydrate). **Therapeutic Indications:** Hypercholesterolaemia Atorvastatin Oral Suspension is indicated as an adjunct to diet for reduction of elevated total cholesterol (total-C), LDL-cholesterol (LDL-C), apolipoprotein B, and triglycerides in adults, adolescents and children aged 10 years or older with primary hypercholesterolaemia including familial hypercholesterolaemia (heterozygous variant) or combined (mixed) hyperlipidaemia (Corresponding to Types IIa and IIb of the Fredrickson classification) when response to diet and other nonpharmacological measures is inadequate. Atorvastatin Oral Suspension is also indicated to reduce total-C and LDL-C in adults with homozygous familial hypercholesterolaemia as an adjunct to other lipid-lowering treatments (e.g., LDL apheresis) or if such treatments are unavailable. Furthermore, atorvastatin oral suspension is also used to prevent cardiovascular events in adult patients estimated to have a high risk for a first cardiovascular event. **Posology and Method of Administration:** The patient should be placed on a standard cholesterol-lowering diet before receiving Atorvastatin Oral Suspension and should continue this diet during treatment with Atorvastatin Oral Suspension. The dose should be individualised according to baseline LDL-C levels, the goal of therapy and patient response. The usual starting dose is 10 mg (2.5 ml) once a day. Adjustment of dose should be made at intervals of 4 weeks or more. The maximum dose is 80 mg (20 ml) once a day. For primary hypercholesterolaemia and combined (mixed) hyperlipidaemia the majority of patients are controlled with Atorvastatin Oral Suspension 10 mg (2.5 ml) once a day. A therapeutic response is evident within 2 weeks, and the maximum therapeutic response is usually achieved within 4 weeks. The response is maintained during chronic therapy. For heterozygous familial hypercholesterolaemia patients should be started with Atorvastatin Oral Suspension 10 mg (2.5 ml) daily. Doses should be individualised and adjusted every 4 weeks to 40 mg (10 ml) daily. Thereafter, either the dose may be increased to a maximum of 80 mg (20 ml) daily or a bile acid sequestrant may be combined with 40 mg (10 ml) atorvastatin once daily. For homozygous familial hypercholesterolaemia. Only limited data are available. The dose of atorvastatin in patients with homozygous familial hypercholesterolemia is 10 to 80 mg (2.5 to 20 ml) daily. Atorvastatin should be used as an adjunct to other lipid-lowering treatments (e.g., LDL apheresis) in these patients or if such treatments are unavailable. **Paediatric population:** Paediatric use should only be carried out by physicians experienced in the treatment of paediatric hyperlipidaemia and patients should be re- evaluated on a regular basis to assess progress. For patients with Heterozygous Familial Hypercholesterolemia aged 10 years and above, the recommended starting dose of atorvastatin is 10 mg (2.5 ml) per day. The dose may be increased to 80 mg (20 ml) daily, according to the response and tolerability. Doses should be individualised according to the recommended goal of therapy. Adjustments should be made at intervals of 4 weeks or more. The dose titration to 80 mg (20 ml) daily is supported by study data in adults and by limited clinical data from studies in children with Heterozygous Familial Hypercholesterolemia. There are limited safety and efficacy data available in children with Heterozygous Familial Hypercholesterolemia between 6 to 10 years of age derived from open-label studies. Atorvastatin is not indicated in the treatment of patients below the age of 10 years. Currently available data are described in the SmPC but no recommendation on posology can be made. Other pharmaceutical forms/strengths may be more appropriate for this population. **Contra-indications:** Atorvastatin Oral Suspension is contraindicated in patients: with hypersensitivity to the active substance or to any of the excipients; with active liver disease or unexplained persistent elevations of serum transaminases exceeding 3 times the upper limit of normal; during pregnancy, while breast-feeding and in women of child-bearing potential not using appropriate contraceptive measures and treated with the hepatitis C antivirals glecaprevir/pibrentasvir. **Special Warnings and Precautions for use:** Liver function tests should be performed before the initiation of treatment and periodically thereafter. Atorvastatin Oral Suspension should be used with caution in patients who consume substantial quantities of alcohol and/or have a history of liver disease. In a post-hoc analysis of stroke subtypes in patients without coronary