



Northern Ireland

# Healthcare

## Review

ISSUE 119 - 2021

# COVID-19

## THE ROAD AHEAD



### SUBSTANCE DEPENDENCY

And lockdown pressures

### ADHD

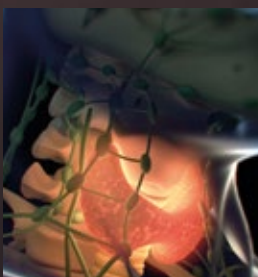
Diagnostic considerations in children

### ENDOCRINE CONDITIONS

What are the coronavirus links?

### CANCER RESEARCH

Making up for lost time





# Connecting with **patients**

**" My journey with epilepsy started out rocky, but evolved into one of self-discovery. It's allowed me to look at my life with a new pair of eyes, change my behavior, and finally think outside the box."**

**LaKeisha**, living with epilepsy

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Our ambition is to offer them innovative new medicines and ground-breaking solutions in two main therapeutic areas: neurology and immunology. We foster cutting-edge scientific research that is guided by patients' needs.

# NIHR

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**THANK YOU**  
TO YOU – OUR HEALTHCARE HEROES

- ASTHMA SUPPORT  
Dileas and disruptions
- CORONAVIRUS  
And the gastrointestinal tract
- NI HEALTHCARE AWARDS  
Entry is now open
- MENTAL HEALTH  
Consequences of the crisis

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# WELCOME

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## EDITOR'S LETTER

Welcome to the latest edition of Northern Ireland Healthcare Review!

It was barely a week into the new year, and yet the familiarity of its predecessor tinged every part of me.

My stomach churned as the reality of COVID-19's escalation hit me with every news alert that bolted onto my phone screen. My eyes widened in horror as my social media pages swam with urgent calls from hospitals asking for off-duty staff to return immediately to work. My mind conjured up harrowing scenario after harrowing scenario; imagining how the vulnerable people in my life could be affected by the devastation.

So much about all these feelings are familiar – so much returns me to those dark days in March last year when I couldn't foresee how the pandemic could possibly be steered forward on a day-to-day basis, never mind how we could find a permanent way out of it.

These days may shroud us in the familiar darkness, but be assured, they are not the same – because we are not the same.

We now know that the rise in cases can be curbed by playing our part and staying at home when necessary. We can see optimism and innovation being regularly practiced via the roll-out of the vaccination programme. We are learning of coronavirus' impact on the individual facets of our sector – and the precautions which we must take to preserve and protect

the patients that they serve.

Knowledge is power and we have more of it. That's a theme we tap into in this edition as we examine how lockdown has created a pressure cooker for many people at risk of addiction, and the measures in place to help (page 16), and highlight calls for those affected by dementia to attain the assistance they urgently need (page eight).

Additionally, experts weigh in on the huge gap in MSK training because of the pandemic (page 46); 17-year-old Beth Wilson reflects on her experience of the crisis as a student (page 36); and we draw on new research relating to COVID-19 incidence and underlying endocrine conditions (page 13).

Don't forget to also check out the current state-of-play of bowel cancer and Inflammatory Bowel Disease (page 22), as well as the support systems implemented for paediatric epilepsy in Northern Ireland (page six).

Take care.



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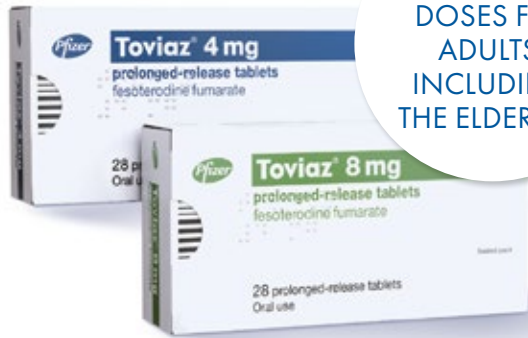


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(See TOVIAZ® Summary of Product characteristics for full Prescribing information)

**Presentation:** Prolonged-release tablets containing fesoterodine fumarate. The 4mg is light blue, oval, engraved FS containing 3.1mg of fesoterodine. The 8mg is blue, oval, engraved FT containing 6.2mg of fesoterodine. **Indications:** Symptomatic treatment of urge incontinence and/or urinary frequency and/or urgency that may occur in adult patients with overactive bladder syndrome. **Dosage:** Adults (including Elderly): 4mg once daily. The tablet should be taken whole with some liquid. The dose may be increased to max daily dose of 8mg once daily. The max dose in patients with severe renal impairment or moderate hepatic impairment is 4mg. Treatment should be re-evaluated after 8 weeks. Children: Not recommended. Cautious dose increase recommended in patients with mild or moderate renal impairment or mild hepatic impairment. Max dose with patients using moderate CYP3A4 inhibitors with mild or moderate renal impairment or mild hepatic impairment is 4mg. Use should be avoided in patients with mild renal or hepatic impairment using potent CYP3A4 inhibitors, or patients with severe renal impairment or moderate hepatic impairment using moderate CYP3A4 inhibitors. In patients receiving concomitant potent CYP3A4 inhibitors the max. daily dose is 4mg. **Contraindications:** Hypersensitivity to fesoterodine, soya, peanut or excipients, urinary retention, gastric retention, uncontrolled narrow-angle glaucoma, myasthenia gravis, severe hepatic impairment (Child Pugh C), severe ulcerative colitis, toxic megacolon. Concomitant use of potent CYP3A4 inhibitors in patients with moderate or severe renal impairment, or patients with moderate hepatic impairment. **Warnings and Precautions:** Use with caution in patients with significant bladder outflow obstruction at risk of urinary retention, gastrointestinal obstructive disorders (e.g. pyloric stenosis), gastro-oesophageal reflux, concurrent medicinal products that may cause or exacerbate oesophagitis, autonomic neuropathy, controlled narrow-angle glaucoma, decreased gastrointestinal motility. Toviaz should not be used in patients with rare hereditary problems of galactose intolerance, the Lapp lactase deficiency or glucose-galactose malabsorption. Fesoterodine should be used with caution in patients with risk factors for QT-prolongation including: electrolyte disturbances, bradycardia and concomitant administration of drugs known to prolong QT-interval, relevant pre-existing cardiac diseases especially when taking potent CYP3A4 inhibitors. Concomitant treatment with potent CYP2D6 inhibitors may increase exposure, and the dose should be increased with caution especially in patients with hepatic or renal impairment. Patients with a combination of hepatic or renal impairment or concomitant administration of potent or moderate CYP3A4 inhibitors or potent CYP2D6 inhibitors are expected to have additional exposure increases and dose dependent side effects – dose increase to 8mg where possible should be preceded by an evaluation of response and tolerability. Organic reasons for urge, frequency or overactive bladder should be

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#### Adverse events should be reported.

Reporting forms and information can be found at the Yellow Card Scheme Website: [www.mhra.gov.uk/yellowcard](http://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 Pfizer Medical Information on 01304 616161.

#### References:

1. Toviaz® Summary of Product Characteristics (SmPC)
2. Wagg A et al. Age and Ageing 2017; 46:620-626
3. Wagg A et al. J Am Geriatr Soc 2013; 61:185-193



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## SURVEY EXPLORES PANDEMIC'S IMPACT ON CHILDREN'S EXPERIENCES AND RIGHTS



A global survey of children's views and experiences of life under COVID-19 has found that the pandemic has had wide-ranging impacts on their experiences and rights.

The Life Under Coronavirus survey was designed by researchers from Queen's University Belfast with children, for children aged between eight-to-17 years, and available in 27 different languages, alongside an easy-read version.

More than 26,000 children from 137 countries across five UN regions participated in the global survey.

The survey was formulated in the spirit of the United Nations Convention on Rights of Child. Researchers from the Centre for Children's Rights at Queen's University Belfast, employing their unique children's rights-based methodology, constructed the survey and analysed

and reported the results, working at every stage with children and young people and other partners to make sure that the survey and findings were produced with children for children.

The key findings included:

- 61 per cent said that they were getting a better education before coronavirus
- 56 per cent said that they got to talk to their friends less than they would like since coronavirus
- 43 per cent said that they felt 'bored', 40 per cent said they felt 'happy', and 39 per cent said they felt 'worried' when asked about their three most common feelings during the coronavirus pandemic
- 62 per cent would go to their family members for 'information that they could trust' on coronavirus
- 21 per cent said that access to medical help was better before coronavirus

Speaking about the survey results, Dr Bronagh Byrne, from the Centre for Children's Rights at Queen's University Belfast, commented, 'Findings show that many children were unaffected during coronavirus and, for some children, things were better. However, other children reported negative impacts since the beginning of the pandemic. Some groups of children were more likely to report negative experiences, including children from migrant communities, those living in a detention centre, refugee camp or homeless centre and children with disabilities.'

## CHARITY DONATION EXTENDS SARCOMA SERVICE

The South Eastern Health & Social Care Trust is working in partnership with BOOM, a Northern Ireland charity dedicated to supporting patients suffering from sarcoma cancer.

Notably, a significant donation to BOOM through a tremendous tribute from an incredibly generous lady has enabled 18.75 additional hours of clinical nurse specialist support to the existing sarcoma cancer service within the trust.

Leona Rankin, BOOM Trustee, explained, 'This is a very exciting time for BOOM and we would like to pay special tribute to the lady who made this possible. A former patient, who sadly lost her life to sarcoma, who continues to be sorely missed by BOOM, her family and friends, made a generous donation to the charity. While she wished to remain anonymous, she and her family hoped that the money would be used for the benefit of other sarcoma patients in Northern Ireland through the provision of clinical nurse specialist services.'

The BOOM Foundation was established in April 2013 and remains the only charity in Northern Ireland dedicated to supporting patients suffering from sarcoma cancer, in addition to facilitating the only support group in the region. The support group, which is held quarterly, provides patients and their families with an open forum, allowing them to discuss any problems or concerns that they may have.

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



## HOME ANTIBIOTICS TEAM SHORTLISTED FOR NATIONAL AWARD

A Southern Health & Social Care Trust team, which is helping patients to have antibiotic treatments at home rather than hospital, have been shortlisted for Patient Safety in the UK-wide HSJ Awards.

The Outpatient Parenteral Antimicrobial Therapy (OPAT) service comprise a team of microbiologists, pharmacists and nurses who look after patients being discharged with ongoing antibiotics – for example, with abscesses, bone, or other infections.

Since the team's establishment two years ago, an estimated 6,000 days which people may have otherwise spent in Southern Health & Social Care Trust hospitals were avoided thanks to the service.

The team work closely with district nursing, helping to prevent hospital admissions, supporting earlier discharge, and enhancing overall experience for suitable patients.

Congratulating the team on being shortlisted for this prestigious award, Tracey Boyce, Director of Pharmacy Services for the Southern Health & Social Care Trust, remarked, 'We are absolutely delighted that the OPAT team has received such well-deserved recognition for their innovative approach and commitment to patient safety.'

'Now in many cases they are avoiding intravenous treatments by finding a suitable alternative oral antibiotic, which frees up busy district nursing colleagues and is much less invasive, lower risk and more convenient for the patient. The enhanced role of the pharmacist in the team is helping to make the most of our consultant microbiologists' time, by reviewing patients and clinical planning in advance.'

'With reduced repeat dispensing and increased use of oral alternatives, we also have much better medicines management.'

## EPILEPSY

# EPILEPSY: A QUESTION OF SUPPORT

Sandya Tirupathi, Paediatric Neurologist at Belfast Health & Social Care Trust, casts a light on the prevalence of paediatric epilepsy, the support available for young people and their families, and why progress towards addressing the stigma must continue.



Sandya Tirupathi

### HOW PREVALENT IS EPILEPSY AMONG CHILDREN IN NORTHERN IRELAND?

Epilepsy is the most common neurological condition that affects people of all ages and backgrounds. It's estimated that one-in-100 people are affected by epilepsy in the UK.

Epilepsy affects 0.5-to-one per cent of children. The incidence of epilepsy is highest in children under one year of age.

There are approximately 20,000 patients in Northern Ireland with epilepsy. 20 per cent of these, 3,000-to-4,000 patients, are children and young people.

### WHAT ARE THE EARLIEST SIGNS AND HOW CAN THESE PROGRESS?

A symptom or sign of epilepsy is called a 'seizure'. A seizure is defined as an abrupt alteration in the muscle tone, movements, behaviours, sensations or state of awareness. It is called an 'epileptic seizure' if it is caused by an aberrant / abnormal electrical discharge in the brain.

Epilepsy is a recurrent predisposition of the brain to cause seizures. There is no such thing as epilepsy – there are epilepsies. There are many different types of seizures in different people and sometimes different seizure types in the same patient.



Any epileptic activity is usually of an abrupt onset and an abrupt offset and usually will be the same every single time. If the initial electrical activity was only from one part of the brain, it's called a focal seizure, and if the discharge involves the whole brain at the onset, it is called a generalised seizure.

Depending on where the electrical discharge is generated, the seizures can be a tingling in the arm or leg or mouth, can be a taste in the mouth, or can be jerking of a limb or thumb or one half of the body, or can look like a black-out, or can present with some vision disturbance, or it can be a speech disturbance, or a déjà vu feeling, or just a blank episode, or it can be what is traditionally known as 'full blown attack' in which the patient is unaware, falls to ground, and can jerk all four limbs (medically-termed tonic-clonic seizure).

In newborns and infants, as they can't verbalise, it can be difficult to diagnose. Some of the regular baby movements can be mistaken for epileptic seizures too. The epileptic seizures can manifest as recurrent sudden jerks, or recurrent stiffening or recurrent cycling movements or full body jerks, or recurrent attacks of briefly stopping breathing or recurrent eye deviation with facial distortion, or recurrent lip smacking and chewing movements, or can even be just a colour change not associated with or triggered by any activity.

One should have a low threshold to investigate any of the above in newborns and infants.

Any focal seizure has the potential to become a more widespread seizure if untreated and can also become much prolonged seizures.

## TO WHAT EXTENT DOES THE MANNER IN WHICH SYMPTOMS ARE EXHIBITED CHANGE AS THE PATIENT GETS OLDER?

The child might become more aware of the changes in herself / himself and may be able to articulate those to their parents. The child may be able to understand the warning symptoms and be able to get to a safe place. The child may be able to vocalise the after-effects of the seizure which could result in weakness in one side of the body or headaches which can persist for a few hours. Some of the symptoms could be disruptive to sleep too. Also, poor sleep could trigger more seizures too. As the child grows older, the problems in other aspects of brain function may also become apparent.

## WHY IS EARLY INTERVENTION NECESSARY?

If epileptic seizures are not treated they could increase in severity and begin to impinge on other activities of the brain which include development and learning. Some of the epilepsies affect overall learning. Developmental delay and learning difficulties can be associated with some epilepsies, either as a symptom of the severe epilepsy or a symptom of the underlying brain dysfunction.

## HOW IS THE DIAGNOSIS PROCESS GENERALLY CONDUCTED?

It all starts with the parental concern or is sometimes picked up by the health visitors or at the developmental checks or concerns raised in schools. The diagnosis is largely based on history or description of the event either by parents or witnesses. They then get referred to their paediatrician via their GP or via A&E if there is an explosive onset. Based on the description of the events and the circumstances, diagnosis of epilepsy is made. EEG, which is brainwave tracing, is then used to confirm or classify the seizure but can be normal in a lot of children with epilepsy. In other words, if the EEG is normal, it does not exclude a diagnosis of epilepsy.

As the diagnosis is history-based primarily, there can be a high degree of misdiagnosis (either over-diagnosis or under-diagnosis).

Depending on the age of onset, birth problems, family history, prior developmental issues or prior brain injury, appropriate investigations are undertaken to find out the cause of the epilepsy.

## HOW PROGRESSIVE HAS THE MANAGEMENT OF PAEDIATRIC EPILEPSY BEEN OVER THE YEARS?

The diagnosis of epilepsy has been revolutionised with the advent of the smartphones, with the ability to capture videos and share easily with professionals.

There are newer anti-epileptic drugs which have fewer side-effects and better tolerated. Epilepsy surgery is curative when a patient has an obvious cause for his / her epilepsy (like a brain malformation, scarring or brain tumour). Dietary therapies are becoming more common to resort to if the child has difficult-to-treat epilepsy. In some epilepsies with a genetic cause, there is increasing evidence that certain medications work better than others. This means that if a cause is established, we can treat with the appropriate treatment from the start and avoid other treatments which may have no effect or be detrimental to the child.

## ARE THERE ADEQUATE SUPPORT SYSTEMS IN PLACE FOR PATIENTS AND THEIR FAMILIES?

Most children with epilepsy (up to 60 per cent) will become seizure-free with the introduction of an anti-epileptic drug. Another 10 per cent will become seizure-free after a trial of another medication or with the addition of another medication. 30 per cent will have refractory or difficult-to-treat epilepsies. For all, the medication has to be taken everyday. If the child is seizure-free for more than two years, they are given a trial off medication.

Most families at diagnosis generally will have been allocated to an epilepsy nurse specialist – especially so if the child is in the 30 per cent of patients who have 'difficult-to-treat' epilepsies.

They are also always directed to online resources and support groups like Epilepsy Action and Epilepsy Ireland. Also, there are support groups specific to certain seizure syndromes, like Dravet syndrome, CDKL5 syndrome etc.

## ARE THERE ANY CHALLENGES THAT THE SECTOR STILL NEEDS TO WORK TOWARDS OVERCOMING?

It is felt that there is still stigma attached to the diagnosis of epilepsy. Families and patients find it difficult to discuss their diagnosis openly with others. Young adults find it hard to talk about their diagnosis. Children face bullying in school. Education and awareness of the different types of epileptic seizures is a necessary element in the curriculum of the schools if we have to remove the deep-seated stigma. More than half the children with epilepsy can have some associated learning difficulties. It is necessary for schools to recognise this.

Uncertainty of the timing of seizures makes it an unpleasant problem. The families can be over-protective and this in the long-term can affect the self-esteem of the child which is so important for confidence and a lot of things you do in later life. We need to work on overcoming the social consequences of this diagnosis and have robust support for people to perform to their optimal capabilities in their work environment.

## ALZHEIMER'S SOCIETY

# WHEN THE GOING GETS TOUGH

As COVID-19 charges on – spreading and sharpening its toll on populations far and wide – Alzheimer's Society is urging improved support for people with dementia in Northern Ireland.

People across Northern Ireland are being urged to support Alzheimer's Society at this difficult time, in which coronavirus is making daily life much harder, as the charity seeks to ensure that no-one affected by dementia goes without the support they need.

The charity has led the way in highlighting the devastating impact which lockdown has posed on those with the condition and their families. And it is at the forefront of a campaign to end restrictions that have prevented family members from hugging, or even holding hands with, loved ones living with dementia in care homes.

Alzheimer's Society is calling for the Care Partner model, announced in September, to be finally rolled out across all of Northern Ireland's care homes, giving access to Personal Protective Equipment and rapid regular testing to facilitate these essential visits in a safe way.

This acknowledges the vital role which families often play in caring for loved ones in care homes, from assisting them with tasks, such as eating and drinking, to helping them articulate their needs, which can prove critical.

The charity's dedicated army of expert dementia support workers in Northern Ireland have just experienced their busiest ever festive period as people continue to struggle with isolation and loneliness, due to the current restrictions.

Dementia support workers in Northern Ireland offer a

personalised support service for people affected by dementia and provide advice, information, and can connect people to other local services.

Bernadine McCrory, Country Director for Alzheimer's Society in Northern Ireland, said, 'Since lockdown began in March, Alzheimer's Society's vital support services have been used more than 2.7 million times and are proving to be a lifeline for thousands.

'More than a quarter of all coronavirus deaths have been people living with dementia, making them the worst-hit by the pandemic. Many more are isolated from social contact, essential health and care support which is why we need people to donate to our appeal so anyone struggling will have a dementia support worker on hand when they need them.

'Your support could help make sure that no-one faces dementia alone. Donating is easy – simply visit [www.alzheimers.org.uk](http://www.alzheimers.org.uk).'



### ACCESSING THE INVALUABLE SUPPORT



#### Harry and Vi Filmer with family

Harry and Vi Filmer, from Bangor, County Down, have accessed services, such as one-to-one dementia support and Singing for the Brain, from Alzheimer's Society in Northern Ireland.

Vi, who is 73, was diagnosed with early onset dementia in January 2020, and due to the COVID-19 restrictions her speech has significantly deteriorated. However, Alzheimer's Society has been supporting the couple and their family since the diagnosis.

Harry, Vi's husband, has found the help they have received from dementia support worker, Lynda Williams, 'invaluable'.

Harry explained, 'It was a massive shock when Vi got her diagnosis. We have been married for 54 years and were childhood sweethearts. The support we have received from Lynda and Alzheimer's Society in Northern Ireland has been amazing. COVID-19 has sadly had a dramatic impact on Vi as she is not getting the face-to-face stimulation which is so needed for people with dementia.