heart disease (CHD) who had a recent stroke or transient ischemic attack (TIA) there was a higher incidence of haemorrhagic stroke in patients initiated on atorvastatin 80 mg compared to placebo. Atorvastatin, like other HMG-CoA reductase inhibitors, may in rare occasions affect the skeletal muscle and cause myalgia, myositis, and myopathy that may progress to rhabdomyolysis, a potentially life-threatening condition characterised by markedly elevated creatine kinase (CK) levels (>10 times ULN), myoglobinaemia and myoglobinuria which may lead to renal failure. Furthermore, there have been very rare reports of an immune-mediated necrotizing myopathy (IMNM) during or after treatment with some statins was reported. Atorvastatin should be prescribed with caution in patients with pre-disposing factors for rhabdomyolysis. A CK level should be measured before starting statin treatment in patients with renal impairment; hypothyroidism; personal or familial history of hereditary muscular disorders; previous history of muscular toxicity with a statin or fibrate; previous history of liver disease and/or where substantial quantities of alcohol are consumed; in elderly (age >70 years), the necessity of such measurement should be considered, according to the presence of other predisposing factors for rhabdomyolysis, situations where an increase in plasma levels may occur, such as interactions and special populations including genetic subpopulations. If CK levels are significantly elevated (>5 times ULN) at baseline, treatment should not be started. Risk of rhabdomyolysis is increased when atorvastatin is administered concomitantly with certain medicinal products that may increase the plasma concentration of atorvastatin such as potent inhibitors of CYP3A4 or transport proteins (e.g. ciclosporin, telithromycin, clarithromycin, delavirdine, stiripentol, ketoconazole, voriconazole, itraconazole, posaconazole, letermovir and HIV protease inhibitors including ritonavir, lopinavir, atazanavir, indinavir, darunavir, tipranavir/ritonavir etc). The risk of myopathy may also be increased with the concomitant use of gemfibrozil and other fibric acid derivates, antivirals for the treatment of hepatitis C (HCV) (boceprevir, telaprevir, elbasvir/grazoprevir), erythromycin, niacin or ezetimibe. If possible, alternative (non-interacting) therapies should be considered instead of these medicinal products. Atorvastatin must not be co-administered with systemic formulations of fusidic acid or within 7 days of stopping fusidic acid treatment. There have been reports of rhabdomyolysis (including some fatalities) in patients receiving fusidic acid and statins in combination. The patient should be advised to seek medical advice immediately if they experience any symptoms of muscle weakness, pain or tenderness. For Paediatric population no clinically significant effect on growth and sexual maturation was observed in a 3-year study based on the assessment of overall maturation and development, assessment of Tanner Stage, and measurement of height and weight. Exceptional cases of interstitial lung disease have been reported with some statins, especially with long term therapy. Presenting features can include dyspnoea, non-productive cough, and deterioration in general health (fatigue, weight loss and fever). If it is suspected a patient has developed interstitial lung disease, statin therapy should be discontinued. Some evidence suggests that statins as a class raise blood glucose and, in some patients, at high risk of future diabetes, may produce a level of hyperglycaemia where formal diabetes care is appropriate. Patients at risk (fasting glucose 5.6 to 6.9 mmol/L, BMI>30kg/m2, raised triglycerides, hypertension) should be monitored both clinically and biochemically according to national guidelines. **Any warning from the MC, CHM CSM or MHRA. Black Triangle notice:** Not applicable. **Legal Category:** Prescription only medicine. **A list of common and serious adverse reactions (include statement to consult the SmPC for full details of other adverse reactions):** nasopharyngitis, allergic reactions, hyperglycaemia, headache, pharyngolaryngeal pain, epistaxis, constipation, flatulence, dyspepsia, nausea, diarrhoea, myalgia, arthralgia, pain in extremity, muscle spasms, joint swelling, back pain, liver function test abnormal, blood creatine kinase increased. **Pack Size and NHS Price:** 150ml - £198.76. **Marketing Authorisation Number:** PL 00427/0256 **Marketing Authorisation Holder:** Rosemont Pharmaceuticals Ltd, Rosemont House, Yorkdale Industrial Park, Braithwaite Street, Leeds, LS11 9XE, UK. **Date of Preparation:** November-2022.