'Lynda is a great asset to Alzheimer's Society and so personable and professional. I really can commend the whole team. The support is invaluable, and all the Alzheimer's Society team are so engaged with people who are affected by dementia. We still access Singing for the Brain via Zoom every week which we really enjoy and is continuing to help Vi.'

Harry and Vi have raised money for Alzheimer's Society in the past by arranging a Your Walk, Your Way memory walk. Harry also arranged a concert to raise funds for Alzheimer's Society in May but this was cancelled due to COVID-19. The couple also have two daughters.

*Anyone affected by dementia can access information or advice through Alzheimer's Society's Dementia Connect support line seven days a week on 0333 150 3456. Its website ([www.alzheimers.org.uk](http://www.alzheimers.org.uk)) and online community, Talking Point, are available 24/7.*

# COVID-19 VACCINE ROLLS OUT IN NORTHERN IRELAND

94-year-old Eileen Lynch became the first person in Northern Ireland in the over-80 category to receive the vaccine developed by Oxford University and AstraZeneca. Eileen received the vaccine from Dr Michael McKenna at her local GP surgery on the Falls Road, Belfast.

The roll-out of the Oxford/AstraZeneca vaccine follows approval from the Medicines & Healthcare products Regulatory Agency (MHRA) and paved the way for a significant acceleration of Northern Ireland's vaccination programme.

Speaking at the vaccination clinic, Chief Medical Officer, Dr Michael McBride, said, 'The vaccine programme will transform the situation but, as always, we must all remain patient.'

'First and foremost we must act to protect those most at risk of severe disease and death. As approved by the MHRA and recommended by the Joint Committee on Vaccination and Immunisation (JCVI) prioritisation will be given to those aged 80 years and over. The programme will then be rolled out based on age and other clinical vulnerability factors.'

The JCVI recently updated its guidance and has recommended that as many people on the JCVI priority list as possible should be offered a first vaccine dose as the initial priority.

Dr McBride said, 'The evidence has very clearly shown that both the Pfizer/BioNTech and the Oxford/AstraZeneca vaccines provide very high levels of protection after the first dose. Providing that level of

protection on a large-scale will have the greatest impact on reducing death and hospitalisations, protecting the health and social care system. It is the right thing to do for the public health.'

Speaking after receiving her vaccine, Eileen said, 'I am delighted and privileged to receive the COVID vaccine today. I feel like I can really look forward to the year ahead now that I have been vaccinated.'



Eileen Lynch received the Oxford/AstraZeneca vaccine from Dr Michael McKenna

## PRESTIGIOUS AWARD FOR TEAM BEHIND COVID-19 DASHBOARD

The Department of Health COVID-19 Statistical Reporting Team have won a prestigious UK-Wide Analysis in Government Award for their work on the COVID-19 Dashboard.

The awards celebrate the achievements of the analysis function within government across the UK. 118 nominations were received across five categories. Against stiff competition from a range of expert statistical teams, the department's Information Analysis Directorate (IAD) picked up the top award in the Impact category for the COVID-19 Dashboard.

The award recognises the major impact which the dashboard has had through its use by the public, as well as its influence on decision-making during the pandemic.

The department's Permanent Secretary, Richard Pengelly, commented, 'The data allows decision-makers to answer questions about the response to COVID-19 and to explore the impact of different decisions. It means that we can ensure that we're in the best position possible to deal with demand, resources and staffing capacity.'

'The work of IAD has proven to be invaluable throughout the pandemic and again highlights that all of our colleagues across health and social care, even if they're not in a direct patient-facing role, make a vital contribution to our collective efforts.'

## RECOGNITION AGREEMENT COVERING PHARMACISTS WORKING FOR GP FEDERATIONS ANNOUNCED

The Pharmacists' Defence Association (PDA) Union have signed a recognition agreement covering pharmacists in Northern Ireland working for GP federations throughout the country. This is the latest recognition agreement for the PDA Union which began negotiating terms for pharmacists via their groundbreaking agreement with Boots which was signed.

The new agreement, which was signed at the Federation Support Units offices in Belfast, will cover over 300 pharmacists working in Northern Ireland and further increases the proportion of pharmacists for whom the PDA now negotiate pay.

The new agreement, reached voluntarily, means that the PDA Union will work with representatives of the 17 individual organisations, negotiating on behalf of members on issues, such as pay, leave, pensions and other terms and conditions.

The agreement also allows for a limited number of PDA Union representatives to be established and provides for time of and training for members interested in taking on this role.

Paul Moloney, PDA Union National Officer, responsible for negotiating the agreement, said, 'This is an important development for the PDA Union and its members in Northern Ireland. This is our second recognition agreement and the first that has not required us to use the statutory recognition process.'

'We would like to place on record our thanks to the team at the Federation Support Unit for co-ordinating the employers' side and working to bring the agreement into force. We look forward to working constructively with them and the individual federations to ensure their pharmacists have a strong voice at work.'

MS



# MULTIPLE SCLEROSIS, DISEASE MODIFYING TREATMENTS AND THE COVID-19 PANDEMIC

The COVID-19 pandemic continues to dramatically affect healthcare services and patients' lives. This is especially true for all people living with a chronic condition, including patients with multiple sclerosis, who are already dealing with an unpredictable and complex disease. In this article, Northern Ireland Healthcare Review and BMS aim to present a brief overview of MS and of the latest official guidelines on disease modifying treatments (DMTs) use during the pandemic, to help patients better understand and manage their condition.

Introducing the basics of Multiple Sclerosis (MS) to patients and present official guidance and considerations for treatment during the COVID-19 pandemic.

MS is a chronic, neurological disease that affects the central nervous system. In MS, the immune system mistakenly attacks myelin (the fatty insulation around nerve fibres), causing damage to axons and leaving lesions (scarring) that interfere with the transmission of signals from the brain to the body. Ultimately, the nerves themselves might deteriorate – a process that is currently irreversible.

While close to 85% of patients present with a relapsing form of the condition (Relapsing Remitting Multiple Sclerosis - RRMS), characterised by 'flare-ups' of disease activity and slow progression (worsening) over time, 10-15% exhibit symptoms of a progressive form of the disease, in which the condition is degenerative from the onset (primary progressive MS – PPMS).

Without disease-modifying therapy (DMT), about 40 per cent of patients diagnosed with RRMS will become progressive (Secondary Progressive MS – SPMS) within 10 years, a disease state characterised by fewer or no relapses but increasing disability.

*(Sources: Lublin et al., 2014; Dobson & Giovannoni, 2019; Iwanowski & Losy, 2015; NHS UK)*

## WHO?

- The disease can affect people of all ages, but the most common onset occurs between the ages of 20 and 40.
- Around 130 000 peoples are currently affected by MS in the UK, with an increasing prevalence from South to North.
- Close to 7000 people are newly diagnosed with MS every year in the UK
- MS is 2 to 3 times more common in women than in men.
- Among young adults, MS is the most common disease of the central nervous system to cause permanent disability in adults.
- MS can affect individuals of any ethnic group, though individuals of European ancestry appear to be at higher risk.
- Individuals with a first degree relative with MS have a 10 to 25 times greater risk of developing the disease than the general population.

*(Source: MS prevalence Report January 2020, MS Society; Public Health England; NHS UK; Ramagopalan et al., 2010; Amezcua & McCawley, 2020)*

## WHAT?

MS patients can present with a wide range of symptoms, associated with the disruption of nerve signals across the body. The common initial symptoms of MS include visual disturbances, numbness and tingling, balance, walking difficulties and fatigue. Other symptoms include muscle stiffness and spasms, bladder and bowel problems and sexual dysfunction.

*For more information about MS, visit: [www.mstrust.org.uk](http://www.mstrust.org.uk), [www.mssociety.org.uk](http://www.mssociety.org.uk), [www.nationalmssociety.org](http://www.nationalmssociety.org); [www.nhs.uk/conditions/multiple-sclerosis](http://www.nhs.uk/conditions/multiple-sclerosis).*

## MS AND COVID-19

What is the impact of the COVID-19 pandemic on MS patients?

For England, NICE guidance for Disease-modifying therapies for multiple sclerosis can be found at [pathways.nice.org.uk/pathways/multiple-sclerosis](http://pathways.nice.org.uk/pathways/multiple-sclerosis). In Scotland, advice for DMT use can be found at [www.scottishmedicines.org.uk/medicines-advice/](http://www.scottishmedicines.org.uk/medicines-advice/). Additional information can be found at the website of UK's two main MS charities: [www.mstrust.org.uk](http://www.mstrust.org.uk) and [www.mssociety.org.uk](http://www.mssociety.org.uk). For more tailored treatment guidance and advices, better suited to their unique

condition, people with MS should contact their local MS team.

## OFFICIAL RECOMMENDATION ON DMT USE DURING THE COVID-19 PANDEMIC.

The Association of British Neurologists (ABN) has recently published a guidance on DMT use in MS during the COVID-19 pandemic (November 2020 – to be reviewed in March 2021). This document constitutes an important point of reference for questions regarding DMT use during the current pandemic.

In addition, peer-reviewed datasets are starting to emerge on the potential risks and benefits associated with DMT treatment during the pandemic (Möhn et al., 2020; Laroni et al., 2020) and will help inform future decisions by regulatory agencies and MS teams.

## COVID-19 VACCINATION AND DMT USE

The ABN has recently published a guidance on COVID-19 vaccination for people with Neurological conditions (January 2021), which include MS.

## PATIENTS FREQUENTLY ASKED QUESTIONS WERE THE COVID-19 VACCINES TESTED ON PEOPLE WITH MS?

The vaccines were tested on large groups of patients in both the active and placebo groups. We do not know if people with MS were in those groups.

## CAN I HAVE THE VACCINE IF I AM TAKING A DMT?

DMTs can affect the immune system. There exist some ongoing discussions as to which extent can DMTs affect the COVID-19 vaccines stimulation of an immune response, and the effect on the resulting protection it can confer to individuals. As more data become available, it is likely that ABN and NHS guidelines will be updated.

## I HAVEN'T STARTED A DMT YET. SHOULD I HAVE MY VACCINE FIRST?

Talk to your MS team about the best strategy for you.

## WHEN WILL I RECEIVE A VACCINE?

The order of priority is based on individual risk, and aims to protect the most vulnerable people and the health and social care systems. This means that the main criteria for the first phase of the vaccination programme will be age.

For patients with no other underlying health conditions apart from MS, we understand that they would be offered a vaccination at priority level six. This is because the list of underlying health conditions considered relevant by the Joint Committee on Vaccination and Immunisation (JCVI) includes chronic neurological disease. If you are older than 65, you will be invited to be vaccinated earlier.

Patients considered extremely clinically vulnerable, and who have been asked to shield, are likely to be included at priority level four. Pregnant women and children under 16 will not be included in this group as there is not enough safety data for the vaccines in these groups. This may change at a later date.

*For more information about the priority levels for vaccination, official information are available at: [www.gov.uk](http://www.gov.uk).*

## STAYING WELL DURING THE PANDEMIC: MS RESEARCHERS SPEAK OUT

Staying well has never been more important for people living with MS, say a group of MS rehabilitation researchers in a published editorial, as the COVID-19 pandemic disrupts lifestyle habits and coping resources. The researchers – representing the National MS Society's Wellness Research Work Group (US based) – present tips for people with MS and their healthcare providers to consider:

- Staying active can improve walking, balance, fatigue, depression and quality of life. If it's challenging now, engage in short bouts of physical activity throughout the day. Guidelines are available for ALL people with MS
- A healthy diet is associated with less depression, lower levels of disability and higher self-reported quality of life. But you don't need to overhaul your diet. Individuals should try simple changes, such as making half of their plate fruits and vegetables, and choosing olive oil or grapeseed oil. Reading labels is also encouraged – any food with less than five ingredients is less likely to have too much salt or refined sugar
- Addressing emotional wellness can not only alleviate the depression that affects people with MS, but can help with MS symptoms, such as pain and fatigue.

*(Source: Motl et al., 2020)*

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## NEWS

### CONSULTATION ON NEW MENTAL HEALTH STRATEGY LAUNCHED

Health Minister Robin Swann has launched a public consultation on a new, 10-year Mental Health Strategy for Northern Ireland. The draft strategy sets out a new vision for mental health in Northern Ireland, as well as 29 high level actions designed to take forward significant strategic change over the next decade.

The Health Minister said, 'I am delighted to publish my department's draft Mental Health Strategy today for consultation. Mental ill health is a huge challenge for our society. Too many people struggle with being mentally unwell and too many people find it difficult to find the help and support they need when they need it. I am determined to change that, and this strategy is a key step towards doing just that.'

Key actions set out in the draft strategy include a commitment to develop a year-on-year action plan for mental health promotion; greater investment in and further roll-out of psychological therapy hubs in primary care; better integration between the statutory and community and voluntary sectors; as well as the creation of a single mental health service to ensure regional consistency, quality and access across Northern Ireland.

The draft strategy has been co-produced with a broad range of stakeholders, including people with lived experience, carers, health and social care staff, the interim Mental Health Champion, other government departments, academia, and professional bodies.

The Health Minister concluded by thanking all those who have been involved in developing this draft strategy, stating, 'Your voice, your experience, your expertise and your input have been instrumental in getting us to this point, and this work could not have been done without you.'



Health Minister Robin Swann

### PHYSIOTHERAPY PRESCRIBING SCHEME TO REDUCE WAITING TIME FOR PATIENTS

Physiotherapists in the Southern Health & Social Care Trust are among the first in Northern Ireland to write prescriptions for patients.

The new scheme is part of a regional pilot looking at new ways of prescribing, to help reduce waiting times for medication and free up GP appointments for those who need them most.

In the first phase, physiotherapists working with patients who have lymphoedema can prescribe medication or garments where appropriate, for example, if the prescription is needed urgently or if the items are complex.

The plan is to extend the service to include orthopaedic ICATS and also community respiratory physiotherapy, which could potentially support recovering COVID-19 patients when discharged from hospital.

Carmel Harney, Assistant Director for Allied Health Professions at the Southern Health & Social Care Trust, explained, 'With around one-third of GP appointments relating to physiotherapy issues, there are huge benefits for the profession working more closely with primary care colleagues.'

'We are delighted to work with GP colleagues to find ways how we can all work better together to improve the patient experience.'

'We already have prescribing first contact physiotherapists, as part of primary care multidisciplinary teams, in a number of GP practices, helping with musculoskeletal problems like back, neck, joint pains or soft tissue injuries.'

'The introduction of this new approach to prescribing is another way that we can make the most of specialist physiotherapy expertise, helping to ensure that patients get the right care as early as possible while freeing up GP time.'

### FLU VACCINATION PROGRAMME FURTHER EXPANDED

The flu vaccination programme in Northern Ireland has been expanded to include those aged 50-to-64 years of age.

The extension of the programme will help protect more people from flu and relieve further pressure on the health service. Those who will be aged 50-to-64 by 31<sup>st</sup> March 2021 can avail of the jab from over 350 community pharmacies or through their local GP practice.

Health Minister Robin Swann explained, 'We have seen an increased uptake in the flu vaccine programme this year and while this is very encouraging it remains extremely important that we take all necessary measures to help reduce the spread of flu.'

'This is especially true given the very high levels of COVID-19 transmission in our communities. Reducing the pressure caused by seasonal flu will help protect our health service and save lives.'

The current groups eligible for a free flu vaccination from their GP are now everyone aged 50 and over, pregnant women, those aged under 65 years of age in clinical 'at risk' groups, all children aged two-to-four, primary school pupils and school children in year eight who missed the school vaccination, household contacts of those who received shielding letters, and frontline health and social care workers. Free flu vaccination from pharmacies are for everyone aged 50-to-64, and frontline health and social care workers.

# MAKING THE CONNECTION

With the release of recent studies showcasing strong links between the endocrine system and COVID-19 incidence and mortality, what are the connotations for patient management and the role of elevated support?

COVID-19 and interlinkages to endocrine and metabolic diseases was an important programme topic at the 2020 European Congress of Endocrinology (ECE) in which, over five days, panel sessions covered the science behind COVID-19 and endocrine and metabolic disorders, as well as e-consulting and e-support to endocrine patients in times of COVID-19.

'One thing that is clear from the beginning of the pandemic is that patients with underlying endocrine diseases, like diabetes, obesity or the lack of vitamin D, were more at risk of developing severe COVID-19,' commented Andrea Giustina, President of the European Society of Endocrinology.

He continued, 'Therefore, disciplines that work in the prevention, such as endocrinology, can focus on creating a healthier population, which can be important in the preparation for pandemics like COVID-19.'

The need to address the links between endocrinology and COVID-19 has not gone unnoticed by policymakers. At the e-ECE opening ceremony, John Ryan, Director of Public Health, Country Knowledge and Crisis Management at the Directorate General for Health and Food Safety of the European Commission, said, 'There is a huge issue regarding non-communicable diseases and the EU is investing heavily together with Member States in trying to find effective ways to prevent it, such as the Farm2Fork Strategy of the EU4Health programme.'

## COVID-19 INCIDENCE HIGHER FOR THOSE WITH UNDERLYING ENDOCRINE CONDITIONS

There is evidence that people with underlying endocrine conditions, such as diabetes, obesity or autoimmune thyroid disease, face an increased risk of infection from COVID-19. In fact, vitamin D deficiency makes people more vulnerable to infection and may increase lung damage. In addition, recent studies show that certain underlying conditions, associated with exposure to endocrine-disrupting chemicals, are exacerbating the effects of COVID-19 in vulnerable populations.

## ENDOCRINE CONDITIONS LEAD TO WORSE OUTCOMES FOR COVID-19

It has been proven that people suffering from underlying endocrine-related diseases, who are infected by COVID-19, are more likely to suffer severe symptoms, be admitted to intensive care units, as well as have an increased risk of death. For instance, in a study by Matteo Rottoli, obesity was shown to be a risk factor for respiratory failure, admission to the ICU and death among COVID-19 patients. In fact, patients with a body mass index over 35kg/m<sup>2</sup> had a dramatically increased risk of death.

Moreover, endocrine systems could suffer in the long-term from the impact of COVID-19, since the hormone system is the key regulator of body weight, energy expenditure and energy (food) intake. In fact, COVID-19 is associated with anorexia, dysgeusia, dysfunction of gastrointestinal absorption and severe weight loss, mostly from muscle mass.

## URGENT POLICY ATTENTION IS NEEDED TO ADDRESS THESE INTERLINKAGES

The European Society of Endocrinology have stated in a COVID-19 and endocrinology position statement that we need urgent policy attention to address the structural factors and underlying conditions that render populations vulnerable and exacerbate healthcare crises, such as the COVID-19 pandemic. The upcoming EU4Health strategy needs a strong endocrine and metabolic element to achieve its objectives. Therefore, it is needed to focus on the following demands: an increase in research funding for the relationship between COVID-19 and hormones; a co-ordinated effort for global surveillance; new models of patient management; and increased collaboration between countries, policymakers and other stakeholders.

## ABOUT THE EUROPEAN SOCIETY OF ENDOCRINOLOGY

The European Society of Endocrinology are working together to develop and share the best knowledge in endocrine science and medicine. The European Society of Endocrinology represent a community of over 20,000 European endocrinologists, enabling them to inform policymakers on health decisions at the highest level through engagement in advocacy efforts across Europe. It is by uniting and representing every part of the endocrine community that the society are placed in the best possible position to improve life for patients.

*For more information, visit [www.es-e-hormones.org](http://www.es-e-hormones.org).*



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SCAN  
ME





# THE MENTAL BATTLE OF CHRONIC HEALTH

Despite the increased visibility of mental health and help available, there's one vulnerable group who are still being left out of the conversation – those living with chronic physical health conditions. Catriona Williams, from online health community, talkhealth, explains further.

In the past few years, mental health has become a hot topic – and with good reason. According to the mental health charity, Mind, one-in-four of us will experience a psychological issue or period of poor mental wellbeing at some point or other. Male suicide rates hit a two-decade high in England and Wales in September (according to ONS data) and experts have called poor mental health among young people an 'escalating crisis'.

## EXPLORING THE CONNECTION

Body and mind are so connected – it's obvious that when things go wrong or become defective in one, the other is affected. We need only look at conditions like psoriasis to see how stress impacts on the biggest organ in the body. Endometriosis survivors often have to manage chronic pain and bleeding alongside depression and anxiety. IBS patients are often diagnosed with generalised anxiety disorders, while severe asthma can trigger panic attacks in some patients.

Living with a long-term illness can present various challenges to mental health and while it's not always possible to look towards a condition-free future, it's worth considering how we can reframe our understanding of physical wellbeing.