**Reference:** 1. Statista. Leading chemical substances dispensed in England in 2020. Available at: https://www.statista.com/statistics/378445/prescription-cost-analysis-top-twenty-chemicals-by-items-in-england/ Accessed 28 February 2022.

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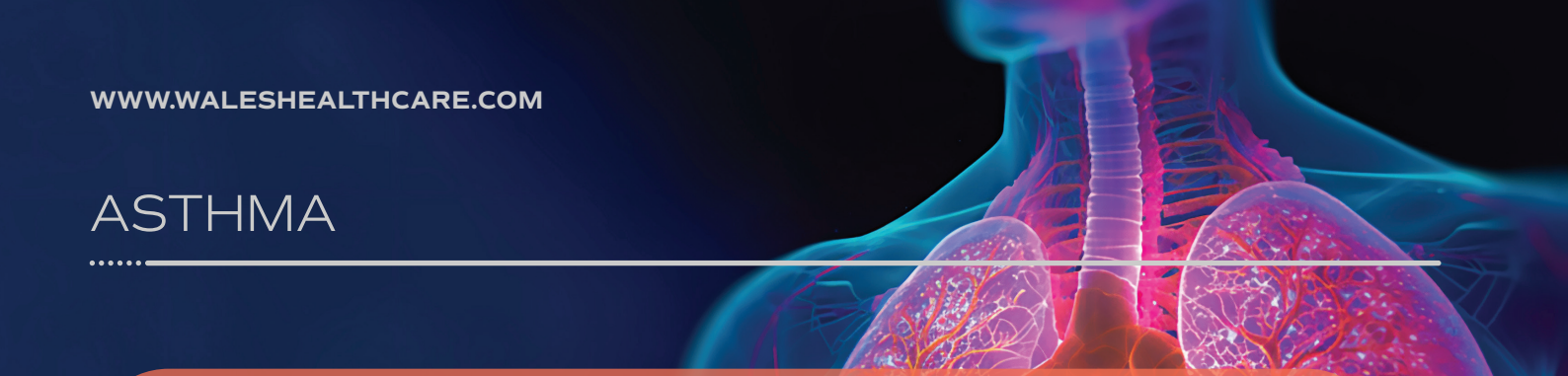
DTM365.1 December 2022



# TIME FOR ACTION

**WPR checks in on how the Forum of International Respiratory Societies is advocating for equal access to the prevention and treatment for respiratory diseases – with the aim of reducing the global burden, leaving no-one behind.**

The Forum of International Respiratory Societies (FIRS) and its founding member, Global Initiative for Asthma, is calling on governments and healthcare providers worldwide to give equitable access to preventative services and treatments for respiratory conditions, and life-saving pneumonia vaccines for children.

The theme for this year's World Lung Day was 'Access to Prevention and Treatment for All. Leave No-One Behind,' reflecting the commitment to equity that is at the heart of the 2030 Agenda for Sustainable Development.

This commitment is especially crucial given that 80 per cent of non-communicable disease-related deaths occur in low- and middle-income countries (LMICs). This huge health burden could be prevented by implementing cost-effective interventions, such as vaccination against pneumonia and improved access to preventative services and inhaled medicines.

Arzu Yorgancıoğlu explained, 'The challenge to respiratory health, especially in LMICs, is evident. There is a clear lack of equal access to preventive measures, such as smoking cessation, and to effective inhaler therapies for managing asthma and COPD.

'The availability of inhaler therapies is far from the target of achieving 80 per cent availability of essential medicines to combat non-communicable diseases, including asthma, chronic obstructive pulmonary disease (COPD) and lung cancer. Healthcare access equity is equally crucial for respiratory infections, including tuberculosis. Through equal access to early detection, treatment can begin as soon as possible, effectively reducing the health burden of both respiratory infections and non-communicable respiratory conditions.'

The FIRS has identified three key target areas to tackle inequalities in the fight against respiratory disease: improving access to preventative services and stop-smoking treatments, expanding access to inhalation therapies, and strengthening access to effective pneumonia vaccines for children. Despite global progress in pneumonia vaccine access, 40 per cent of infants are still left behind.

To reduce the global burden of respiratory diseases, it's crucial to take action in these key areas.

## ACCESS TO PREVENTATIVE SERVICES AND STOP-SMOKING TREATMENTS

- Smoking tobacco is the leading cause of respiratory diseases, including COPD, lung cancer and asthma, and increases the risk of respiratory infections, such as pneumonia and tuberculosis
- Exposure to tobacco smoke harms children even before birth. Reducing exposure to tobacco smoke helps improve children's long-term lung health
- Educational, counselling, and pharmacological interventions for smoking cessation are effective. They should be available for anyone who smokes

## EXPANDING ACCESS TO DEVICES AND INHALATION THERAPIES

- Effective and essential inhaled medicines for treating asthma and COPD are often unavailable and unaffordable in LMICs. We need urgent collective global action to achieve WHO's target of 80 per cent availability of essential medicines to treat major non-communicable diseases
- Respiratory devices and inhalational therapies, including oxygen therapy, should be available to anyone who is affected

## ACCESS FOR ALL CHILDREN TO EFFECTIVE, AFFORDABLE PREVENTIVE INTERVENTIONS FOR PNEUMONIA

- Pneumonia is the leading cause of death from infection in children worldwide. Prevention is vital as any severe lower respiratory tract infection can affect lung development
- Vaccines are critically important to prevent bacterial and viral cases of pneumonia, reducing illness, death and national healthcare expenditure. They should be a priority for all children and adults
- Access to newer vaccines, especially the pneumococcal conjugate vaccine (PCV), must be strengthened. While it is encouraging to see global progress in PCV coverage, 40 per cent of infants are still missing out
- Full coverage of PCV can prevent the death of 1.6 million children under five years by 2030

## ABOUT THE FIRS

The FIRS is a collaborative organisation consisting of the world's foremost international respiratory societies. Comprising over 70,000 members globally, the FIRS is dedicated to advancing lung health on a global scale.

# Luforbec now offers a 52% NHS list price saving vs Fostair pMDIs.[1]


## The 1st certified carbon neutral pMDI

ACHIEVED THROUGH CARBON OFFSETTING[2-4]

carbon footprint standard™ Carbon Neutral Product

Luforbec®
beclometasone/formoterol
100/6 & 200/6
Extrafine formulation

To discuss the cost improvement potential Luforbec could offer your ICS/Health Board, contact:

ukrespiratory@lupin.com

or scan here

Luforbec 100/6 is indicated for adult asthma and COPD ($FEV_1$ <50% predicted normal).[5] Luforbec 200/6 is indicated for asthma in adults.[6]

**Prescribing Information: Luforbec® 100/6 and 200/6 pressurised metered dose inhaler (pMDI) Consult the full Summary of Product Characteristics (SmPC) before prescribing. Presentation:** Pressurised inhalation solution. Luforbec 100/6 pMDI: Each dose contains beclometasone dipropionate (BDP) 100 micrograms (mcg) and formoterol fumarate dihydrate 6 mcg. Luforbec 200/6 pMDI: Each dose contains beclometasone dipropionate (BDP) 200 mcg and formoterol fumarate dihydrate 6 mcg. **Indications:** ***Asthma:*** Regular treatment of asthma where use of an inhaled corticosteroid/long-acting $beta_2$-agonist (ICS/LABA) combination is appropriate: patients not adequately controlled on ICS and as needed short-acting $beta_2$-agonist, or patients already adequately controlled on both ICS and LABA. ***COPD*** **(Luforbec 100/6 only):** Symptomatic treatment of patients with severe COPD (FEV, <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); not recommended for children and adolescents under 18 years. ***Asthma:*** **Maintenance therapy:** Luforbec 100/6 pMDI: 1–2 inhalations twice daily. Luforbec 200/6 pMDI: 2 inhalations twice daily. The maximum daily dose is 4 inhalations, ensuring a separate short-acting bronchodilator is available as needed. Patients should receive the lowest dose that effectively controls symptoms. **Maintenance and reliever therapy (Luforbec 100/6 pMDI only):** 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*** **(Luforbec 100/6 pMDI only):** 2 inhalations twice daily. Luforbec pMDI can be used with the AeroChamber Plus® 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 individual patient's needs. **Contraindications:** Hypersensitivity to the active substances or to any of the excipients. **Warnings and precautions:** Not intended for initial management of asthma. Treatment should not be initiated during an exacerbation, or during significant 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, aortic stenosis, hypertrophic obstructive cardiomyopathy, severe heart disease, particularly acute myocardial infarction, ischaemic heart disease, congestive heart failure, occlusive vascular diseases, arterial hypertension, aneurysm, thyrotoxicosis, diabetes mellitus, phaeochromocytoma 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 $beta_2$-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. Caution is recommended in unstable asthma when a number of rescue bronchodilators may be used. 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 due to 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, 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 hence 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 $beta_2$-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 $beta_2$-agonists. Hypokalaemia may increase the likelihood of arrhythmias in patients receiving digitalis glycosides. There is a small amount of ethanol in Luforbec pMDI hence a 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. **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, headache, dysphonia, pneumonia (in COPD patients). *Uncommon:* Influenza, oral fungal infection, oropharyngeal candidiasis, oesophageal candidiasis, vulvovaginal candidiasis, gastroenteritis, sinusitis, rhinitis, granulocytopenia, allergic dermatitis, hypokalaemia, hyperglycaemia, restlessness, tremor, dizziness, otosalpingitis, 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, peripheral oedema, decreased bone density, growth retardation in children and adolescents. *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:** £13.98 1x120 actuations. **Marketing authorisation (MA) No(s):** PL 35507/0204, 35507/0205 **MA holder:** Lupin Healthcare UK Ltd, The Urban Building, Second Floor, 3-9 Albert Street, Slough, Berkshire, SL1 2BE, United Kingdom. **PI Last Revised:** November 2023. AeroChamber Plus® 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 Yellow Card in the Google Play or Apple App store. Adverse events should also be reported to Lupin Healthcare UK Limited on +44 (0)1565 751 378 or EU-PV@lupin.com**