## MANAGEMENT MECHANISMS

Each month at talkhealth, we interview a healthcare professional with the aim of providing our members with a little insight into their work. We recently spoke to Physiotherapist Tony Linkson on how therapy can help people managing chronic health. He told us that on a very basic level, simply having the focussed support of a person who's willing to listen and understand the challenges of illness can be liberating.

He went on to explain that 'another aspect of chronic illness is the possibility of exploring the ways in which life choices might be causing or exacerbating illness. I've worked with a large

number of people who have had physical ailments that heal once emotional and psychological issues have been processed.'

That, to many of us, might sound incredible, but it seems reasonable to suggest that the mind may wield more power over our chances of recovery from physical illness than some would have us believe.

As Tony explained, 'If and when a chronic illness can be remedied, sometimes people can find themselves habituated as an ill / vulnerable person or a person in pain.' That can be a fear response and talking therapies can help people to embrace health again and to let go of what may be negative coping mechanisms.

## A MULTIFACETED PROBLEM

Of course, therapy isn't the be-all and end-all. At talkhealth, we work with lots of bloggers and patient advocates who spend much of their time building communities of people who live with similar issues. One such person is Clare Baumhauer, who has been busy raising awareness of vulval cancer and lichen sclerosus (LS) by setting up a support group and Instagram page. She was diagnosed with both conditions at 43 – nearly 40 years after first experiencing LS symptoms.

'The stress of not getting a diagnosis for many years did impact a lot on my mental health as you're led to believe that it's all in your head. Once I was diagnosed, I was so angry. Now it's hard to not always think that LS is going to turn to cancer again so it takes over my thoughts, especially at night,' she told us.

Clare went on to say that the single most useful tool she's found for coping with LS has been talking about the condition with other people living with it.

It's clear from Clare's experience that the mental health aspect of chronic health is multifaceted; isolation, frustration and fear come together to send patients into a spiral.

talkhealth is a patient-centric platform that largely looks at ways in which people can better self-manage their long-term issues. While we understand the need for better and more comprehensive mental health support, we're focussed on addressing the specific challenges that chronic health can pose to mental wellbeing. As such, we've been busy interviewing mental health professionals on how therapy and self-care can help those of us who are managing complicated health profiles. We understand that it's impossible to implement a blanket approach to mental health; not only does everyone have their own ways of coping with challenging situations, but even patients with the same physical condition will find that it metabolises mentally in different ways.

## BUILDING AN OPEN SPACE

Talking and allowing people to open up about their experiences is such an obvious tool but it's still the most effective one. Our online expert clinic on LS – a debilitating and often embarrassing condition that affects millions of women – was one of the most popular clinics that we've ever done. It's not that LS is so incredibly common; its popularity was down to the fact that it's such a difficult subject to openly discuss. Giving people the space to vent, confide, and receive advice was hugely powerful.

We're fortunate that our platform improves the mental health of our members almost as a byproduct; connecting and creating communities necessarily affords people a space to open up and share the burden.

For more information, visit [www.talkhealthpartnership.com](http://www.talkhealthpartnership.com).



## SUBSTANCE DEPENDENCY

# ON DANGEROUS GROUND

Lockdown has created a pressure cooker for many people at risk of addiction. As a result, Dr Youssef Beaini, GP, GPwER Substance Misuse and Chief Executive at the BONDS™ Clinic, highlights what to look out for in your patients and how to subsequently deliver effective help.



COVID-19 has brought the greatest public health catastrophe of our times and caused a huge spike in pathological stress levels, with the number of adults experiencing depression doubling.<sup>1</sup> In primary care, many of us have already seen a large increase in consultations for mental illness.

Any form of prolonged stress can trigger addiction or substance dependency in high-risk people, but it can also trigger a spike in the general population who would not normally be at risk. Some people will 'self-medicate' with alcohol or drugs to try to cope with stress. Those already addicted to drugs or alcohol may struggle to get their usual supplies during lockdown, due to social distancing and disruption to medical supplies. Some people will be spending much more time at home with family or loved ones who may suddenly see indicators of addiction.

COVID-19 lockdowns have increased the risk of existing alcohol dependency worsening. For those who were previously abstinent, COVID-19 has been a risk factor for relapse, with a high risk of harmful misuse.<sup>ii</sup> Similar risks for other drug dependency would be expected, such as opioids and cocaine.

All of these factors have combined together to create a potential crisis in addiction.

### HOW DO I SPOT THE SIGNS AND SYMPTOMS OF ADDICTION?

Each person's experience of addiction will be slightly different, but there are common signs and symptoms that may present directly to health professionals:

- Changes in mood, such as being depressed, anxious or elated
- Being tired all the time, or hyperactivity or physical agitation
- Changes in weight
- Changes in sleep, such as insomnia or hypersomnia
- Looking unwell at certain times but rapidly looking better soon after, in a repeating cycle
- Pupil size can be larger or smaller than expected
- Unexpected persistent cough without having an URTI or LRTI

Be cautious though – both symptoms and signs can be due to other causes. Triangulation is key, as with a lot of medicine: it is much more useful to look for groupings of these signs and symptoms, rather than just one or two in isolation.

### WHAT DO I DO IF I SUSPECT A PATIENT HAS AN ADDICTION ISSUE?

1. Apart from signposting or referring a patient to your local drugs or alcohol services, you can signpost patients and their loved ones to good national resources:

- [www.nhs.uk/live-well/healthy-body/drug-addiction-getting-help](http://www.nhs.uk/live-well/healthy-body/drug-addiction-getting-help)
- [www.talktofrank.com](http://www.talktofrank.com)
- [www.adfam.org.uk/help-for-families/useful-organisations](http://www.adfam.org.uk/help-for-families/useful-organisations)

2. It is crucial to assess for any co-existing mental health disorders. Untreated depression or anxiety will massively increase the risk of relapse since patients often self-medicate as a maladaptive coping strategy. Our clinic's real-world audit data shows that around 70 per cent of substance dependency patients have a co-existing mental health disorder, or 'Dual Diagnosis'.<sup>iii</sup> If depression or anxiety is present, consider treating while the patient seeks treatment for the dependency

3. Consider the risk of hepatitis or HIV and test if needed

4. Consider any safeguarding issues – are there any children at home?

# SUBSTANCE DEPENDENCY

## TREATMENT OPTIONS

The main goal of addiction treatment is to reduce harm to the person and to those around them, as well as to society in general.

For alcohol and non-opioid drugs, the two main approaches are abstinence or harm reduction if the person is not willing to consider abstinence.

For opioid addiction, there are two main options:

- Substitution therapy (methadone or buprenorphine)
- Abstinence

## SUBSTITUTION THERAPY

There is a large body of evidence to support replacing the opioid with an alternative prescribed opioid that is less harmful. These don't give the same highs as other illicit opioids, such as heroin or fentanyl, and stay in the blood stream for longer.

Choosing this route can help to reduce the use of illicit opioids and allow the person a chance to work on psychological and medical treatment for their addiction, as well as trying to improve their social health through rebuilding family life or getting back to work.

The majority of UK services provide substitution therapy for

opioids. Substitution therapy can aim for abstinence in the longer-term or for 'maintenance' therapy where the substitute is continued long-term to reduce harm. The main risk of substitution therapy is that a person stays on it long-term or just misuses it to supplement their addiction.

## ABSTINENCE

The abstinence option means that a person will undergo a 'detoxification' from the opioid and then embark on a programme to help them stay off the drug. Some people are highly motivated towards abstinence rather than longer-term substitution, and with the help and support of a professional team this is another valid option in NICE guidance.<sup>iv</sup> Any option needs to be chosen using a shared decision-making process between the specialists, the individual, and their loved ones / family.

Any person wishing to become abstinent from opioids in particular must be made aware of the risks if they go back to using drugs. Once abstinent from opioids, a patient's body will gradually become more sensitive to them again and if they were to take a previously-used dose of opioids, there is a risk of overdose in the opioid-naïve state. Therefore, it is particularly important for abstinence-

oriented treatment to include education on the risks of overdose if a person relapses and the body's sensitivity to opioids after a detox.

At The BONDS™ Clinic, we operate an abstinence and supported recovery programme which helps individuals get back to life by using a Bio-Psycho-Social model to address the biological / medical, psychological and social features.

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# RISKY BEHAVIOUR

As winter rolls on – representing the deadliest season for people with lung conditions – the backlog of basic care could lead to an ‘avalanche’ of unscheduled admissions. How can the sector stay on top of this heightened pressure?

Every year annual winter pressures on the NHS are driven by a spike in respiratory hospital admissions. Plummeting temperatures, colds, flu – and now COVID-19 – can all cause symptoms to flare up and trigger potentially life-threatening exacerbations. There are 80 per cent more lung disease admissions in the winter months of December, January and February than there are in the warmer spring months of March, April and May.

The government are calling on everyone to protect the NHS this winter by taking steps to look after themselves, but Asthma UK and the British Lung Foundation have said that this can't happen if people with chronic lung diseases aren't receiving basic care, including monitoring, treatment and interventions, to keep themselves well and out of hospital.

While some people with lung conditions have been able to access basic care throughout this turbulent time, it has not been consistent. The pandemic has had a huge impact on people with lung disease, with many having experienced appointments being cancelled, annual reviews postponed, and face-to-face care suspended.

Asthma UK and the British Lung Foundation estimate that up to 1.8 million people with lung conditions could have missed out on annual reviews during lockdown, essential for helping people stay on top of symptoms and ensuring that they are on the correct medication.

GP practices have had to implement vast changes to the way in which they deliver care in order to protect staff and patients across the healthcare system from coronavirus. Challenges they have had to overcome include the shift to remote care at the height of the lockdown, the build-up of people waiting for specialist care referrals, and addressing the backlog of basic care which patients have missed due to COVID-19.

## SEEKING RELIEF

Results of a survey conducted by Asthma UK revealed that over half (58 per cent) of respondents said that their asthma self-management was deteriorating and that they are using their reliever inhaler three or more times a week.

Utilising a reliever inhaler three times a week or more is a red flag that a person's symptoms are getting worse and they are at an increased risk of an asthma attack. Every day in the UK, an average of three people die from an asthma

attack.

Asthma UK are now issuing an urgent call to anyone who is using their reliever inhaler three times a week or more to book an appointment with their GP as soon as they can, which might be offered over telephone or video call.

Sarah Green from Birmingham knows only too well how important it is to seek help if your asthma is getting worse. Her daughter Holly was using her reliever inhaler every day before she died from an asthma attack in 2016 at just 28-years-old.

Sarah said, 'When I look back on the months leading up to Holly's death, all the signs were there that she was really struggling with her asthma. I'd become used to seeing her puff on her blue inhaler every day and she was going through them really quickly. She had an asthma attack suddenly one evening and she was gone forever.'

'Holly was a busy mum of two young boys and was more focused on looking after them than taking care of her own health. I'd say to anyone with asthma, please do everything you can to look after yourself this winter. I didn't realise how serious asthma could be until it took Holly away from me and left her twin boys without their mother.'

## THE IMPORTANCE OF PLANNING AHEAD

Basic care relating to respiratory disease gets people in the best shape to deal with winter and prevent ending up in hospital. Asthma UK and the British Lung Foundation are now calling for an increase in support for primary care professionals, including pharmacists, GPs and nurses, in delivering the basic care respiratory patients need, to prevent an avalanche of unscheduled care and respiratory hospital admissions which could threaten to overwhelm the NHS.

Asthma UK and the British Lung Foundation have carved out a roadmap in an effort to restore and improve basic care – calling for changes in order to:

- Ensure that all GP practices have the digital tools they need to support video and telephone consultations, as well as face-to-face consultations
- Clearly communicate that patients can choose how they are seen based on their preferences and clinical need

- Outline how primary care can identify, diagnose and treat people with new symptoms of respiratory illness this winter and also address the current backlog of diagnostic tests
- Support primary care professionals to address the backlog of annual reviews for respiratory conditions by prioritising those most at risk

Margaret Dempsey is 76 from Leicestershire and has asthma and bronchiectasis along with other serious chronic health issues, including diabetes and a heart condition.

She explained, 'I've tried to get a face-to-face appointment at my GP practice recently, but they can only offer one over the phone. I want to be seen by a GP because I have multiple health issues and feel without being seen things might get missed.'

'This system isn't working for me and, if anything, is making my health worse. Over the last couple of months my lungs have really been playing up and I'm wheezing, coughing and bringing up mucus everyday which is a real struggle. I already feel incredibly isolated and my experiences so far have completely put me off contacting the doctor for more support. It feels like there's no point in trying.'

## DON'T DELAY

Dr Andy Whittamore, a practising GP and Clinical Lead for Asthma UK and the British Lung Foundation, said, 'The signs are pointing to a very difficult winter and it's vital that people can access the care that they need to stay well. Prevention will play a crucial role in helping practices across the country manage seasonal pressures and support patients with lung conditions, including asthma and COPD, avoid urgent care. Annual reviews, a mainstay of lung disease basic care, need to resume to pre-COVID levels.'

'We want to remind and reassure anyone with a lung condition struggling with symptoms to seek help from their GP, delaying care could put your life at risk.'

Tracey Lonergan, Policy Co-Ordinator for the Primary Care Respiratory Society, explained, 'Restoring the range of necessary services for patients with respiratory disease is critical if we are to avoid an imminent crisis not only for patients but also for the stability and capability of the NHS to deliver the care they need.'



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# PARKINSON'S:

## A NEW PATH

Colin Cheesman was diagnosed with Parkinson's disease in 2001 and actively uses his experiences with the condition to help inform and shape the provision of services and support for people with Parkinson's. Colin has been keeping a record about living with Parkinson's. In this article he describes recent changes to his medication regime.



Colin Cheesman

Parkinson's disease can affect people in a host of different ways. I was diagnosed with Parkinson's in 2001, when I learned that the condition was both progressive and incurable, both of which remain true today. Some of the symptoms are obvious – such as tremor, difficulty in walking, problems with balance, and involuntary movements. In the last 20 years it has been recognised that the condition is also linked with a range of non-motor symptoms affecting mood and behaviour. These symptoms are not necessarily visible but are just as real.

Although we do not have a cure, we now know so much more about the condition. Doctors now have a wide range of treatments, which can be targeted at individual needs. However, Parkinson's is progressive which means that these treatments can lose their effectiveness over time, making it increasingly difficult to cope.

### REVIEWING MY OPTIONS

Since my diagnosis, I have been extremely fortunate in having had excellent support and guidance, particularly in relation to the management of medication, and the progression of Parkinson's has been very gradual. However, in the last few months it became clear that my symptoms were becoming more severe and I was getting less relief from my usual medication. The drugs were no longer keeping me stable throughout the day. It was clearly time to review my options! Together with my very supportive neurologist and my wife (a major stakeholder in the outcomes), we discussed all the possibilities, which ranged from

increasing my current medication on the one hand, to brain surgery on the other. The result of this discussion was that I should increase my medication, but delivered through an apomorphine pump. I had always resisted having the encumbrance of an external device attached to the skin – but something had to be done!

### HOW IT WORKS

The pump itself is a clever little device, capable of giving a constant infusion of the drug from morning until night. I carry it in a small pouch attached to my waistband. The drug is delivered through a very fine tube to a connection point in the skin. A new point on the skin is chosen each morning and the connection is made by placing a small spring-loaded device on the skin. A single click on the device leaves a ring of sticking plaster, about the size of a 50p piece with a small plastic connector mounted in the middle of it.

Once I had made the decision to go ahead, things moved very quickly. The specialist nurse team visited me at home and ran through the whole process until they were satisfied that we understood how to get the pump up and running. Their readiness and availability gave us enormous reassurance, and getting set up was all pretty straightforward.

When I first explored the idea of using this pump, it all felt a bit complicated. What would it really be like being hooked up 24/7? Would it involve a lot of time to set up and run? What if I wanted to swim, cycle or kick a football with my grandchildren? I need not have worried. At any time during the day, I can stop the pump and detach it from the body. The line is easily removed from the infusion point and replaced with a dummy cap. I can then do my activity and all that can be seen is something the size of a coat button stuck on the skin.

### PROMISING RESULTS

It's early days, but I'm convinced that it's having a positive effect on me already. I can still sense the underlying symptom pattern of the day, but the pump has smoothed out the peaks and troughs so that overall my stability is much improved. Setting up for the day obviously takes a few minutes, but once I'm up and running I can pretty much forget about it.

Parkinson's disease has a bespoke impact on each person who has it. Thankfully, we now have a wide spectrum of treatments to tackle it, which can be different for every individual. I know I will have to review the situation again, but until then I am grateful to have the support and treatment that I need.

# BOWEL'D OVER

In this interview, Director of Research and PPIE (Patient and Public Involvement and Engagement) at newly-launched charity, Bowel Research UK, Lesley Booth, discusses why bowel research is so important – highlighting the crucial role played by the charity and offering key insight on the development of bowel research and what more needs to be done. Having been diagnosed with IBD herself, Lesley is uniquely placed to support the work of Bowel Research UK and has been a driving force behind the patient-centred approach to research championed by the charity.



Lesley Booth



## CAN YOU GIVE US AN INSIGHT INTO THE CURRENT STATE-OF-PLAY OF BOWEL CANCER AND IBD?

It's estimated that around 42,000 new bowel cancer cases are diagnosed each year in the UK, where it is the fourth most common cancer. Since the early 1990s, bowel cancer incidence rates have remained stable in the UK. Every year over 16,000 people die from bowel cancer in the UK, however bowel cancer mortality rates have decreased by approximately 44 per cent over the last decade. (1) Survival rates are high if it is caught early but it is still the nation's second leading cancer killer, highlighting that many people are still not being diagnosed soon enough. Around half of the population are not adequately screened (2) and many patients end up in A&E at Stage III or IV diagnosis, rendering it potentially incurable.

The two major types of IBD are Crohn's disease and ulcerative colitis and there are up to 300,000 sufferers in the UK. It is a chronic inflammatory condition for which there is currently no medical or surgical cure. IBD is primarily a disease found in young people with most cases being diagnosed when the patient is between 10-and-35 years, and the disease is becoming more common, particularly targeting adolescents. (3) Scientists don't know if this is due to diet, lifestyle or pollution.

## WHY DOES AWARENESS AND SUBSEQUENT DETECTION REMAIN SUCH A MAJOR CONCERN IN SOCIETY?

Research shows that early diagnosis saves lives which is why raising awareness of symptoms and encouraging GP visits are so important. Qualitative studies suggest that stigma can discourage people from attending cancer screening. (4) There is significant reluctance and embarrassment when talking about bowel 'issues'. Social taboos often put bowel patients off visiting their GP and chronic and terminal diseases often present too late. This is of particular concern in the case of bowel cancer where patients who are diagnosed late have a poor prognosis compared to those that present early.

## CAN YOU TELL US ABOUT THE ORIGINS OF BOWEL RESEARCH UK AND THE MOTIVATION BEHIND ITS ESTABLISHMENT?

Bowel Research UK was founded in 2020 following a merger between two well-respected charities – Bowel Disease Research Foundation and Bowel & Cancer Research. Together the two charities have over 50 years' worth of experience in helping to fund cutting-edge research, helping to make enormous progress in the fight against bowel



cancer and other bowel diseases. By focusing resources and expertise, we will be able to fund more research and ultimately impact more lives.

In the UK, bowel cancer and other bowel diseases require much more funding, particularly as these conditions can affect anybody; one-in-15 men and one-in-18 women will suffer from bowel cancer during their lifetime. We believe that a cure for bowel cancer and effective treatments to mitigate, or entirely eradicate, other bowel diseases remains possible – but only if we continue to fund leading research and invest in our scientific and medical communities.

In addition to research funding, we aim to raise the profile of bowel cancer and other bowel diseases in the UK. Embarrassment can cost lives and we believe that the unnecessary stigma around the bowel must be overcome in order to make progress.

## HOW DID YOU GET INVOLVED WITH THE CHARITY AND WHAT HAS BEEN YOUR FOCUS?

I have had IBD for approximately 30 years and then, following a diagnosis of early-stage bowel cancer, I had an ileostomy in 2016. I had worked in the higher education sector for 25 years and have a strong understanding of research. I wanted to give back to the professions that had given so much to me, so I joined Bowel & Cancer Research in 2018 to connect patients to researchers and researchers to patients. I have felt truly humbled in meeting so many amazing people willing to give so much of their time to improve the lives and wellbeing of those suffering from bowel disease.

As the Director of Research and PPIE (Patient and Public Involvement and Engagement) at Bowel Research UK, I play a key role in developing and delivering the charity's research strategy and driving the research agenda. This includes identifying research priorities, the research grant and PhD programmes, facilitating and overseeing partnerships, promoting patient and public involvement on a wide range of research activities, and the dissemination of research outcomes.

This year I have been heavily involved in CovidSurg, an international collaboration that was established to understand the outcomes of COVID-19-infected patients who undergo surgery. Covering 88 countries, 1,032 centres, and over 52,300 patients, CovidSurg has already influenced World Health Organisation guidelines and is informing the management of patients across the globe during the COVID-19 pandemic.