**Ref: 1.** NHS BSA. Drug Tariff. https://www.nhsbsa.nhs.uk/pharmacies-gp-practices-and-appliance-contractors/drug-tariff Accessed: November 2023. **2.** Certifications of carbon neutrality for Luforbec 100/6 and 200/6 pMDI. **3.** Carbon Footprint Limited, Luforbec Life Cycle Assessment Report 2022. Data on File. **4.** MIMS: Inhaler Carbon Emissions. https://www.mims.co.uk/inhaler-carbon-emissions/respiratory-system/article/1739635. Accessed: November 2023. **5.** Luforbec 100/6 pMDI. Summary of Product Characteristics (SPC). Lupin Healthcare UK Limited. **6.** Luforbec 200/6 pMDI. Summary of Product Characteristics (SPC). Lupin Healthcare UK Limited. Fostair® is a registered trademark of Chiesi Ltd

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Delivering quality medicines and value to patients and the NHS

UK-LUF-2311-00007 November 2023

# A PLAN OF ACTION

## Danielle Hunt, Chief Executive of Pharmacist Support – the profession's independent charity, shares the organisation's journey to prioritising workplace wellbeing.

In a small and busy charity focused on delivering support to our pharmacy family, it could be easy to overlook the importance of employee wellbeing. However, as wellbeing is at the centre of all that we do, we understand investing in staff wellbeing and creating the right organisational culture is vital not only for our own success, but also for the wellbeing of the pharmacy family we serve.

The events of 2020 and the ongoing challenges presented by the COVID-19 pandemic re-enforced and highlighted more widely the need to support our teams. People are at the heart of what we do, so why wouldn't we support and invest in them!

## WHERE WE STARTED

Our aim was to create a culture within the team where everyone felt valued, felt able to speak up, and where there were high levels of trust. This aim was built on our values of People First, Empowerment, Positivity and Fairness.

We knew we needed to engage our team to find out where we could improve things to improve wellbeing, so we decided to implement an annual staff survey. We launched a staff survey in 2019 to gain insights into the challenges our team members were facing and committed to repeating this annually to track progress and keep abreast of emerging trends.

The survey was the catalyst to drive change. Crucially, if we were asking people their thoughts, we knew we needed to show we were acting on them, and that their voice matters. Importantly, there was commitment from the leadership within the charity and the openness to change to allow this to happen.

## KEY WELLBEING INITIATIVES

The survey enabled us to develop a plan, that is updated each year. The plan contains areas of focus that are most important to staff members. Some of the initiatives that have taken place include:

• Changed internal structures and policies: we recognised some of our policies and procedures were creating problems. There was lack of clarity in some areas, that created frustration and confusion. As a result, we created a suite of new policies and also created a staff handbook. Some key areas we reviewed or created new policies included:

- Flexible and hybrid working – we had standard working hours 9am-to-5pm in the Manchester office. We recognised this created stress and pressure and didn't support people to create a healthy work-life balance. We created a more flexible approach built on trust, which has by far had the greatest positive impact on wellbeing

- A review of our approach to reward and recognition – we have reviewed our whole approach to reward and recognition and made a number of changes. We implemented a new pay review structure to ensure fairness and transparency

• Wellbeing budget and resource: as part of our internal wellbeing service, we are lucky to have wellbeing experts in the charity who have supported this work. However, we also set a wellbeing budget for the year and bring in other experts when appropriate to work with the team. The wellbeing budget is spent on a range of things, from small exercise equipment to wellbeing lunches

• Investment in training for our senior management: we recognised that our senior management team played a pivotal role in driving forward our plans. We focused on building a solid high-functioning senior management team which then in turn has allowed us to create this across the team. Their support and commitment were essential in creating a culture of wellbeing within the organisation

• Time for the team: particularly since COVID, we have tried to make time for the team to be together. We now have an annual team away day and make time for regular wellbeing sessions, led by both external and internal experts. We have also created space on our monthly team meeting agendas which focus on being open and honest so we can work through any issues as a team. In these meetings we discuss individual team priorities and try to identify crunch points, so that the wider team can support, or at the very least have an awareness

• Developed a training and development plan for staff: we recognised that people felt more valued when we invested in their personal development. As 'learning' is a key pillar in the five-ways to wellbeing, we knew that this would be good from an individual wellbeing perspective and, in turn, the wider organisation

• Implemented the HSE Survey: More recently, we have also utilised the Health and Safety Executive (HSE) survey to assess and improve our workplace conditions, ensuring the physical and mental wellbeing of our team. This delves deeper than our own survey and has provided us an opportunity as a team to discuss workload and crunch points

• Focused on communication: effective communication is fundamental to wellbeing. We have now started to focus on training in communication techniques to enhance interpersonal skills. We also encourage people to speak up if they are having a difficult time, and ensure that an element of monthly one-to-ones is a wellbeing check-in

## WHAT NEXT?

Development of the Embracing a Workplace Wellbeing Culture Course for Pharmacy Leaders and Managers has allowed us to further reflect on our own practices. In developing the course, the team have looked at a range of workplace wellbeing practices and have identified a few areas where we could implement further changes. One such concept which we plan to introduce in 2024 is 'My Wellbeing Plans', we hope these plans allow us to be even more open and honest and enable us to better support individuals if they are having a difficult time.

In addition, we recognise that our work on equality, diversity and inclusion cuts across our wellbeing work, and our commitments around equality, diversity and inclusion will work to improve our workplace culture further and the wellbeing of our beneficiaries.

## HAS IT BEEN WORTH IT?

To create change we have invested both budget and staff time – and it has been absolutely worth it! Our annual staff survey has allowed us to track trends and there has been improvement in staff satisfaction. We have also seen an increase in staff retention. Through our journey, we have learned that by living and breathing the principles of wellbeing, we can create a supportive workplace culture that benefits everyone.

***For further information on Pharmacist Support and their free and confidential services, visit www.pharmacistsupport.org.***

Danielle Hunt


PHARMACIST
SUPPORT
Our vision is for no one in our pharmacy family to face challenging times without us by their side.
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We need your help to continue making an impact. Please scan the QR code to make a donation and help us to support our pharmacy family. Thank you.
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# Phenylephrine