## WHAT PRIORITIES NEED TO BE AT THE FOREFRONT OF THE BOWEL RESEARCH AGENDA?

Bowel Research UK has set out a clear list of priority areas to ensure that we effectively drive the bowel research agenda. Firstly, we need to encourage society to become more aware of, and to support, bowel disease research. We must ensure that we are offering up-to-date, accurate and accessible information on our research programme – including priorities, outcomes and impact – tailored to the needs of people affected by bowel diseases. This is a crucial step towards making research more user-friendly and ultimately more patient-centred. Embedding patient involvement and public engagement in developing our research and funding decisions is also a priority to ensure that research delivers on both clinical and patient needs. Additionally, we must ensure that we are supporting the scientists of tomorrow by

funding the next generation of research 'rising stars' today. With this, we can help to drive change as a result of our endeavours, and campaign for further investment in research.

## WHEN IT COMES TO BOWEL DISEASES, HOW CAN HEALTHCARE PROFESSIONALS INCREASE THEIR MOMENTUM AND IMPACT IN SHAPING PATIENT CARE?

The mental and physical impact of bowel cancer and other bowel diseases on patients is often unimaginable and the best treatment option frequently changes from patient-to-patient. Patient-centred research is essential to improving the experience of people living with bowel cancer and bowel disease. Bowel Research UK is uniquely connected with patients, industry and researchers.

Healthcare professionals can enhance patient care through proactively working with patients on co-produced research to identify what patients regard as important. This includes listening to, informing and involving patients and focusing on saving as well as improving patients' lives.

## LOOKING AHEAD, WHAT WOULD YOU LIKE THE FUTURE TO HOLD FOR THE CHARITY AND BOWEL RESEARCH MORE WIDELY?

We want to eradicate bowel disease through researching cutting-edge treatments and investing in the best science. By pushing boundaries for health solutions and innovative models that connect care across the continuum and the lifespan, we aim to help educate and fund future research that might lead to a cure tomorrow.

We believe, however, that research into bowel cancer and other bowel diseases is heavily underfunded when compared with other conditions. We would like to see more funding and it is our duty to help spread the word and let people know that by funding research – together – we can save and improve thousands of lives.

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

# Rethinking Pharmacy

## The Cambrian Alliance Group Launches New Platform to Enable Pharmacies To Buy and Sell Stock From Each Other

The Cambrian Alliance Group today announces the launch of e-CASS market, a new platform designed to enable pharmacy contractors to buy and sell stock from each other with ease. The new platform will transform the way that contractors manage their surplus stock and also provide a vital new channel for contractors to source stock that may be in short supply via traditional methods. e-CASS is already the most widely used buying platform across independent pharmacy and this new additional platform continues to strengthen the Cambrian Alliance Group offer.

What is commonly referred to as 'dead stock' costs the average pharmacy approximately £12K per year, a significant cost at a time when independent pharmacy has never been under more pressure to maintain margin. e-CASS market will allow contractors to list stock and make it available to buy to a chosen and specified group of buyers or to the entire Cambrian Alliance Group membership of 1200. Following on from the success of e-CASS web which launched last year, the platform is easy to use, designed with contractor feedback in mind and meets with the usual high standards and reliability that the group have become known for.

**Nathan Wiltshire, Group CEO said** "We are really pleased to be able to bring yet another new product to the independent pharmacy market. When we first launched e-CASS some 10 years ago, it revolutionised the way that pharmacy thought about purchasing and delivered immediate benefits to our user community, we believe that e-CASS market will have a similar impact".

The new platform includes an industry first 'market match' feature available to buyers, which matches all available stock in the market to buyers specific requirements based upon their most recent product usages. The platform also ensures that buyers get notified every time relevant stock becomes available.

Use of the platform meets with current MHRA guidance with regards to the implications of the repeal of Section 10(7) for the supply of licensed medicines by pharmacy in that transactions are on a small and occasional basis and not for profit.

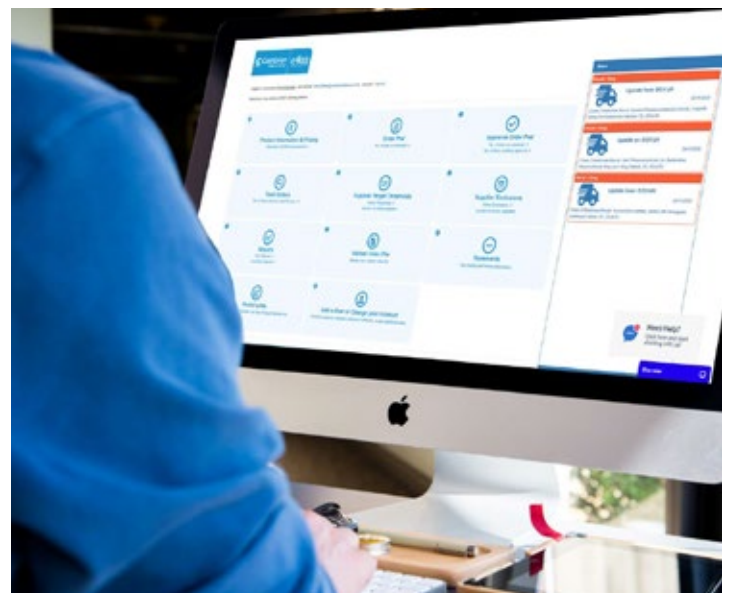
"The new platform gives contractors a vital alternative to supply at a time when product shortages and availability have never been more prevalent. In addition, we are pleased to be able to provide the market with a new tool that really enables contractors to help and support each other at such a challenging time". **Said Wiltshire.**

**Editor's Note:** For more information please contact Tom Griffiths at [TomGriffiths@cambrianalliance.co.uk](mailto:TomGriffiths@cambrianalliance.co.uk) or 02920 782 957.

### About Cambrian Alliance Group

Cambrian Alliance Group is the leading independent pharmacy buying group with over 1200 members across the UK. The group supports its members in achieving better purchasing margins by leveraging the buying power of its collective membership, which now exceeds £0.6Bn annually.

The group also develops technologies to support more efficient purchasing and stock management within independent pharmacy including e-CASS, e-CASS web, and e-CASS warehouse.





# Introducing e-CASS Market

from The Cambrian Alliance Group



- ✔ e-CASS Market offers independent pharmacies the ability to trade stock with each other
- ✔ Use our unique Market Match feature to find stock available within our e-CASS Market community based upon your usages
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**Saving you more time,  
and more money.**

NEWS

## RESEARCH TO EXPLORE HOW COVID-19 DAMAGES BLOOD VESSELS

Queen’s University Belfast has been awarded a grant from Science Foundation Ireland and the Northern Ireland Department for the Economy to research how COVID-19 damages blood vessels.

The research project is led by Professor Alan Stitt, from Queen’s University Belfast, and Dr Roger Preston, from The Royal College of Surgeons in Ireland.

COVID-19 is thought of as a disease of the lungs, but it can also damage blood vessels elsewhere in the body, including in the brain and retina, causing serious damage, leading to stroke and vision loss. This new study will look into how and why this damage is caused by examining what happens to endothelial cells (that normally line blood vessels) when they are infected with the coronavirus.

The research will examine how differences in endothelial cell-types from different blood vessels could affect how they respond to COVID-19. With a particular emphasis on how vessels in the brain and retina become prone to inflammation and promoting blood clots, the study will help to inform treatment strategies to protect blood vessels from COVID-19, and thereby help to avoid serious symptoms, particularly in the brain and retina.

Professor Alan Stitt, lead researcher on the study, and Dean of Innovation and Impact within the Faculty of Medicine, Health and Life Sciences at Queen’s University Belfast, commented, ‘This project seeks to decipher the molecular mechanisms that underpin vascular damage in the brain and retina, with a particular focus on the clotting system in these fragile vessels. This research will seek to understand why the brain and retina are susceptible to vascular damage in some COVID-19 patients and identify novel therapeutic pathways that can protect against stroke and ischaemic retinopathies.’



## CALL FOR NEW ALL-ISLAND CANCER RESEARCH INSTITUTE



Leading Northern Ireland cancer specialist, Professor Mark Lawler, has called for an All-Island Cancer Research Institute which he said would yield far-reaching benefits for the population.

Speaking at an online meeting of Stormont’s All-Party Group on Cancer, Professor Lawler said that now was the time to change the way we approach cancer.

A new institute would build on the work of the All-Island Cancer Consortium over the last 20 years and would drive better outcomes and care for patients in the future. Cancer is now the biggest killer on the island of Ireland and the COVID-19 pandemic has had a disastrous impact on cancer patients and services.

Professor Lawler explained, ‘We are calling for an All-Ireland Cancer Research Institute with a multidisciplinary, multi-sectoral composition, bringing together the best minds on the island working collaboratively to improve the outcome for cancer patients and the health of the general public. The patient will be at the very heart of our work. We need to compete, not against each other, but against our common enemy – cancer.’

‘Not only would an all-island approach benefit patients by improving access to innovative medicines and diagnostics, it will also help to enhance healthcare systems benefitting policymakers and the clinical community, increase cancer research activity and accelerate innovation and new product development, contribute to increased prosperity and entrepreneurship across the island. The benefits would be far-reaching. There is no time to waste.’

## FUNDING APPROVED FOR NEW PERINATAL MENTAL HEALTH DELIVERY MODEL

Health Minister Robin Swann has approved funding for the development of new specialist perinatal mental health services for the region.

The Health Minister said, ‘I am delighted to announce the approved funding to establish a new specialist perinatal mental health community service model for Northern Ireland.’

At present, mental health support for new or expectant mothers is provided in the community through general mental health services, with only the Belfast Health & Social Care Trust providing limited specialist perinatal mental health services for the region.

This new service will provide new multidisciplinary community perinatal mental health teams in each of the five Health & Social Care Trusts and will include a new stepped care model to ensure regional consistency. Perinatal mental health community teams will provide wrap-around maternity and mental healthcare to women in the perinatal period experiencing mental health difficulties.

The cost of the new specialist perinatal mental health services is estimated at £4.7 million per year. The psychological impact of the COVID-19 pandemic shouldn’t be underestimated in that women in the perinatal period are particularly vulnerable, not least due to the uncertainty that the virus poses for the health of both them and their infant. As a result, investment in this important mental health service is much-needed and welcomed.

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\*The 2'-FL (2'-fucosyllactose) used in this formula is biosynthesised and structurally identical to the human milk oligosaccharide (HMO) 2'-FL, found in most mothers' breast milk.<sup>1</sup>

†MIMS, September 2020.

‡Studies conducted in healthy-term infants consuming standard Similac formula with 2'-FL (not EleCare), compared to control formula without 2'-FL.

§Studies conducted in infants fed standard EleCare formula without 2'-FL.

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BRITISH DIETETIC ASSOCIATION

# A FORCE TO BE RECKONED WITH

In their first column of 2021, the British Dietetic Association provide an insight into the impact of a Prescribing Support Dietetic Team – working across divisions – in the effective and appropriate prescribing of oral nutritional supplements within primary care.



## THE TEAM

Elizabeth Armstrong, Kathryn Duff, Fiona Hegarty, Sarah Murphy, Marie-Claire Kane (team lead) and Aideen O'Hagan (prescribing support dietitians), David Cairns, Margretta McCully, Emma McPeake, Shelley Hinds and Ursula Quinn (prescribing support assistants), Northern Health & Social Care Trust.

## WHAT DOES IT MEAN TO BE PART OF A PRESCRIBING SUPPORT DIETETIC TEAM?

The collective of dietitians and prescribing support assistant staff came together in the summer of 2017, placed regionally across Northern Ireland under the management of one Health & Social Care Trust. The aim and ethos of the team is to promote the safe and effective prescribing of oral nutritional supplements, underpinned by providing patient-centred care in the management of malnutrition.

The population of Northern Ireland is currently 1.8 million, with 336 GP practices across the country. The Prescribing Support Dietetic Team deliver services into each of the areas highlighted on the map. As a regional team this unique nature allows for the promotion of regional guidelines and strategies, such as the Promoting Good Nutrition Strategy, in addition to the Northern Ireland formulary.

Strong multi-professional working has been an essential element from the outset for the team. Close working with key stakeholders; GPs, pharmacy and dietetic colleagues, AHPs and members of the voluntary sectors, to mention a few, have been paramount.

Each day, it is estimated that over one million people within the population will be cared for by their GP surgery. The number of people aged 85 years and over in Northern Ireland has grown 900 per annum throughout the decade ending mid-2016, with rate of growth among this age group almost six times that of those under 85 years of age. (Northern Ireland Statistics and Research Agency, 2016) With this in mind, and the cost of oral nutrition now double that of which is spent among counterparts across the UK, the team have been well-placed to address prescribing patterns and promote medicine optimisation across Northern Ireland.

The annual spend on oral nutritional supplements in Northern Ireland from March 2018-to-March 2019 totalled £7,864,515. It was proposed that

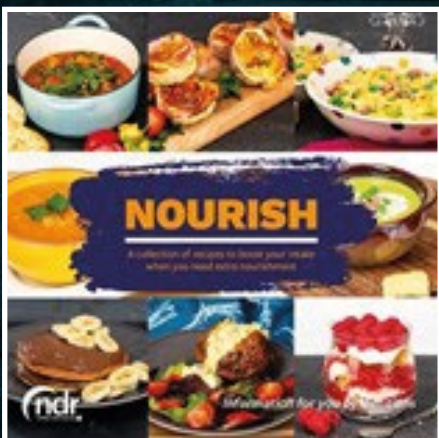
## BRITISH DIETETIC ASSOCIATION

the nutritional spend in primary care could be reduced with appropriate dietetic intervention. The team optimise a food-first approach in the management of malnutrition, ensuring that prescriptions of supplements are appropriate and cost-effective.

Over the period March 2018-to-March 2019 a total of 65 GP practices have had interventions commenced or completed with 1,205 patients offered a dietetic appointment. Following assessments prescribing support dietitians recommended 66 per cent prescriptions of oral nutritional supplements were discontinued / amended to a more appropriate choice or volume with estimated total efficiencies of £535,333 over the 12-month period.

Over the past three years patient-centred care has been at the forefront of the Prescribing Support Dietetic Team's working. The team have set out and identified innovative ways of working and explored avenues in which practical advice can be brought to the attention of all of those involved in the care and management of patients at risk of malnutrition.

## MAKING A DIFFERENCE IN NORTHERN IRELAND AND BEYOND



Since the development of the team, a number of opportunities have arisen to become involved in work that would make a real difference to not only residents of Northern Ireland, but those living across the UK and further afield.

In November 2018, the team commenced working with National Diet Resource UK (NDR-UK), the not-for-profit provider of nutrition and diet resources, to support production of a patient-centred care resource.

As prescribing support dietitians working regionally across Northern Ireland, NDR-UK considered the team well-placed to collaboratively work on the publication of a recipe book to support clients suffering with poor appetite and unintentional weight loss. The content of the publication displays over 30 recipes, encompassing a collection of high calorie and high protein snacks, light meals, main meals, nourishing drinks and puddings. The involvement of client engagement and decision-making was of fundamental importance in the development of the resource.

The team arranged a 'tasting morning' with 60 older adults in conjunction with Age NI (a leading charity for older people in Northern Ireland) to gain feedback for proposed recipes to be included. The publication of Nourish for the team truly was 'a Flourishing Partnership for Nourishing Care'.

*Further information can be found in relation to the publication and how to purchase:*

- [www.ndr-uk.org/news/a-flourishing-partnership-for-nourishing-care](http://www.ndr-uk.org/news/a-flourishing-partnership-for-nourishing-care)
- [www.ndr-uk.org/item/258/FoodFortification/Nourish.html](http://www.ndr-uk.org/item/258/FoodFortification/Nourish.html)



## PROMOTING GOOD NUTRITION

A new digital online learning resource has been developed to support social care workers and, in particular, care at home / domiciliary staff, to understand what good nutrition is and to help them recognise and support individuals that may be at risk of malnutrition.

The resource was developed by the Northern Ireland Social Care Council in partnership



with; the Prescribing Support Dietetic Team, social care employers (Belfast Health & Social Care Trust, Northern Health & Social Care Trust, and South Eastern Health & Social Care Trust) and the Northern Health & Social Care Trust Dysphagia Support Team. The resource supports the Northern Ireland Department of Health Promoting Good Nutrition Strategy. Social care workers play a very important role as they may be the first person to notice when a person is not getting all the food they need to stay healthy. This resource provides 'bite-size chunks' of key information on a nutritious diet, recognising signs of malnutrition, food first advice, diet and dementia with interactive quizzes and reflective learning activities. It includes dietary and video resources to support individuals at risk of malnutrition. In addition, there is information about recognising when there may be a swallowing problem (dysphagia) and what action to take.

The learning module can be accessed from a smart phone, tablet, desktop computer or laptop with internet access. It is freely available to anyone via the Northern Ireland Social Care Council's Learning Zone: [www.learningzone.nisc.info/learning-resources/90/promoting-good-nutrition](http://www.learningzone.nisc.info/learning-resources/90/promoting-good-nutrition).



22<sup>ND</sup> NORTHERN IRELAND  
HEALTHCARE AWARDS

# COMING SOON

Keep an eye out for  
the next edition of  
NIHR which will reveal  
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## PANCREATIC CANCER

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# TURNING THE TIDE

**How can we tackle the burden of Europe's deadliest cancer? Leading pancreatic cancer experts, Professor Matthias Löhr and Professor Monique van Leerdam, both members of United European Gastroenterology's Public Affairs Committee, discuss the importance of early diagnosis and the latest developments in treatment.**

Pancreatic cancer has the lowest rate of survival among all cancers across Europe.<sup>1</sup> In the EU alone, it is responsible for over 95,000 deaths every year<sup>2</sup> and life-expectancy at the time of diagnosis is less than five months.<sup>3</sup> Recent estimates have indicated that the number of pan-European deaths caused by pancreatic cancer overtook breast cancer fatalities in 2017, placing the condition as the third leading cause of cancer-related deaths.<sup>2</sup> There have been few advancements in patient outcomes over the last four decades, with mortality rates having seen no improvement and just three per cent of patients diagnosed with pancreatic cancer surviving beyond five years.<sup>4</sup>

### **EXPERT VIEW: PROFESSOR MATTHIAS LÖHR**

'One of the biggest challenges concerning pancreatic cancer is awareness. Understanding of the condition, including its symptoms which are notoriously difficult to identify, is alarmingly low. This, combined with the severity of pancreatic cancer, means that most patients have little or no hope of long-term survival at the point of diagnosis.

'Perhaps the most significant consequence of poor awareness around pancreatic cancer is that it prevents early detection of the disease, particularly among those at highest risk. Early diagnosis is crucial to delivering improved patient outcomes in all cancers, but particularly so in pancreatic cancer given the cripplingly low survival rates.

'It is estimated that two-thirds of the major risk factors associated with pancreatic cancer could be modifiable, providing an opportunity for preventing the disease.<sup>5</sup> However, to convert this into reality, rather than potential, we need to drive awareness of pancreatic cancer so that people know what to look out for.

'The risk factors associated with pancreatic cancer include smoking, chronic pancreatitis, diabetes, obesity, and a family history of the condition, while incidence rates increase with age. Smoking is related to 20 per cent of all pancreatic cancer cases and causes a 75 per cent increase in the risk of pancreatic cancer when compared with non-smokers.<sup>6</sup> Obese patients are found to have a 47 per cent higher risk of pancreatic cancer as opposed to patients with a healthy BMI.<sup>7</sup> Having a parent, sibling or child with pancreatic cancer makes the risk of being diagnosed with the condition two-to-three times higher,<sup>8</sup> and it is believed that up to 10 per cent of cases are linked to genetic conditions.<sup>9</sup>

'The symptoms of the disease include jaundice, nausea, a change in bowel habits, abdominal and back pain, and unexplained weight loss. Crucially, these are all non-specific which compounds the issue around a lack of awareness and demonstrates why education on pancreatic cancer needs to improve.

'Research has shown that pancreatic cancer can be present in the body for many years before patients fall ill or display symptoms.<sup>10</sup> The condition is therefore often asymptomatic, and in those cases where symptoms are detected, it is typically at an advanced stage and too late to treat successfully. Problematically, this means that a critical opportunity for early detection is often missed. This complexity explains the main reason for slow progress in improving pancreatic cancer mortality rates.

'Improvements in outcomes for pancreatic cancer patients have stalled over the past 40 years, which can be starkly contrasted to the survival rates seen with other types of cancer. This is partly down to the difficulties in detecting the disease, but is also down to a lack of targeted initiatives devoted to pancreatic cancer and the fact that only select countries have deployed registries to collect data on pancreatic cancer.

'Limited funding for research into pancreatic cancer has also contributed to patient outcomes not improving further. While the number of deaths from pancreatic cancer has almost doubled

# PANCREATIC CANCER

in the past three decades, European funding for the disease only accounts for two per cent of the total for all cancers.<sup>1</sup> Forecasts predict that there is no sign of this situation improving with the number of cases and deaths from the condition both estimated to increase by 40 per cent by 2035.<sup>11</sup> It is therefore essential that more funding is delivered for research into pancreatic cancer.

‘While the burden currently posed by pancreatic cancer is severe, it is currently not feasible to implement population-based screening for the disease, placing an emphasis on the need for new treatment options.’

## EXPERT VIEW: PROFESSOR MONIQUE VAN LEERDAM

‘New and improved treatments will be key to securing improved outcomes for pancreatic cancer patients moving forward. To help this process, it is important to maximise what is known about the different subgroups of pancreatic cancer patients, particularly which groups are benefitting most from what treatment, as this helps to inform treatment pathways and maximise positive outcomes for patients.’

‘Pancreatic cancer occurs when malignant cells begin to form and multiply in the tissues of the pancreas, which is an organ found behind the stomach. It is increasingly being recognised as a systemic disease made up of micro-metastases when diagnosed. Consequently, a combination of treatments rather than just resection – known as multimodality therapy – is now seen as the first-choice treatment. Within this, neoadjuvant therapy, which serves to shrink tumours as a first step prior to surgery, is now preferred as it can be used to treat the disease earlier. By reducing the size of the tumour, clearer resection can be achieved, helping to improve patient outcomes. However, this therapy is still in urgent need of more funding to help improve the precision of staging tools, confirm the correct treatment schedule and reduce toxicity. Only then can the impact of neoadjuvant therapy be maximised.’

‘It is also important that we enable the centralisation of care for pancreatic cancer patients moving forward. In Finland, for instance, a law is in place that ensures that pancreatic cancer patients only receive treatment at five specialised hospitals as part of a strategy to centralise care.<sup>1</sup> This is a promising step in the right direction but needs to be replicated across Europe if we are to achieve optimal patient care.’

‘Where research has been commissioned for pancreatic cancer it has yielded important developments. One study has shown that removing bacteria from the gut and pancreas has slowed cancer growth and reprogrammed immune cells to react against cancer cells.<sup>12</sup> These findings are significant and could be practice-changing as the removal of certain bacterial species could enhance the efficacy of chemotherapy or immunotherapy. This means there is the potential for increasing patients’ good bacteria in order to slow tumour growth or decrease pancreatic cancer risk. Another study revealed that serum MIC-1 levels may present a new diagnostic biomarker for the early detection of pancreatic cancer.<sup>13</sup> Lastly, research into imaging has shown that diagnosis could also be improved using positron emission tomography techniques where computed tomography and endoscopic ultrasound are not completely diagnostic.<sup>14</sup>

‘The development of imaging has become increasingly

important, not just for the diagnosis of pancreatic cancer, but also for achieving the best treatment and management decisions. While multidetector computed tomography is the current imaging tool of choice for pancreatic cancer assessment, ultrasonography, endoscopic ultrasound, contrast-enhanced ultrasound, and MRI with MRCP can help compliment this with more detailed information. This multimodality approach has seen considerable improvements in recent times, but each imaging tool has its own purpose, advantages and disadvantages across the diagnosis, treatment and management of pancreatic cancer. Again, it is paramount that more dedicated funding is provided so that clinicians are given the means to effectively evaluate the available pancreatic imaging modalities and apply the relevant options as required.’

‘Ultimately, if we are to comprehensively address the pancreatic cancer burden facing Europe, we need to drive more funding, defined strategies and treatment innovation for the condition. The lack of improvement in patient outcomes over the last four decades can’t be ignored and we must act now.’

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## COW'S MILK ALLERGY

# TAKING CARE

Claire Dobbs, a Community Pharmacist in Belfast, shares with NIHR her experience assisting and supporting patients with cow's milk allergy and the crucial role played by the profession during this turbulent time.

### HOW PREVALENT IS COW'S MILK ALLERGY (CMA) WITHIN YOUR PATIENT COMMUNITY?

CMA has become increasingly prevalent in the local community. It is one of the most common food allergies, even more so than peanut allergy, in infants. Most children grow out of it by around five years of age but it can be a very challenging condition to both diagnose and manage for both the infant and parents.

### IS IT DIFFICULT TO RECOGNISE THE SIGNS OF CMA WITHIN YOUR PATIENT COMMUNITY?

CMA can be delayed (Non-IgE-mediated) or acute (IgE-mediated). The most common being a delayed onset of symptoms, occurring within a few hours up to a few days after having food containing cow's milk. An acute allergy can see symptoms develop immediately after having cow's milk.

The immediate allergy is easier to diagnose, with symptoms such as itchy skin rashes, hives, swelling of the eyes and lips. Allergy testing can be undertaken to confirm the diagnosis.

Delayed CMA can prove more challenging to diagnose as the clinical manifestations are variable in type and severity and there are no skin or blood tests

for delayed onset CMA.

Symptoms typically include vomiting, loose stools, abdominal pain, food refusal / aversion, blood or mucus in the stools or constipation. Eczema and sometimes airway / nasal symptoms are also present.

In a community pharmacy setting it can be difficult to diagnose CMA as the symptoms experienced are common presentations that may not usually be attributed to this condition.

### WHAT DIFFICULTIES HAVE YOU FACED WHEN TREATING INFANTS WITH CMA, BOTH IN TERMS OF PATIENT CARE AND ALSO LOGISTICALLY WITH ORDERS ETC?

In the pharmacy setting the difficulties faced are ensuring the most suitable prescribed infant formula is obtained in a timely manner for the patient. An appropriate hypoallergenic formula will be prescribed for the child by their GP or paediatric dietitian using the Northern Ireland HSCB Infant Feeding Guidelines but often this involves trial and error to find the most suitable preparation for the child. Parents can find it frustrating when a newly-prescribed infant formula does not appear to ease the symptoms.

As a community pharmacist it is important to reassure parents that there are several alternative milk substitutes available on the market. We can advise other healthcare professionals as to what products are available and indeed what formulas are in stock with the wholesalers at the time.

Some specialist infant formulas are only stocked by one specific wholesaler so it is essential we have access to these products for a same day / next day delivery for the patient.

### DO YOU BELIEVE THERE IS CURRENTLY ENOUGH TRAINING AND INFORMATION AVAILABLE FOR COMMUNITY PHARMACISTS SURROUNDING CMA?

Most community pharmacists will encounter children with CMA in the pharmacy setting. While it may not be a condition that some pharmacists are confident in

dealing with there are resources available to help pharmacists expand their knowledge on the subject. The specialist infant formula companies offer training packs for community pharmacists and the HSCB Infant Feeding Guidelines is an excellent resource.

### HAS THE COVID-19 PANDEMIC IMPACTED ON THE CARE OF THESE PATIENTS AND, IF SO, HOW WERE YOU ABLE TO OVERCOME THESE CHALLENGES?

Community pharmacies have shown resilience during this pandemic and have managed to overcome many obstacles.

Patients have greatly relied on the advice of community pharmacists for conditions such as CMA during the pandemic as we have remained accessible and continued to provide the majority of our services as normal. Parents concerned about their infant's feeding, on occasions, have resorted to telephone consultations with a pharmacist during lockdown.

Ensuring the pharmacy has adequate stock of specific specialised infant formula is essential to ensure a safe, efficient service. Also, the collection of prescriptions by pharmacy delivery drivers from GP surgeries has meant that patients still receive their medication within an appropriate time frame without having to go to the GP surgery.

### WHAT ADVICE WOULD YOU GIVE THE PARENTS OF A NEWLY-DIAGNOSED INFANT?

I would assure parents that there are no associated long-term complications with CMA and that most children with delayed onset CMA will be milk tolerant by three years of age and for acute CMA by five years of age.

If a specialised infant formula does not ease symptoms there are alternatives that the dietitian or GP can prescribe.

When reintroducing cow's milk this should be done using the milk ladder but it is advisable to do this under the supervision of a healthcare professional. And, as always, community pharmacists are available and accessible to offer advice and support.

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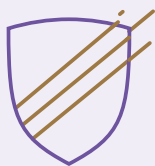
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†MIMS, August 2020.

‡Studies conducted in healthy-term infants consuming standard Similac formula with 2'-FL (not Alimentum), compared to control formula without 2'-FL.

§Studies conducted in infants fed standard Alimentum formula without 2'-FL.

¶Parent reports from a single-arm study, where all infants were consuming an extensively hydrolysed formula before being switched to Alimentum with 2'-FL for 60 days. After 7 days of switching to Alimentum with 2'-FL, the majority of parents reported that the following persisting symptoms had improved or resolved: 84% of infants with constipation, 71% of infants with eczema, 100% of infants with vomiting.<sup>7</sup>

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COVID-19

# A NEW NORMAL

Last year, as COVID-19's clutch tightened with every passing day, the world was catapulted into a state of uncertainty. In this issue of NIHR, experience the pandemic through the lens of a student as 17-year-old Beth Wilson reflects on how the crisis disrupted her daily routine, and what has helped her to manage the unknown.



Beth Wilson

## EARLY UNCERTAINTY

For most teenagers, COVID didn't start as something serious. I remember sitting in the classroom, when one of my friends began going on and on about this new illness all the way in China – the rest of us simply rolled our eyes! In another of my classes, one of my friends had a mask and it was pretty much a joke. Multiple people were trying it on! Clearly, things have changed.

It wasn't until it was suspected that some students in my school had it, and news of other schools shutting down occurred, that people really started to worry. Suddenly we couldn't be sure of anything. Would more people be infected? Would our exams still go ahead? So many of us had worked so hard on projects and notes for our GCSEs. A lot of people had not been putting as much effort into classwork, hoping to pull an all-nighter before the actual exam. Suddenly nothing was certain.

On our last day of school – we were just about to go off for St Patrick's Day – I was sitting in the music room and overheard some students in the year above saying we probably wouldn't be back to school for a long time. They were right. From that day on we were off school. Exams were cancelled, the formal was cancelled, and no-one knew what was going to happen next.

## MAKING ADJUSTMENTS

We were all impacted by the new restrictions. For me, all of my activities outside of school were shut down. My music lessons were conducted over Zoom; I could no longer volunteer with the girl guiding group, Rainbows; and I was unable to attend my drama classes. In school, people had talked about how this summer would be the best ever; how we would feel so relieved after GCSEs; and how we would do so many things – and then restrictions hit.

I imagine quite a few students wanted to believe that the situation would have ended by the summer, but of course it was not to be. While a few restrictions lifted, summer was still quite an isolating time. Our exams were cancelled, and we had little work to do. Most of our time was likely spent stressing over what our predicted grades would be. Would we even have our predicted grades? Would our grades be based off which school we went to? We had no control, we just had to hope for the best.

## THE MENTAL HEALTH FACTOR

The emotional impact of COVID was very great for so many teenagers. Upper Sixth didn't have a chance to say goodbye to their year, and we had to rely on social media more than ever.

For me, personally, I enjoyed the time to myself, but I felt lonely often too. Teenagers are used to seeing friends and talking to them everyday – but now there was just online, and if you didn't have someone in your contacts, you didn't talk to them. Even then, people didn't have much to talk about since no-one could go out. Mental health is already a massive issue for teenagers. Stress from school, our social lives, looking to the future, and now we had no idea how long this would be going on for or what school would be like when we went back.

## ONE THING AT A TIME

I, as well as many other teenagers, took up new hobbies with this time. One of my friends began knitting. I personally took up baking and rediscovered my love of drawing and writing. This really helped to pass the time and keep my mind engaged.

Another thing I found helpful was keeping a routine. By getting up at a certain time, having lunch at a certain time, and going to bed around a certain time, I was able to give the day structure. I know that if I didn't have that I probably would have been bored a lot more.

Another thing I did was catch up on reading. With school work I'd had so many books on my bookshelf that I'd never so much as read the first page of. Over lockdown I decided I'd read as many books as I could, often aiming for 100 pages a day. I also listened to more audio books and tried to exercise more. I tried as hard as I could to turn the experience into something positive, so I could look back and feel confident that I didn't waste the time.

I think a lot of teenagers in today's society are pessimistic. All we're ever seeing is what a terrible state the world is in, and then making jokes about it, and this virus is no exception. Exams have just been announced as cancelled and classes are going forward online. This hit particularly hard as many students were just getting used to being back at school and now, we're back in lockdown. Many teenagers are simply trying to learn to take things one at a time.

# A SHOW OF SUPPORT

We all know that malnutrition is both a key culprit and consequence of declining healthcare – but the implications it drives for cancer patients may be more intricate than widely believed. BAPEN highlights the importance of managing malnutrition risk for people living with cancer.

Malnutrition is a serious health problem, with more than three million people across the UK either malnourished or at risk of becoming malnourished. While anyone can be at risk of malnutrition, particular groups and demographics are at greater risk. This includes people with chronic progressive conditions, such as cancer.

The impact of cancer treatment, together with the local effects of a tumour, unintentional weight loss, pain, changes in appetite, and other potential side-effects of therapies, all add to the risk of decline in the nutritional wellbeing of cancer patients.

Furthermore, cancer patients often must spend significant periods of time in hospital and we know that 70 per cent of patients weigh less when they are discharged from hospital than when they were admitted. <sup>(1)</sup> Patients with some cancer types may be more likely to require tube feeding, such as head and neck cancer. Many centres do have bolt-on services for patients with specific cancers, and patients with pancreatic cancer can have automatic referral to nutrition services. Generally, however, all healthcare professionals must be aware of additional nutritional risks to cancer patients, and focused on what can be done to support patients, identify risk early, and secure support where needed.

Malnutrition can have a devastating impact on

somebody's health and wellbeing. Malnutrition affects every system in the body and results in increased vulnerability to illness, with impairment of immune function, performance status, and muscle function. It is also associated with debilitating morbidities, such as depression and fatigue. <sup>(2)</sup> The major consequence of progressive weight loss and decline in nutritional status in cancer patients is reduced survival, as responses to chemotherapy are decreased while complications are more likely and more acute. <sup>(2)</sup>

## THE IMPORTANCE OF SCREENING

Screening for malnutrition risk is vital for cancer patients. BAPEN's Malnutrition Universal Screening Tool ('MUST') is the most commonly-used nutrition screening tool in the UK.

'MUST' is widely validated in both hospital and community settings, and by governmental and non-governmental organisations, including NICE. 'MUST' has been designed to identify adults who are underweight and at risk of malnutrition, as well as those who are obese. Early nutritional screening can help overcome the dangers of malnutrition in cancer patients and offer some indication of how the patient's body may react to cancer

# MALNUTRITION

therapy.

The 'MUST' calculator establishes nutritional risk using either objective measurements to obtain a score and a risk category, or subjective criteria to estimate a risk category. In cancer patients who are pre-treatment, the interpretation of acute disease score is relevant to predict future risk of malnutrition as they may not have weight loss, low BMI or lack of intake.

The results of 'MUST' should be used to form the foundation of an individualised nutritional care programme, which at-risk patients ought to have access to. This could take the form of dietary advice and signposting to fortification resources, or intervention with oral nutritional supplements that may improve the quality of life of the patient.

Screening plays a vital role in preoperative rehabilitation, and many healthcare professionals and organisations, such as Macmillan Cancer Support, advocate that prehab should be incorporated into routine cancer care. <sup>(5)</sup> 'MUST' is therefore also effective as a form of early intervention for all, and not just those at risk of malnutrition.

'MUST' is available to download for free from BAPEN's website, along with practical guidance on how healthcare professionals can continue to screen using 'MUST' during the pandemic, which can be found in the 'Useful Resources' section later on.

BAPEN has a self-screening tool which patients and carers can use to check their weight and to see if they are at risk of becoming malnourished, to help support in pre-treatment and during the recovery and rehabilitation phase.

With health and social care sectors under exceptional amounts of pressure from the pandemic and the subsequent devastating disruption of cancer services, it is more important than ever to raise awareness of the risks of malnutrition and of how healthcare professionals can ensure their patients still receive good nutritional care including nutrition education. Unfortunately, neglecting nutrition can have a devastating impact, not just on the individual concerned, but also on the health and care system because of the need for management of the consequences.

If you are interested in learning more about nutritional care of cancer patients, BAPEN hosted a webinar series as part of their Annual Conference in November last year. This series included a webinar focused on achieving lasting change in the nutritional care of cancer patients, which is available to watch on-demand on their website. In particular, the webinar explores new evidence emerging on the identification and management of sarcopenia and cachexia in cancer patients. The overwhelming message that was consistently emphasised, was that nutrition should become an integral component of cancer care.

*If you are particularly interested in lung cancer, we recommend a visit to The Malnutrition Pathway resource: A Practical Guide for Lung Cancer Nutritional Care, available at [www.lungcancernutrition.com](http://www.lungcancernutrition.com).*

## REFERENCES

1. <https://www.bapen.org.uk/malnutrition-undernutrition/introduction-to-malnutrition?start=1> Last accessed January 2021.
2. Van Cutsem E, Arends J., 'The causes and consequences of cancer-associated malnutrition.' European Journal of Oncology Nursing 2005 vol.9:S51-S63. Supplement 2:S51-63.
3. Macmillan Cancer Support. Principles and guidance for prehabilitation within the management and support of people with cancer. 20 November 2020.

## USEFUL RESOURCES

- 'MUST' <https://www.bapen.org.uk/screening-and-must/must/introducing-must>
- Practical guidance on using 'MUST' during the pandemic <https://www.bapen.org.uk/pdfs/covid-19/covid-mag-update-may-2020.pdf>
- Self-screening tool <https://www.malnutritionselfscreening.org/>
- BAPEN Annual Conference webinars on demand <https://www.bapen.org.uk/webinar-series-2020-on-demand>

## ABOUT BAPEN

BAPEN (the British Association for Parenteral and Enteral Nutrition) is a charity which seeks to raise awareness of malnutrition and works to advance the nutritional care of patients and those at risk from malnutrition in the wider community. BAPEN is made up of various core groups of dietitians, doctors and scientists, nurses, patients, and pharmacists working to deliver safe, timely and appropriate nutritional care across all health and social care settings, as well as at home.

*For more information, visit the BAPEN website <https://www.bapen.org.uk/> and social media.*

**Twitter: @BAPENUK Facebook: @UKBAPEN.**

## GET INVOLVED WITH UK MALNUTRITION AWARENESS WEEK

In October BAPEN hosts its annual UK Malnutrition Awareness Week in partnership with the Malnutrition Task Force. The aim of the campaign is to ensure that the risks and consequences of malnutrition are better understood in all settings among health and social care workers, as well as community groups, the public, parliamentarians and policymakers. It is a fantastic opportunity for various healthcare professionals to share their expertise and to raise the profile of nutrition.





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#### References

1. <https://www.fresenius-kabi.com/ie/products>
2. SmofKabiven Central emulsion for infusion. Summary of Product Characteristics. Fresenius Kabi.