0.08mg/ml solution for injection/infusion

**READY TO USE 100ML INFUSION BAG**

**CONTAINING 10MG OF PHENYLEPHRINE HYDROCHLORIDE**

## Just 4 steps to prepare

1. Wash hands
2. Put on gloves
3. Open the infusion bag
4. Connect to infusion device

### Prescribing information

Refer to the full Summary of Product Characteristics (SmPC) before prescribing. **Name and active ingredient:** Phenylephrine 0.08mg/ml, solution for injection/infusion. **Pharmaceutical form:** Solution for injection/infusion. Clear colourless solution, pH 4.5 – 5.5, osmolality 270 – 330 mOsm/Kg. Each ml of solution for injection/infusion contains 0.1mg phenylephrine hydrochloride equivalent to 0.08mg of phenylephrine base. **Indications:** Hypotension during spinal, epidural and general anaesthesia. **Posology and method of administration: 1. Intravenous bolus injection:** Normal dose 50 – 100mcg. Can be repeated until desired effect is attained. One bolus dose should not exceed 100mcg. **2. Continuous infusion:** Initial dose is 25 – 50mcg/min. Dose may be increased or decreased to maintain systolic blood pressure close to normal value. Doses between 25 – 100mcg/min have been assessed to be effective. **Renal impairment:** Lower doses of phenylephrine may be needed in patients with impaired renal function. **Hepatic impairment:** Higher doses of phenylephrine may be needed in patients with cirrhosis of the liver. **Older people:** Treatment should be carried out with care. **Paediatric population:** Safety and efficacy not known, no available data. **Method of administration:** Parenteral administration by intravenous infusion. Phenylephrine should only be administered by healthcare professionals with appropriate training and relevant experience. **Contraindications:** Hypersensitivity to phenylephrine or to any of the excipients listed in section 6.1 of the SmPC; in patients with severe hypertension or peripheral vascular disease; in combination with non-selective monoamine oxidase inhibitors or within two weeks of their withdrawal; hyperthyroidism. **Special warnings and precautions for use:** Caution is required when administering phenylephrine in patients with: pre-existing cardiovascular disease, diabetes mellitus, arterial hypertension, ischaemic heart disease, arrhythmia, bradycardia, incomplete heart block, tachycardia, occlusive peripheral vascular disease including arteriosclerosis, aneurysm, angina pectoris, angle closure glaucoma, atherosclerosis, the elderly, compromised cerebral or coronary circulation, severe heart failure, cardiogenic shock. Special attention should be given to the injection of phenylephrine to prevent extravasation, as this may cause tissue necrosis (see section 4.8 of the SmPC). This medicinal product contains 366.2mg sodium per 100ml, equivalent to 18.3% of the WHO recommended maximum daily intake of 2g sodium for an adult. **Contraindicated combinations:** non-selective monoamine oxidase inhibitors. Paroxysmal hypertension, possibly fatal hyperthermia. Due to the long duration of MAO inhibitory action, this interaction is still possible 15 days after the MAO inhibitor is discontinued. **Combinations not advisable:** Dopaminergic ergot alkaloids; vasoconstrictor ergot alkaloids; tricyclic antidepressants; noradrenergic-serotonergic antidepressants; selective monoamine oxidase inhibitors type A; linezolid; guanethidine and related products; cardiac glycosides, quinidine; sibutramine; halogenated volatile anaesthetics. **Combinations requiring precautions for use:** Antihypertensives including α and β receptor blockers; oxytocic agents. **Pregnancy and breastfeeding:** See SmPC section 4.6 for full details. **Adverse reactions:** The most common adverse events of phenylephrine are bradycardia, hypertensive episodes, nausea and vomiting. Hypertension is more frequent with high doses. See SmPC section 4.8 for full details. **Legal classification:** POM. **Presentations:** 100ml solution in 100ml flexible polypropylene bag with aluminium overpouch or 100ml solution in a 100ml PVC-free polyolefin bag with an aluminium overpouch. Each bag contains one non-PVC point for filling and closure and one non-PVC administration port. **NHS Cost:** £250.00. **Marketing Authorisation Number:** PL 46788/0024. Distributed by Kent Pharma UK Ltd. **Date of preparation:** December 2022 UK21/011/02 - SmPC Feb 2020.

**Adverse events should be reported.** Reporting forms and information can be found at: www.mhra.gov.uk/yellowcard or search for MHRA Yellow Card in the Google Play or Apple App Store. Adverse events should also be reported to Kent Pharma UK Ltd on 01233 506574 or medical@kent-athlone.com. For a copy of the SmPC or further medical information, please contact medical@kent-athlone.com. Additional information available on request.

Date of preparation: December 2022 Ref: UK22/46/00

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