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**Date of preparation:** October 2020  
**Job code:** ONCO/002/20  
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**Active ingredients: 1970ml bag** Amino acid solution with electrolytes 1000ml, Glucose 42% 595ml, Lipid emulsion 375ml - corresponding to: Soya-bean oil, refined 22.5g, Medium-chain triglycerides 22.5g, Olive oil, refined 18.8g, Fish oil, rich in omega-3-acids 11.3g, Glucose (monohydrate) 250g, Alanine 14.0g, Arginine 12.0g, Glycine 11.0g, Histidine 3.0g, Isoleucine 5.0g, Leucine 7.4g, Lysine (as acetate) 6.6g, Methionine 4.3g, Phenylalanine 5.1g, Proline 11.2g, Serine 6.5g, Taurine 1.0g, Threonine 4.4g, Tryptophan 2.0g, Tyrosine 0.40g, Valine 6.2g, Calcium chloride (as dihydrate) 0.56g, Sodium glycerophosphate (as hydrate) 4.2g, Magnesium sulphate (as heptahydrate) 1.2g, Potassium chloride 4.5g, Sodium acetate (as trihydrate) 3.4g, Zinc sulphate (as heptahydrate) 0.013g **1477ml bag** Amino acid solution with electrolytes 750ml, Glucose 42% 446ml, Lipid emulsion 281ml - corresponding to: Soya-bean oil, refined 16.9g, Medium-chain triglycerides 16.9g, Olive oil, refined 14.1g, Fish oil, rich in omega-3-acids 8.4g, Glucose (monohydrate) 187g, Alanine 10.5g, Arginine 9.0g, Glycine 8.2g, Histidine 2.2g, Isoleucine 3.8g, Leucine 5.6g, Lysine (as acetate) 5.0g, Methionine 3.2g, Phenylalanine 3.8g, Proline 8.4g, Serine 4.9g, Taurine 0.75g, Threonine 3.3g, Tryptophan 1.5g, Tyrosine 0.30g, Valine 4.6g, Calcium chloride (as dihydrate) 0.42g, Sodium glycerophosphate (as hydrate) 3.1g, Magnesium sulphate (as heptahydrate) 0.9g, Potassium chloride 3.4g, Sodium acetate (as trihydrate) 2.6g, Zinc sulphate (as heptahydrate) 0.0097g **986ml bag** Amino acid solution with electrolytes 500ml, Glucose 42% 298ml, Lipid emulsion 188ml - corresponding to: Soya-bean oil, refined 11.3g, Medium-chain triglycerides 11.3g, Olive oil, refined 9.4g, Fish oil, rich in omega-3-acids 5.6g, Glucose (monohydrate) 125g, Alanine 7.0g, Arginine 6.0g, Glycine 5.5g, Histidine 1.5g, Isoleucine 2.5g, Leucine 3.7g, Lysine (as acetate) 3.3g, Methionine 2.2g, Phenylalanine 2.6g, Proline 5.6g, Serine 3.2g, Taurine 0.50g, Threonine 2.2g, Tryptophan 1.0g, Tyrosine 0.20g, Valine 3.1g, Calcium chloride (as dihydrate) 0.28g, Sodium glycerophosphate (as hydrate) 2.1g, Magnesium sulphate (as heptahydrate) 0.60g, Potassium chloride 2.2g, Sodium acetate (as trihydrate) 1.7g, Zinc sulphate (as heptahydrate) 0.0065g **493ml bag** Amino acid solution with electrolytes 250ml, Glucose 42% 149ml, Lipid emulsion 94ml - corresponding to: Soya-bean oil, refined 5.6g, Medium-chain triglycerides 5.6g, Olive oil, refined 4.7g, Fish oil, rich in omega-3-acids 2.8g, Glucose (monohydrate) 63g, Alanine 3.5g, Arginine 3.0g, Glycine 2.8g, Histidine 0.8g, Isoleucine 1.3g, Leucine 1.9g, Lysine (as acetate) 1.7g, Methionine 1.1g, Phenylalanine 1.3g, Proline 2.8g, Serine

1.6g, Taurine 0.25g, Threonine 1.1g, Tryptophan 0.5g, Tyrosine 0.10g, Valine 1.6g, Calcium chloride (as dihydrate) 0.14g, Sodium glycerophosphate (as hydrate) 1.1g, Magnesium sulphate (as heptahydrate) 0.30g, Potassium chloride 1.1g, Sodium acetate (as trihydrate) 0.9g, Zinc sulphate (as heptahydrate) 0.0033g. **Indications:** Parenteral nutrition for adults and children aged 2 years and above when oral or enteral nutrition is impossible, insufficient or contraindicated. **Dosage and administration:** Intravenous infusion into a central vein. The dose should be individualised to the patient's clinical condition, body weight (bw) and nutritional requirements. **Adults** - The dose range of 13-31 ml/kg bw/day covers the needs of the majority of patients. In obese patients the dose should be based on the estimated ideal weight. The recommended maximum daily dose is 35ml/kg bw/day. Infusion rate should not exceed 2.0ml/kg bw/hour (corresponding to 0.25g glucose, 0.10g amino acids, and 0.08g lipids /kg bw/hour). The recommended infusion period for adults is 14-24 hours. **Children (2-11 years)** - The infusion rate should not exceed 2.4ml/kg bw/hour (corresponding to 0.30g glucose, 0.12g amino acids and 0.09g lipids /kg bw/hour). At the maximum infusion rate, do not use an infusion period of longer than 14 hours and 30 minutes. The recommended infusion period in children aged 2-11 is 12-24 hours. The recommended maximum daily dose is 35ml/kg bw/day. **Adolescents** - SmofKabiven Central can be used as in adults. To provide total parenteral nutrition, trace elements, vitamins and possibly electrolytes should be added according to the patient's need. **Contraindications:** Hypersensitivity to fish-, egg-, soya- or peanut protein or to any of the active substances or excipients, severe hyperlipidaemia, severe liver insufficiency, severe blood coagulation disorders, congenital errors of amino acid metabolism, severe renal insufficiency without access to hemofiltration or dialysis, acute shock, uncontrolled hyperglycaemia, pathologically elevated serum levels of any of the included electrolytes, general contraindications to infusion therapy (acute pulmonary oedema, hyperhydration, decompensated cardiac insufficiency), hemophagocytotic syndrome, unstable conditions, infants and children under 2 years of age. **Special warnings and precautions for use:** See SmPC for further information. Use with caution in conditions of impaired lipid metabolism, in patients with a tendency towards electrolyte retention, in lactic acidosis, increased serum osmolality and insufficient cellular oxygen supply. Contains soya-bean oil, fish oil and egg phospholipids which may rarely cause allergic reactions. Cross allergic reaction has been observed between soya-bean and peanut. Use a continuous and well-controlled infusion. Strict aseptic precautions should be taken. Electrolyte and fluid balance disturbances should be corrected prior to infusion. Special clinical monitoring is required at the beginning of any

infusion and should any abnormal sign occur (including anaphylactic reaction), the infusion must be stopped. Carefully control phosphate and potassium intake in patients with renal insufficiency. Monitor triglyceride levels (serum concentration should not exceed 4mmol/l during infusion), serum glucose, electrolytes, osmolality, fluid balance, acid-base status and liver enzyme tests. When lipids are given for a longer period, monitor blood cell count and coagulation. Lipid content may interfere with certain laboratory measurements if blood sampled before lipid clearance. Consider trace element dosing as intravenous infusion of amino acids is accompanied by increased urinary excretion of trace elements, in particular copper and zinc. Careful and slow initiation is recommended in malnourished patients with close monitoring and appropriate dose adjustments. Do not administer with blood in the same infusion set. Exogenous insulin may be necessary in patients with hyperglycaemia. No clinical experience in children (aged 2 to 16/18 years). **Undesirable effects:** Common - Slight increase in body temperature. Uncommon - Lack of appetite, nausea, vomiting, elevated plasma levels of liver enzymes, chills, dizziness, headache. Rare - Tachycardia, dyspnoea, hypotension, hypertension, hypersensitivity reactions, heat or cold sensation, paleness, cyanosis, pain in the neck, back, bones, chest and loins. Other adverse reactions can occur (including fat overload syndrome), see SmPC for details. **Legal Category:** POM **Marketing Authorisation Number:** UK - PL 08828/0187. IE - PA 2059/058/002 Biofine Bags. **Marketing Authorisation Holder:** UK - Fresenius Kabi Limited, Cestrian Court, Eastgate Way, Manor Park, Runcorn, Cheshire, WA7 1NT, UK. IE - Fresenius Kabi Deutschland GmbH, Else-Kroener Strasse 1, Bad Homburg v.d.H. 61352, Germany. **Package size and cost:** 1970ml €67.73, 1477ml €64.05, 986ml €63.58, 493ml €58.00. **Further information:** Available from Fresenius Kabi Limited, Cestrian Court, Eastgate Way, Manor Park, Runcorn, Cheshire, WA7 1NT. Tel +44 (0)1928 533 533. **Date of preparation:** October 2020 API/SMOFKabiven-02

Adverse events should be reported.  
Reporting forms and information can be found at:  
[yellowcard.mhra.gov.uk](http://yellowcard.mhra.gov.uk)  
[www.hpra.ie/homepage/about-us/report-an-issue](http://www.hpra.ie/homepage/about-us/report-an-issue)

Adverse events should also be reported to Fresenius Kabi Limited,  
Cestrian Court, Eastgate Way, Manor Park, Runcorn, Cheshire, WA7 1NT  
Tel +44 (0)1928 533 533.

M.E.



# M.E.: THE LATEST ADVICE

The NICE draft guideline acknowledges that people with M.E. have faced stigma and neglect for a long time. Could the tide finally be turning for the estimated 250,000 people in the UK who live with this debilitating condition? UK charity Action for M.E. consider the possibility.

We aim to improve the lives of adults, children and families living with the serious neurological condition, myalgic encephalomyelitis (M.E.), sometimes diagnosed as chronic fatigue syndrome (CFS or M.E. / CFS).

This has been made all the harder thanks, in no small part, to decades of misunderstanding about the condition. Despite growing evidence, we are still hearing from patients encountering some clinicians who believe M.E. is a psychological, rather than biological, illness.

The 2007 guideline for M.E. / CFS from the National Institute for Health Care Excellence (NICE) attracted widespread criticism among the M.E. community over some of its key findings and treatment recommendations. Of particular concern was the advice that patients should be offered graded exercise therapy (GET) and cognitive behavioural therapy (CBT) despite a lack of reliable evidence of their safety and efficacy.

## MAKING SYMPTOMS WORSE

Action for M.E.'s 2019 Big Survey found that 61 per cent of respondents who tried GET, supported by a non-M.E. specialist

health professional, reported a worsening effect on their symptoms. But even with help from a M.E. specialist, 47 per cent said that their symptoms were made worse with GET.

One survey respondent said, 'I did GET and after three months it left me severely affected, house-bound, bed-bound half the day, and unable to have visitors. All my symptoms worsened and I have lots of new symptoms.'

Four years later, the PACE trial (short for Pacing, graded Activity, and Cognitive behaviour therapy; a randomised Evaluation), part-funded by the Department of Work and Pensions (DWP), claimed that patients treated with CBT and GET (alongside specialist medical care) experienced moderate improvement in self-rated fatigue and physical function, more than those who used adaptive pacing therapy or specialist medical care alone.

However, the PACE trial was based on a flawed hypothesis that M.E. 'was largely being maintained by abnormal illness beliefs and behaviours, along with inactivity and deconditioning' (Shepherd, 2017; Journal of Health Psychology) Repeated questions have been raised about the methodology of this trial, and the reliability of its results, including potential harm caused by GET.

Following a long legal battle, unpublished data from the trial was released and independently analysed. The results showed that changes to the recovery criteria part-way through the trial meant that ‘it was possible to score below the level required for trial entry, yet still be counted as ‘recovered’. (Wilshire et al, 2016; *Fatigue: Biomedicine, Health & Behavior*)

*You can read more about the PACE trial at [www.actionforme.org.uk/pace-trial](http://www.actionforme.org.uk/pace-trial).*

The cause was taken up by politician Carol Monaghan, SNP MP for Glasgow North West, who led a debate in Westminster, saying, ‘The failure of PACE [...] could simply be put down to bad science. But, unfortunately, I believe there is far more to this. One wonders why the DWP would fund such a trial, unless of course it was seen as a way of removing people on long-term benefits and reducing the welfare bill.’

The issues with the PACE trial were reflected in mounting evidence about the harms caused by GET and CBT through extensive patient surveys. (Geraghty et al, 2017; *Journal of Health Psychology*)

## FULL REVIEW

In September 2017, after originally proposing not to update the guideline, NICE announced that there would be a full review and detailed consultation with stakeholders began.

Getting to the stage where a new draft guideline could be released has been a lengthy process and, given the pressure imposed by coronavirus, subject to several delays. The draft guidance was finally published in November 2020.

Markedly, it acknowledges that people with M.E. have faced stigma and neglect for a long time, and that doctors, therapists and other professionals must take time to build trust with patients, taking a person-centred approach.

The guideline is also crystal clear that GET is off the agenda, a move welcomed by Action for M.E. and the patient community, ‘Do not offer people with M.E. / CFS any therapy based on physical activity or exercise as a treatment or cure for M.E. / CFS.’

Instead, it says, patients should be offered support with energy management to help prevent worsening of symptoms. Activity should be reduced, not ‘pushed through’, if it is having a negative effect, and should only ever be increased if led by the patient.

The draft goes on to say that psychological support, such as CBT, may be used to reduce distress and support for patients to develop coping skills – but not as a treatment or cure for M.E.

## FOCUS ON CBT

However, Action for M.E. remain concerned about the exclusive focus on CBT as a means of psychological support; this differs from guidelines for other chronic conditions, which offer mindfulness and person-centred counselling as options.

One survey respondent told us, ‘I agree that providing psychological support is very important – to deal with the impact of this condition – but my view, both as a doctor and as a patient, is that CBT is largely promoted based on cost, rather than it really being the best treatment modality. Particularly for people with more severe disease, I think CBT can be harmful in that it applies a general technique to a vulnerable group who are often unable (physically / mentally) to engage with or benefit from this technique [and] may well result in more harm than good if the person is actually very

disabled and cannot do much for themselves. Other psychological modalities / techniques (including mindfulness, acceptance-based strategies) may be far more beneficial.’

The draft NICE guideline for M.E. says that it must not be assumed that deconditioning is the cause of M.E., nor that people with M.E. have ‘abnormal’ illness beliefs and behaviours as an underlying cause. This is a welcome clarification.

It recommends that patients should be given advice on managing sleep, orthostatic intolerance, pain, nausea and diet, and professionals should recognise the importance of an early, accurate diagnosis and regular monitoring and review, particularly if symptoms are worsening or changing.

It also recommends making clear to patients and their family members / carers that they have the right to decline or withdraw from any part of their management plan, and that this will not affect other aspects of their care.

It’s noted that medical professionals should realise that symptoms of M.E., particularly at its most severe, can often be confused with signs of abuse or neglect. This is an important clarification given that our 2017 survey of families with children affected by M.E. shows that one-in-five who responded have faced accusations of fabricated / induced illness (FII), abuse or neglect, leading to child protection referrals; this heightened frequency of FII claims sits widely outside the national prevalence rate.

## CONSULTING ON THE DRAFT

Action for M.E. received hundreds of comments by phone, email and social media, as well as more than 1,500 responses, to our survey on the draft NICE guideline. These informed our detailed response to NICE’s consultation on the draft.

One survey respondent told us, ‘As a patient who has no ongoing support or care (ie. health or social) I can see some great benefits from the draft guideline, assuming the resources are there for education and ensuring the specialist services are available and providing the correct support.’

The comments detailed in our submission reflect the positives in the guideline but also highlight some areas that need further development. These include the need for more emphasis on a patient’s personal choices and decision-making power in their relationship with doctors and other healthcare professionals, and clarity around advice on physical activity, which needs strengthening to ensure that it can’t be misused or misinterpreted.

One survey respondent told us, ‘Some physical activity is required for the basics of living, e.g. chewing. Many bits of ‘normal’ physical activity need to be balanced and traded off against each other in a ‘robbing Peter to pay Paul’ manner. I’ve been eating recently, but have not been able to have a shower or wash my hair for over two months. It’s been 10 years since I’ve been to a hairdresser. I’m two years overdue for the dentist and four years overdue for the optician.’

The Guideline Committee is now considering responses in order to review and finalise the draft; the new guideline for M.E. / CFS is expected on Wednesday 21st April 2021.

Given the robustness of NICE’s guideline development process, we are hopeful that the positive changes set out will be upheld. The next crucial steps in taking it forward will be to work collaboratively with health professionals to promote the guideline and its recommendations, and improve medical education for those working with M.E. patients of all ages.

*For information and resources to help you support people with M.E., visit [www.actionforme.org.uk/medical](http://www.actionforme.org.uk/medical).*

## CANCER

# PAUSE FOR THOUGHT

Through the loss of national facilities and introduction of barriers to scientists working together, major advances in cancer research could be delayed by 17 months. Stay sussed on the repercussions of the delay – and the support that could accelerate recovery.

Cancer researchers fear that progress for patients could be delayed by almost a year-and-a-half because of the effects of the COVID-19 pandemic, a new survey has indicated.

Scientists at The Institute of Cancer Research, London, told the survey that their own research advances would be pushed back by an average of six months by the initial lockdown, subsequent restrictions on laboratory capacity, and the closure of national scientific facilities.

With broader effects on charity funding, disruption of collaboration and personal interaction between scientists, and diversion of research efforts to COVID-19, the respondents estimated that major advances in cancer research would be delayed by an average of 17 months.

But the researchers remarked that science had now adapted in many ways to the pandemic and that long-lasting damage to cancer research could be mitigated through extra funding from charitable donations or government support – calling for investment in staffing, new technology – such as robotics – and computing power.

## THE EFFECTS OF LOST TIME

The Institute of Cancer Research, which has discovered more cancer drugs than any other academic centre in the world, has like many research organisations been hit by cuts to its own fundraising income and to grants from other charities. The Institute of Cancer Research had to pause much of its work during the initial lockdown, and is now running a major fundraising appeal to help kickstart its research and make up for lost time.

The Institute of Cancer Research surveyed 239 of its researchers in order to detail the impact the pandemic has had on its research and to point towards ways of moving research forward again as quickly as possible.

Respondents explained that they had lost an average of 10 weeks of research time to the first lockdown itself, and that their own scientific advances would be pushed back by an average of six months. Almost all explained that COVID-19 had had an impact on their work –

with 36 per cent saying it had had a ‘moderate’ impact, another 36 per cent a ‘substantial’ impact, and five per cent an ‘extreme’ impact.

The respondents were strongly supportive of efforts to keep labs open to prevent any further disruption to research advances for cancer patients. The Institute of Cancer Research’s labs have managed to stay open during the second lockdown period while taking significant measures to help prevent risk of spread.

The Institute of Cancer Research’s researchers did feel that science had adapted to COVID-19 and that there were various ways to make up for lost time – over 60 per cent felt funding for extra staff time would help; almost 40 per cent wanted upgrades in technology, for example, for robotics, and 29 per cent, increased computing power.

## SALLY’S STORY

Mother-of-two Sally Steadman-South, from Sheffield, is living with stage four melanoma. She was first diagnosed in 2014 at the age of 35, after having a mole removed on her chest. Despite trying numerous treatments, including surgery, radiotherapy and immunotherapy, the cancer continued to spread.

For the last two years she has been on the targeted drugs, dabrafenib – a treatment underpinned by The Institute of Cancer Research’s science – and trametinib, and currently has no evidence of disease.

Sally celebrated her 40th birthday with her family – a milestone she

never thought she would reach.

Sally shared her concerns about the impact of COVID-19 on cancer patients, saying, ‘The coronavirus has been especially devastating for many cancer patients – I have been lucky my treatment has been unaffected but we know many have not and their care has been affected. It’s also clear that future research advances have also been delayed.’

‘I feel lucky that my treatment has worked well so far but I know that the cancer could become resistant to the drugs at any time. When you get a diagnosis like mine it changes what time means to you – maybe this pandemic has made many more people value and appreciate quality time with family and loved ones. I want to be around for school plays and sports days, see my daughter go to secondary school, and see my son enjoy his time there too, and start planning his own future.’

‘We recently went to pick our Christmas tree and they are planting fields of new trees which will be ready in 2028. We agreed that this would be our new goal. I would be there to see this new field of Christmas trees and we would go as a family to pick one. We need to make up for the time lost to this virus so people like me can live longer and make important memories like these.’

*For more information, and to support The Institute of Cancer Research’s kickstart appeal and help their researchers make up for lost time, visit [www.ICR.ac.uk/KickstartICR](http://www.ICR.ac.uk/KickstartICR).*

# TAKING IT TO HEART

The pandemic has brought about increased consumer adoption of digital health options and a rise in demand for remote monitoring tools, as patients and clinicians strive to minimise exposure to the COVID-19 virus. NIHR examines how one remote patient monitoring device could be adopted in order to curtail the need for clinic and hospital visits and offer reassurance to patients.

## THE MEDTECH INNOVATION BRIEFING

NICE has developed a medtech innovation briefing (MIB) on KardiaMobile for the ambulatory detection of atrial fibrillation (AF). KardiaMobile is a portable single-lead ECG recorder, which works with a compatible mobile device (such as a smartphone or tablet) running the Kardia app. It analyses the ECG recording, which the patient can share with their physician for interpretation.

The KardiaMobile heart monitor and Kardia app is intended for adults to detect abnormal heart rhythms. It can be used in patients with existing AF (to determine AF burden), in patients after treatment (to investigate AF recurrence), and in patients with unclear palpitations (investigation). It is particularly suitable for people with suspected paroxysmal AF, which might not be detected using a standard 12-lead ECG if the person is not in arrhythmia at the time of recording. Because the KardiaMobile heart monitor is portable, readings can be taken at home, or in any other setting, and at any time of the day. This increases the

diagnostic yield of an arrhythmic episode being detected and recorded.

Evidence from 11 studies and 1,218 patients are summarised in the MIB, including two randomised controlled trials (RCTs), one pilot (case-control) study, one cohort feasibility study and seven diagnostic accuracy studies (comparators included 12-lead electrocardiogram [ECG], external loop recorder, transtelephonic monitor, and comparison of automated algorithm in arrhythmia detection versus clinical interpretation of KardiaMobile acquired ECG). Three of the diagnostic accuracy studies were done after AF therapy in a monitoring setting.

## EXPERT OPINION

Comments on this technology were invited from clinical experts working in the field and relevant patient organisations. All six experts described the technology as innovative. One stated that it had already changed clinical pathways for those with suspected arrhythmia, and another stated that it had potential to change standard of care. Another suggested it could be used in novel

settings, outside of healthcare.

Four experts stated that the technology would help increased detection of AF, with two highlighting quicker time to diagnosis. Three experts commented on the ease of use of the device, two stated that the device offers reassurance to patients with palpitations and one stated that the technology was patient-orientated, enabling high correlation between recorded symptoms and captured data. The experts could see the benefits of the technology across a variety of patient groups and settings.

Four experts suggested that this technology could be more reliable than other methods because it could be used in a number of settings and at any time, including when symptoms happen. All experts stated that this technology had the potential to change standard care in some way (earlier diagnosis, quicker intervention, fewer hospital visits and referrals, fewer strokes), improving both patient outcomes and patient satisfaction.

Four experts stated that the technology would reduce hospital resource use (fewer hospital visits, referrals, investigations). Four

## ATRIAL FIBRILLATION

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experts referred to existing use in primary care and felt that use in community settings would increase. One expert stated that the technology had the potential to direct management to a primary care setting, and two experts stated that the technology would allow remote consultations (which are increasing because of COVID-19). Two experts also felt it was ideal for use in care homes, and for home visits, and two experts had used the device on patients who were unable to attend for a 12-lead ECG. One expert highlighted that KardiaMobile would lead to more efficient working, one stating that the device could be implemented by a range of staff, another commenting on how use of the device would lead to expansion of professional roles (for example, training). Two experts highlighted that reviewing the device output needs no additional staff or skills than interpreting outputs from the standard care 12-lead ECG. All experts agreed that use of the technology could reduce overall healthcare costs compared with standard care, and three referred to costs associated with reduction in stroke admissions. Two experts highlighted that KardiaMobile can detect other cardiac abnormalities, not just AF, and therefore has wider benefits.

All experts agreed that the device would be in addition to standard care, but four experts stated that there was potential for the device to replace standard care in some settings and patient groups, and one suggested that it could replace standard care in the next five years. One expert highlighted that the device would not directly replace 12-lead ECG for confirmation of arrhythmia because the instructions for use state that KardiaMobile interpretations should be reviewed by a medical professional for clinical decision-making.

### PATIENTS' PERSPECTIVE

Representatives from patient organisations (AF Association and Arrhythmia Alliance) also contributed to the briefing. The patient organisation commented that patients who have AF are often anxious, stressed, exhausted, breathless, have heart pounding and are scared. The technology can provide

reassurance by confirming if symptoms are being caused by an arrhythmia. Patients can share evidence with doctors and carers or family members to make sure their symptoms are managed appropriately. Without this evidence, patients can be left feeling alone and isolated.

Patient subgroups who could particularly benefit from the technology include symptomatic patients who have yet to be diagnosed, and those who have paroxysmal AF (which is hard to detect on a standard 12-lead electrocardiogram or Holter monitor).

The organisation noted that compared with long waits and travel to and from hospital or GP appointments (and appointments cancelled or postponed because of COVID-19), the technology is proven to be cost-efficient with the same or similar outcomes. In some cases, outcomes are better because the patient can keep the monitor for longer and capture intermittent spells of AF if needed. Patients prefer this technology to having electrodes on their skin for seven-to-14 days and having to travel back and forth to hospital. The patient organisation thought that there was an urgent need for guidance on the technology and highlighted evidence in the European Heart Journal from Denmark that there was a 47 per cent reduction in AF detection in March and April 2020 compared with March and April 2019 because of the COVID-19 pandemic. This may have led to an increase in AF-related strokes. Having KardiaMobile readily available across the NHS and in pharmacies would: make sure that patients can capture their irregular heart rhythms; allow collection of the evidence to show their doctors AF; protect against AF-related stroke with anticoagulation therapy; help patients to access appropriate treatments to manage the symptoms and correct arrhythmia.

### THE IPED STUDY

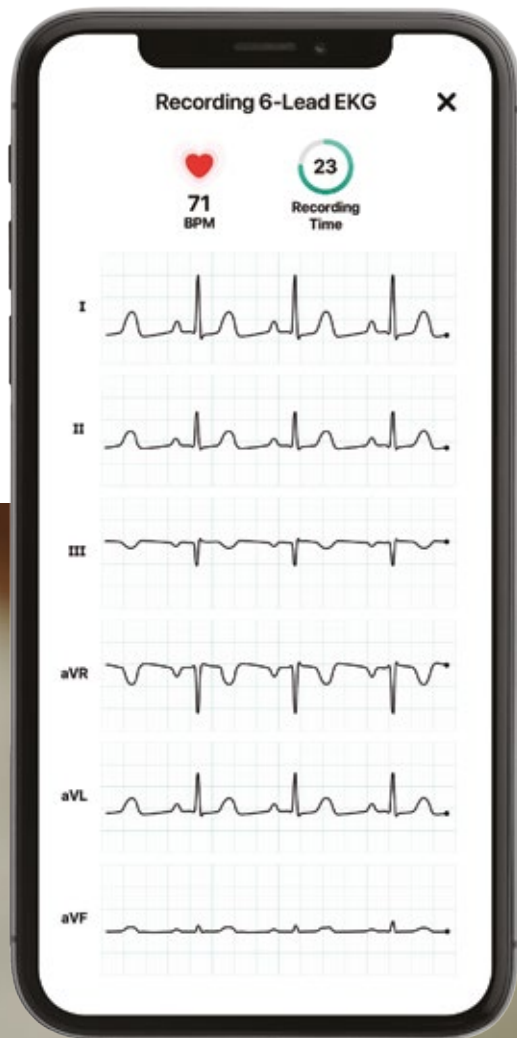
The IPED (Investigation of Palpitations in the ED) trial sought to clarify whether there is any benefit to adding a smartphone-based electrocardiogram monitoring

event recorder to standard care. The trial recruited patients presenting to the ED with palpitations and pre-syncope and no obvious cause in the ED. The principal outcome measure was the rate of detection of the underlying symptomatic rhythm at 90 days. This study shows that use of a smartphone-based event recorder increased the number of patients in whom an ECG was captured during symptoms over five-fold to more than 55 per cent at 90 days. These are clinically significant rhythms as they diagnose the underlying cause of the patient's symptoms. The smartphone-based event recorder also increased the number of patients diagnosed with cardiac arrhythmia.

### KEY OUTCOMES

Statistically significantly more patients had symptomatic cardiac arrhythmias detected at 90 days in the intervention arm (n=11) than in the control arm (n=1, p=0.006). Mean time to symptomatic cardiac arrhythmia detection was reduced from 48.0 days in the control arm, to 9.9 days in the intervention arm (p=0.004). Serious outcomes at 90 days (including all-cause death and major adverse cardiac events) were 11 in the intervention arm and two in the control arm. Treatment was planned or ongoing in 12 patients in the intervention arm and six patients in the control arm. Cost per symptomatic rhythm diagnosis was £474 in the intervention arm, and £1,395 in the control arm. 80 out of 92 (87.0 per cent) patients found KardiaMobile easy to use.

The study determined that a smartphone-based event recorder should be considered as part of ongoing care for all patients presenting acutely to EDs with unexplained palpitations or pre-syncope. It is safe, non-invasive, easy to use and far more efficient at diagnosing the underlying cause of the patient's symptoms than current standard care, which in the healthcare system studied does not serve this patient group well.



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\*Information on Atrial fibrillation in Northern Ireland can be found at <https://nichs.org.uk/information/risk-factors/atrial-fibrillation>

## ARTHRITIS

# A LEARNING CURVE

Despite the fact that musculoskeletal (MSK) conditions, including arthritis, affect almost 19 million people in the UK, a huge gap in MSK training for medical students endures – a concern which is exacerbated by the further challenges to learning which lockdown has brought. NIHR examines the scale of the problem, the consequences it can pose to wider practice, and the MSK educational resource which is providing much-needed support.

Did you know that only around two-to-six per cent of the medical undergraduate curriculum is focussed on MSK teaching? This statistic represents a worrying reality for not only professional practice, but patient care – with GPs reporting a lack of confidence treating and managing MSK conditions, and 53 per cent of people with arthritis thinking that GPs lack specialist knowledge of these conditions.

## MY EXPERIENCE

David Hanna, a third-year medical student at Newcastle University, shares the barriers impeding his MSK training and the value of improvement – particularly as the pressure of the pandemic continues.

### HOW HAS THE COVID-19 PANDEMIC IMPACTED YOUR MEDICAL STUDIES?

Given the degree we're studying, we have been affected a bit more than other students, especially considering this is my first clinical year. Usually you increase your time in hospital, see a lot more patients, and figure out more about what medicine actually is, other than what the books say – but this year they want to minimise risk to us while still allowing us to progress with our training.

Due to COVID-19, our clinical work time has been cut down and freedom to work on other areas that enrich our academic studies has also been cut. So, for example, when we're studying MSK cases, we would usually be able to go into hospital and see patients with rheumatoid arthritis and osteoarthritis, so we can actually see the signs in real life, but it's all simulated this year through pictures and imitations because of the need to minimise contact and risk of COVID-19. We have been able to continue seeing some patients in their GP check-ups and teaching fellows have done a good job of explaining everything, but it's not the same. We have had to rely a lot more on simulation and our own imagination to predict what the signs would look like in real life.

### DO YOU THINK THERE NEEDS TO BE AN INCREASED FOCUS ON MSK CONDITIONS WITHIN MEDICAL TRAINING?

It's hard to say at this stage in my career, as I haven't seen the number of patients I'm supposed to have seen by now due to the pandemic. But from my learning so far, I know that so many people live with MSK conditions and we only covered it at the end of second year – right before exams – and it only made up a week or two of our essential study.

This year we have one-to-two weeks combined with frailty and bones and dermatology within the first eight weeks – and I'm not sure if we have any more planned.

It would be good to have more time allocated to the management of arthritis and what's happening in the field, given the scale and impact of the condition.





## WHAT ADVICE WOULD YOU SHARE WITH OTHER MEDICAL STUDENTS IN YOUR POSITION?

There are lots of additional resources out there to support your learning, so try to make the most of them and give yourself some variety from online learning.

The Versus Arthritis MSK handbook has been vital in supporting my current rheumatology studies – at our hospital we have physical copies which everyone has really depended upon for examinations, especially given we couldn't attend practice examinations in person and everything moved to online.

It can be very hard to distinguish the different types of arthritis, it's a vast field that we have limited time allocated to study, so having this resource with structured examinations and flow charts for patient assessment has given me a lot more confidence in examinations and when treating people on the wards.

## THROUGH EXPERT EYES

David Coady, a Consultant Rheumatologist at Sunderland Royal Hospital, overviews the challenges currently imposed on MSK learning and the wider detriment of this in practice.



David Coady

## WHAT HAVE BEEN THE MAIN CHALLENGES ENCOUNTERED BY MEDICAL STUDENTS IN THEIR EFFORTS TO LEARN DURING LOCKDOWN – PARTICULARLY RELATING TO MSK CONDITIONS?

Patient access and limited contact has been

a big problem for the students, as well as negotiating the technology which they're trying to use and adapting their learning styles. Additionally, managing their expectations from how it should have been to how it has been may be difficult for medical students – the reality might feel unsatisfactory.

## PRIOR TO COVID-19, WHAT WAS THE GAP IN MSK TRAINING LIKE?

Medical students don't generally have a lot of time for MSK training in their busy curriculum. MSK conditions are very common – for GPs, 20 per cent of their patients might present with a MSK problem, yet for medical students, this area doesn't account for 20 per cent of the curriculum. Having enough time training students and helping them get comfortable with examining patients and starting to understand the area has always been a challenge.

Another issue is reinforcement in that the students may be taught how to examine MSK conditions, but when they go on to the wards, they're not carrying out examinations on joints routinely, and therefore not getting active practice.

## WHAT CAN CLINICIANS DO TO CLOSE THIS GAP?

It's all about raising awareness and confidence among our colleagues, as well as attending medical sessions and receiving hands-on experience. GPs have been undergoing training and getting clinical updates. However, the trouble is that this education only reaches those who already have an interest – it doesn't tap into hospital specialties or those who perhaps don't have the skills.

The question is, who should be managing MSK disease? And I think the answer is that we all should to some extent, particularly GPs, general physicians and the care of the elderly consultants have an important role.

We can all play our part by updating ourselves on what medical students are being taught – looking at what resources are out there and improving our engagement. Raising the profile of physiotherapists and what they are capable of is important too.

## A HELPING HAND

The launch of new MSK-focused learning support is sparking new hope for the sector.

A MSK learning resource has been crafted for medical students and healthcare professionals.

The Versus Arthritis free MSK study guide and condition-specific videos have been developed by leading medical educators, giving students and clinicians the foundation knowledge and skills in clinical assessment and diagnosis of MSK conditions.

The resource's features include:

- A step-by-step study guide
- Detailed information for examination of patients with a range of musculoskeletal conditions
- Revision checklists
- A series of videos to take you through the GALS (gait, arms, legs and spine) screening examination and a detailed regional examination of the musculoskeletal system

*Students and healthcare professionals can download the MSK study guide by visiting [www.flipsnack.com/BC857F5BDC9/versus\\_arthritis-hcp\\_handbook-interactive.html](http://www.flipsnack.com/BC857F5BDC9/versus_arthritis-hcp_handbook-interactive.html) or emailing [professionaleengagement@versusarthritis.org](mailto:professionaleengagement@versusarthritis.org) for a free hard copy.*

For further support, the Versus Arthritis professional network has been established, targeted at all healthcare professionals, medical students and trainees.

## WHAT IS THE PROFESSIONAL NETWORK?

The professional network is an active community that brings together healthcare professionals to transform care for people with arthritis.

## WHAT WILL YOU GAIN FROM BEING A MEMBER OF THE NETWORK?

- You'll be joining a growing network of professionals
- You will be kept up-to-date on the latest news, educational resources and developments in MSK care
- You can share best practice with other professionals and feed intelligence back into the organisation
- You will be involved in shaping the future of MSK healthcare

*For more information, visit <https://www.versusarthritis.org/professionalnetwork>.*

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## PROMOTION

# THE NEXT CHAPTER

**NIHR catches up with Brendan Moffatt, Key Account Manager for Bestway Medhub, about his reflections on 2020 and what we can expect from Bestway Medhub in 2021.**



**Brendan Moffatt**

Bestway Medhub is a short-line wholesaler supplying products and services to the independent pharmacy and dispensing doctor sectors, supporting over 3,000 customers across the UK. As part of the Bestway Group, the company has the backing of the largest independent wholesale business in the UK.

Established in 2015, Medhub has grown significantly, working to the values of being open and transparent, fair, and simple with a dedicated Field and Telesales Team supporting customers day in and day out.

The business is led by Paul Inasley, who sits on the Healthcare Distribution Association (HDA), a body that helps shape the wholesaling and distribution landscape to support the ever-changing and challenging world of pharmacy.

### **WHAT DO YOU LIKE ABOUT WORKING AT BESTWAY MEDHUB?**

It's really exciting to be part of a business that is growing. No two days are ever the same and we are focussed on delivering an outstanding service to our customers and their patients. This is my third year working for Bestway Medhub and in that time the Field Sales Team has grown from three-to-10. I've been promoted to Key Account Manager and our Telesales Team has doubled in size!

As a business we continue to innovate for the benefit of our customers – we've launched a buying platform and web portal, making it easier to order products with us and access past invoices and orders – we've also increased our ranges significantly.

What I am most proud of is that all through this growth we have stayed true to our values and customer promise – to be transparent, fair and simple. We have no minimum order values, no targets to hit, or rebates to keep track of at the end of each month. It's really as simple as the price you see is the price you pay, and we always strive to make sure that it's as competitive as it can be.

### **WHAT ARE YOUR REFLECTIONS FROM 2020?**

The way pharmacy has stepped up and responded to the pandemic is incredible. While coping with their own worries, pharmacists and pharmacy teams have shown levels of determination every day looking after the health and wellbeing of their local communities, which I find inspirational. I felt an immense responsibility to make sure that we make the purchasing process as simple and hassle-free for our customers as possible during these challenging times.

For me, that's all about great partnership working and communication with my customers. At Bestway Medhub, I am trusted to do what's right for my customers and that empowers me to act quickly in their best interests. Also, our business values are more than just words – it's how we work. It's not our policy to go into huddle rates and retros – the price you see is the price you pay, so I can focus on what's most important to them.

### **WHAT CAN BESTWAY MEDHUB CUSTOMERS EXPECT IN 2021?**

We will continue to grow and offer an improved experience to our customers – we're passionate about making our services accessible to as many independent pharmacies as possible. We believe making our offer simple and straightforward means our customers can focus on delivering great patient care.

We launched a web portal in 2020, giving our customers an additional order method, creating a self-service element that supports pharmacies 24/7. We plan to add new features to this, and we are increasing our range in line with customer feedback, adding OTC and surgical lines. We have a lot of work going on behind-the-scenes to extend our customer offer as the demand on pharmacy increases.

### **WHAT ARE YOU LOOKING FORWARD TO MOST IN 2021?**

2020 was a challenging year and we've still got a long way to go before we can get back to seeing those we care about and love – our family and friends. With three vaccinations now approved, for me, there is light at the end of the tunnel, and I hope that at some point this year I will be able to return to pharmacy and start meeting my customers face-to-face.

I've missed being in pharmacy and attending pharmacy events that give me a better understanding of the priorities for community pharmacy.

I am very much looking forward to seeing my customers and being able to thank them personally for their outstanding work over the last year – thank you to everyone in community pharmacy for everything you continue to do to support the nation's health and wellbeing.

*For further information about opening an account with Bestway Medhub, to speak to an Account Manager, or to find out more about the company's new ordering portal, call 0800 050 1055 or email [Brendan.Moffatt@bestwaymedhub.co.uk](mailto:Brendan.Moffatt@bestwaymedhub.co.uk)*



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**BESTWAY MEDHUB**

## ANTIBIOTIC RESISTANCE

# TIME FOR ACTION

**With the COVID-19 vaccine, we have hope of a way to curb a virus that has had a devastating impact on so many people. But we need to be considering another threat to our health too – drug-resistant infections, explain Dr Tina Joshi, Lecturer in Molecular Microbiology, and Matthew McKracken, Biomedical Sciences student, from the University of Plymouth.**

Currently, the global loss of life caused by antibiotic resistance is estimated at over 700,000 deaths every year. This is predicted to climb exponentially to over 10 million deaths per annum by the year 2050 if no action is taken.

It's not an exaggeration to say that antimicrobials and antibiotics will soon become useless if we keep considering them as a 'miracle pill', meaning sepsis, pneumonia and other lethal bacterial infections could become untreatable. If we don't raise awareness and act quickly, we could be facing another threat to human health, long after the pandemic has passed.

The first thing to note is that viruses and bacteria are different – COVID-19 is caused by a virus (SARS-CoV-2), while infections like sepsis are bacterial. Antibiotics can only treat bacterial infections, not viruses.

## THE STATISTICS

COVID-19 is highly contagious and when a patient is suffering from the infection, separate opportunistic bacteria can enter into the equation. This bacterial co-infection, along with secondary infection, are additional factors causing illness and mortality.

From 24 separate studies that were recently conducted, figures have shown that 72 per cent of hospital inpatients testing positive for COVID-19 were given antibiotics as a preventive measure to treat a suspected bacterial infection. However, only 17.8 per cent of COVID-19 patients were confirmed as having co-infection or developed secondary infections like bacterial pneumonia. This is a worrying fact, as many of these patients might have never had a bacterial infection, but they were still treated with antibiotics. Clinicians are forced to do this in the hope of preventing patient death from co- / secondary infections because they are unable to diagnose an infection in a more efficient way.

Nevertheless, the education regarding antibiotic awareness in both the community and hospital environment (where the majority of human broad-spectrum antibiotics are prescribed) needs to be improved.

## WHY ARE SOME BACTERIA RESISTANT TO ANTIMICROBIALS?

It is an entirely natural process for bacteria to evolve resistance to chemicals that target it – they have been doing it for billions of years. However, as modern medicine has progressed, bacteria have become more exposed to newly-developed antibiotics and survived. The surviving bacteria then pass down antibiotic-resistant genes to their offspring. Our misplaced reliance and overuse of antibiotics has compounded the problem, making bacteria even more robust.

Knowing how resistant bacteria are evolving is not the only way to curb the rising trend of superbugs. Following basic hygiene practices, like regularly washing hands / surfaces, using sanitiser when hand washing is not available, preventing cross-contamination between foods / surfaces, and sneezing onto the inner elbow, rather than onto hands, are just some of the ways to help prevent the transmission of any microbial infection. Obtaining clean, safe water is also a priority – microbes can spread rapidly in developing regions that do not have access to clean water and good sanitation.

## THE FUNDING CHALLENGE

Another big challenge faced by scientists is obtaining the funding needed to combat antibiotic resistance. The field of antibiotic research and development is grossly underfunded. While some private companies within the industry understand this issue and invest money into an 'alliance' they have created, the public sector is falling behind drastically. Data from 2018 has shown that the total European public sector investment fund for antibiotic development totalled roughly €430 million annually – this is less money than the annual income made by the top 10 footballers in the world combined.

Governments must take steps to invest more time, funding, and effort into all aspects of this global crisis. A much-needed increase in public spending towards the antibiotic development pipeline would relate to an increase in output by scientists. The public also need to be confident that their money is going towards combatting an issue that will not only affect us in our lifetime, but have massive consequences for our children's lifetime thereafter.

## THE FUTURE

As antibiotics play a considerable part in healthcare, the ramifications if nothing is done are unthinkable. A simple scratch could kill a child, cancer treatments could kill a patient, and childbirth could kill an expectant mother and her baby.

Scientists and clinicians need to start educating a broader demographic to understand global and personal impacts caused by antibiotic resistance. COVID-19 has demonstrated how vulnerable the human race is to an infectious agent. The pandemic has been a massive struggle for all, putting people and services under enormous pressure. However, to prevent this sort of scenario from becoming a regular occurrence with even greater loss of life, the global community must act now.

New solutions are on the horizon, and with every new solution, no matter how big or small, comes the possibility to reduce death caused by antibiotic resistance, simultaneously bringing hope to so many of those already affected by this microbial war.

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\* GOS/FOS = Galacto-oligosaccharides and fructo-oligosaccharides.

<sup>†</sup> UK 4 week single split arm study<sup>3-5</sup>: infants with non-IgE mediated CMA, baseline non-synbiotic EHF vs Aptamil Pepti Syneo.

<sup>‡</sup> 12 week randomised controlled trial<sup>2</sup>: infants with atopic dermatitis, Aptamil Pepti Syneo vs Aptamil Pepti.

<sup>§</sup> subgroup of n=48 infants with IgE associated atopic dermatitis.

Accurate at date of publication December 2020. © Nutricia 2020.

# MUTUAL SUPPORT

Living under the shadow of a General Medical Council investigation or claim can have serious consequences for doctors' mental health. However, they can draw strength and solace from talking to fellow professionals who have come through similar experiences, explains the Medical Defence Union's Dr Caroline Fryar.



Dr Caroline Fryar

Every year, the Medical Defence Union (MDU) opens thousands of files on behalf of members who need our expertise and legal representation, including allegations of clinical negligence, fitness-to-practise concerns, and even police investigations. Very few of these cases result in findings against the doctor, but many still tell us they feel like their world is collapsing around them.

Many are already struggling to process the events which led to the investigation. Doctors who are involved in a serious incident where a patient suffers harm or death report that it can have a traumatic effect on them, prompting feelings such as guilt, risk aversion and anxiety about the consequences.

While doctors generally reflect on and try to learn from adverse events, many are concerned that they may be blamed for system failures outside their control or be judged on a single incident.

A General Medical Council (GMC) investigation has long been the realisation of many doctors' worst fears, plunging some into the depths of despair. The GMC has recognised the serious effect that the fitness-to-practise process can have. After commissioning a 2014 report into 28 cases

of suicide or suspected suicide by doctors under investigation, the GMC appointed an independent expert to review its procedures and has implemented a series of changes in recent years, including using provisional inquiries to reduce the need for full investigations, pausing investigations where a doctor is unwell, and providing support during the process.

This more proportionate approach is welcome – particularly in the midst of the current crisis. Even so, there is no doubt that a letter from the GMC can cause considerable anguish, particularly when the resilience of many clinicians has been diminished by chronic work stress, both before and during the pandemic. Many report difficulties in sleeping, or find that the experience affects their behaviour and relationships. Some find that the case takes up so much of their emotional energy that it is impossible to focus on their clinical practice and they have to take time off work. Some have to seek professional help because the constant strain has had such a detrimental impact on their mental and physical health.

The MDU is committed to supporting members throughout the medico-legal process and our advisers, claims handlers and in-house legal team are on hand to provide practical advice and support. Additionally, being doctors themselves, advisers can empathise and see things from the members' perspective, although they may not have direct experience of this level of scrutiny.

However, members who are facing an ongoing investigation are now given the option to speak to a fellow member who has 'been in their shoes' and who can offer both practical and emotional support and guidance as part of the MDU's new peer support network. While they do not discuss the specifics of a case, members who participated in the pilot scheme explained that it was wonderful to speak to somebody who had been 'in the same boat' as them and who understood what they were feeling and why.

It has been encouraging to see the willingness of members to become peer supporters and offer their time and support to help others when it would have been natural to want to move on. As one peer, who faced a GMC investigation, describes, 'When I was facing the stress of a fitness-to-practise investigation, this service would have been enormously helpful. Whether they need a one-off session or ongoing support, someone to talk to, or just someone to listen, I'm going to be here for them.'

This attitude perfectly illustrates the camaraderie that exists within the medical profession despite the considerable challenges we face. If, as seems likely, we see a rise in GMC complaints and claims arising from the extraordinary circumstances of the pandemic, that mutual support will continue to be a valuable source of strength and resilience.



# No child should face cancer alone

Young people impacted by cancer need Cancer Fund for Children's support now more than ever.

---

In Northern Ireland we support children and young people (aged 0-24) diagnosed with cancer, their siblings and parents, as well as young people who are struggling to cope with their parent's cancer.

For families living with cancer this has been a particularly anxious time as they try to cope with the emotional, financial and practical impact of cancer whilst navigating the challenges of the coronavirus pandemic.

Cancer Fund for Children understands the devastating impact a cancer diagnosis has on the whole family and that cancer patients are incredibly vulnerable. Throughout the pandemic we have continued to accept referrals for support and have adapted our services to ensure that young people don't have to face cancer alone.

Our team of Cancer Support Specialists are currently delivering individual and group support online so that young people feel less isolated, more resilient and are empowered to cope better with the emotional impact of cancer.

The whole family can also benefit from free therapeutic short breaks at Daisy Lodge, our residential centre in Newcastle Co. Down. Therapeutic short breaks of three to four days provide families with an opportunity to spend time together in a safe and supportive environment. They encourage rest and relaxation, teamed with unique support provided by our Cancer Support Specialists.



The Hardiman Family, with daughter Clodagh who was diagnosed with cancer at 16 months old.

## How to Make a Referral

Referral forms are available on our website or by calling us on T: 028 9080 5599. We accept referrals from the family's clinical team, allied health professional and GPs. We also welcome self-referrals. For more information, please contact Cancer Fund for Children's Community Services Manager Neil Symington E: [services@cancerfundforchildren.com](mailto:services@cancerfundforchildren.com).



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# PLANTING THE SEEDS

Sheetal Ladva Kanwar, Pharmacist and team member of Plant-Based Health Professionals UK, breaks down the basics, benefits, and concerns relating to health and plant-based nutrition.

Research has shown that poor diet is responsible for more deaths than any other risks globally, including smoking. In particular, dietary risk factors for mortality are diets high in sodium, and low in whole grains, fruit, nuts and seeds, vegetables, and omega-3 fatty acids.<sup>1</sup>

## WHAT IS A PLANT-BASED DIET?

A healthy plant-based diet is a diet where the amount of animal products and processed foods are reduced or eliminated in favour of fruits, vegetables, whole grains, legumes (beans), nuts and seeds.

At Plant-Based Health Professionals UK, we recommend a 100 per cent plant-based diet, which is one of the healthiest choices you can make. It is more specifically known as a whole food plant-based (WFPB) diet and is considered the optimal diet both for human and planetary health.<sup>2</sup>

Whole food describes natural foods that are not heavily processed. That means whole, unrefined, or minimally-refined ingredients.

Plant-based means food that comes from plants and doesn't include animal ingredients, such as meat, fish, dairy and eggs.

Often the term 'plant-based' is used interchangeably with 'vegan'.



Practically speaking, a healthy vegan diet is just one example of a plant-based diet. A vegan diet which relies primarily on processed foods would be considered unhealthy and not optimal for health.

A healthy plant-based diet or WFPB diet is supported by a number of international organisations, including the American College of Lifestyle Medicine, the American College of Cardiology, American Institute of Cancer Research, Harvard Medical School, True Health Initiative and the British Dietetics Association.

## WHAT ARE THE BENEFITS OF A PLANT-BASED DIET?

Plant-based diets are abundant in health-promoting micronutrients and anti-inflammatory compounds that are often lacking in the standard diet.<sup>3</sup>

Research has demonstrated that plant-based diets can reduce the risk of a number of chronic diseases and help reduce BMI, and increase the sense of emotional wellbeing and longevity. There are also additional environmental and ethical benefits associated with this pattern of eating.

## WHAT ARE THE CONCERNS ABOUT PLANT-BASED DIETS?

With some education and planning, and a reliable source of vitamin B12, omega-3 fatty acids and vitamin D, a well-balanced a plant-based diet can easily meet nutrient requirements.<sup>3</sup> A plant-based diet is suitable for all stages of the lifecycle, at every stage and at every age.

In some cases, referral to a dietitian can be useful, especially for those with complex medical conditions, such as Inflammatory Bowel Disease.

## HOW CAN ONE TRANSITION TO A PLANT-BASED DIET?

The Plant-Based Eatwell Guide is a good place to start and is based on Public Health England's Eatwell Guide (2016). It applies to most people, regardless of weight, dietary restrictions / preferences or ethnic origin.<sup>4</sup>

### THE PLANT-BASED EATWELL GUIDE RECOMMENDS ONE TO:

- Eat at least five portions of a variety of fruits and vegetables a day, but aim for more, as eating up to 10 portions a day has additional benefits for health
- Base meals on potatoes, bread, rice, pasta or other starchy carbohydrates. Choose intact whole grains over refined versions
- Include some fortified dairy alternatives, such as soya drinks and yoghurts; choose unsweetened options
- All plant foods contain some protein. Higher amounts are found in beans, peas, lentils, nuts, seeds, and tofu
- Choose unsaturated oils and spreads. Extra virgin olive oil for salads and cold-pressed rapeseed oil for cooking are better options although whole sources of fats, such as avocado, nuts and seeds, are usually preferable
- Drink six-to-eight cups / glasses of fluid a day, mainly water
- Make sure you get an adequate amount of vitamin B12. Choosing a B12 supplement is the cheapest and most reliable option. Vitamin B12

is manufactured by microorganisms and therefore deficiency is a potential issue for all dietary patterns, particularly over the age of 65

## HOW CAN PHARMACISTS HELP PROMOTE A PLANT-BASED DIET?

Pharmacists in all sectors can advocate a plant-based diet as part of counselling for prevention and treatment of chronic diseases and management of an overall healthy lifestyle.

Pharmacists already advise on various nutritional supplements and the interactions of these with foods and medicines. Increasingly they advise on alternatives to medicines that may contain animal-derived ingredients like lactose, gelatine and magnesium stearate for a growing number of vegan or vegetarian patients or those with religious, cultural or environmental beliefs.

A popular request is for vegan formulations of vitamin D – check the Plant-Based Health Professionals UK factsheet.

## WHERE CAN I GO FOR FURTHER INFORMATION ON PLANT-BASED DIETS?

Plant-Based Health Professionals UK is dedicated to providing education and advocacy on WFPB nutrition for the prevention and treatment of chronic disease. The group's website hosts a number of evidence-based resources, including CPD-accredited fortnightly webinars, factsheets, a weekly critique of the latest plant-based dietary news and a CPD-accredited six-week online education course for health professionals at Winchester University with additional benefits for members.

There are a growing number of advocates of plant-based diets and an incredible array of vegan-friendly recipe books and products – some of which are healthier than others.

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

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Northern Ireland

# Healthcare

Review

## THANK YOU TO ALL OUR HEALTHCARE PROFESSIONALS

As the spread of COVID-19 presents pressing and continued challenges to our community, the team at Northern Ireland Healthcare Review would like to express our gratitude to the tremendous members of our healthcare teams as they work tirelessly to assist and support patients.

**Thank you for all that you do.**

If you would like to share your story or utilise our platform to communicate messages of awareness, please don't hesitate to email the team at [sarah.nelson@medcom.uk.com](mailto:sarah.nelson@medcom.uk.com).

# FEELING THE BURN

Research into Google data – focussing on online searching habits – has indicated that we're in danger of an early 2021 'burnout spike'. This is due to the alarming discovery that searches for symptoms online with terms such as 'signs of burnout' have increased by at least 24 per cent throughout 2020 compared to the previous year.

Leadership teams should be ready to address issues of burnout following the gruelling work schedule that has been placed on healthcare professionals, disruption of people's regular Christmas break plans, and impacted personal lives due to coronavirus. Additional support will be needed for stress this winter in order to maintain mental health and productivity.

A recent poll from the British Medical Association of doctors found that once the pandemic is over 51 per cent are more likely to work fewer hours; 26 per cent say that they are more likely to retire early; and 22 per cent responded that they are more likely to leave the NHS for another career.

Despite the recent peaks, there's evidence of a consistent yearly increase in searches for symptoms of burnout. Google search data, collected from search volume tool kwfinder.com, highlights a gradual increase in volume of searches for 'signs of burnout' over the last four years, culminating in a notable spike in January 2020. On average, total searches have increased by 41 per cent annually since 2017.

Global online searches for the term 'occupational burnout' have increased by more than 2,500 per cent since 2015, and the COVID-19 pandemic is fuelling an even faster rise in work-related mental health issues.

## WHAT CAN YOU DO TO REDUCE EXCESSIVE STRESS

**WORKPLACE HEALTH EXPERTS HAVE WARNED THAT WE NEED TO BE MORE PREPARED THAN EVER TO DEAL WITH EMPLOYEE BURNOUT – TRADITIONALLY ASSOCIATED WITH LOW MOOD, DEPRESSION AND DEMOTIVATION. STAY ALERT TO THE WARNING SIGNS, AS WELL AS THE CRUCIAL STEPS FOR WARDING OFF ANY FURTHER ESCALATION.**

### AND BURNOUT?

It's clear that understanding of the problem among employers remains relatively low. Angela Knox, Director of workplace employee wellbeing programme, Keep Fit Eat Fit, explained, 'Recognising burnout or excessive stress in employees is a vital part of the HR manager's work, and one which sadly often gets overlooked. If employers have systems in place that are designed for regular monitoring of each employee then problems can be identified and dealt with before they escalate.'

'Opportunities to intervene can easily be missed. In larger companies with higher head counts it is a good idea for the head of HR to have eyes and ears in the various departments so that they can keep track of any key developments or problems before they occur.'

There are plenty of steps that

people can take in order to reduce stress and the risk of burnout, and employers can proactively encourage these among their employees.

### ENCOURAGE REGULAR EXERCISE

Even the shortest 10-minute brisk walk can have a real impact on mood and motivation; it doesn't have to be a 10-mile run. Getting away from the desk to exercise in the fresh air has a direct link to increased productivity.

### ENSURE EMPLOYEES DON'T SIT AT THEIR DESKS FOR TOO LONG

Humans are not made to sit for long periods, and a five-minute desk break every hour reduces the risk of injury, refocuses the mind, and helps break the monotony of both home and office working – even if it's just a walk to the kitchen for a

cup of tea.

### ENCOURAGE QUITTING UNHEALTHY HABITS

Poor diet and excessive drinking both have a major impact on a person's stress levels, as does smoking. In fact, a recent study found that quitting smoking made immediate positive improvements to mental health, especially after the first four weeks.

### MAKE SURE PEOPLE TALK TO THEIR LINE MANAGER

Communication is what prevents those initial feelings of pressure, anxiety or demotivation from becoming mental health problems like burnout. The sooner an employer is aware of the problem, the sooner they can do something about it.

### SET UP ROUTINE CATCH-UPS WITH THE TEAM

With a large number of employees now working from home, it's important to keep lines of communication open to keep the social aspect of work. This reduces the feeling of isolation and has a positive impact on wellbeing.

### PROMOTE MENTAL HEALTH DAYS

Fostering a workplace culture where people don't feel guilty for occasionally taking the day off sick – even if they've not got a physical illness – will help alleviate longer-term stress and maintain morale.

### PUSH ANNUAL LEAVE

Employees should be encouraged to use all of their holiday allowance each year, even if they're not going away anywhere. This fosters a healthier work environment and creates a better work-life balance that benefits everybody.

ADHD

# ALL KIDDING ASIDE

ADHD is underdiagnosed in the UK, with less than three per cent diagnosed and less than one per cent of the childhood population receiving medication as part of their treatment plan. Sparked by this startling incidence, Dr Tony Lloyd, CEO of the ADHD Foundation, sheds light on the diagnostic considerations for ADHD in children.

ADHD is a lifespan neurodevelopmental disorder that impacts on many aspects of physical and mental health. ADHD is costing the NHS substantial sums of money through hidden costs in other areas of healthcare – something that many clinicians, primary care practitioners and commissioners are not aware of.

The health outcomes and long-term healthcare costs for undiagnosed and untreated ADHD are now better understood. Undiagnosed untreated ADHD is a public health issue; ADHD correlates with increased risk of eating disorders, obesity, diabetes, allergies, hypertension, and increased risk of brain haemorrhage, early onset cardiovascular disease, lung cancer, injury through physical accidents, as well as increased risk of mental health comorbidities. Comorbidity with other neurodevelopmental conditions is the rule rather than the exception.

Early identification, intervention, assessment and diagnosis is therefore a new priority in NHS service design and delivery of ADHD in community paediatrics and CAMHS. NHS England in conjunction with NICE, leading clinicians across a range of disciplines, and patient-led organisations, have established a national strategy committee to address how this need can be met. The need for a greater role in primary care, and how this is funded and implemented, is currently under discussion with Royal Colleges and the Department of Health. GP hubs and nurse-led clinics increasingly play a crucial role in safe, cost-effective pre- and post-diagnostic pathways across the UK. This will become more widespread as the post-pandemic recovery plan addresses even longer waiting times for assessments which, before the pandemic, were at a record rate of up to two years for children in some parts of the UK and up to five years for adults.

A National Expert Consensus Statement on Health Inequalities in ADHD, funded by the ADHD Foundation and led by Dr Suzy Young, Dr Tony Lloyd, CEO of the ADHD Foundation, and Professor Philip Asherson of King's College London, will be published in

February 2021. This statement, endorsed by members of all Royal Colleges, also calls for a systemic approach to improving outcomes and life chances through improvements in training for clinicians and also in education settings so as to address the impact of environmental factors on the developing neurology of children. The Consensus Statement also emphasises research about the greater understanding of the interplay between genetic heritability and childhood experiences in the developing neurocognitive capacity of children, and how pervasive learner anxiety in childhood impacts on mental health in adulthood.

NICE guidelines state clearly that treatment should be multi-modal, providing psycho-educative approaches to empower patient self-care, psychological therapies, and parent skills training and peer group support. In practice, treatment is invariably limited to prescribing of medication. There is also growing concern among patient-led charities and support groups and primary care clinicians that children diagnosed with ADHD who are referred to CAMHS for psychological therapies – having reached the threshold for a referral (self-harm, attempted suicide and eating disorders) – are often declined on the premise that their ADHD is the cause, and therefore does not meet the criteria for psychological therapies, in breach of the Equalities Act of 2010 and NICE guidelines.

New models of care also offer the opportunity to provide more user-friendly environments for young people to access adult ADHD services, such as local GP surgeries and specialist hubs away from psychiatric hospital clinics and the opportunity to create lifespan services. This is critical for young people transitioning from community paediatric services and CAMHS to adult services who, understandably, do not view themselves as 'psychiatric' patients.

## HOW DO WE IDENTIFY, ASSESS, AND TREAT ADHD

### IN CHILDREN?

ADHD is genetic in origin and heritable. That doesn't always mean one or both parents also have ADHD, rather the combination of their genetic profile can result in having a child with ADHD. ADHD is a lifespan condition; by adulthood, many people have learned to live happy, healthy, and successful lives, using a range of interventions and strategies that include medication, daily exercise, healthy nutrition, stress management strategies, and what are known as 'executive functioning skills', to help them better plan and organise their lives, especially in school and in the workplace.

Many underachieve in education, with implications for life chances and economic wellbeing. The co-occurrence of autism (26 per cent) and dyslexia, dyscalculia and dyspraxia evident in over 40 per cent of those with a primary diagnosis of ADHD, often results in education providers and parents assuming the child is of low academic ability.

Viewing ADHD as a spectrum disorder in the same way we do with autism will enable us to understand that the characteristics of ADHD are 'natural' presentations of human behaviour, but in a more extreme form. All children are hyperactive, inattentive, and impulsive – traits which decline with neurological maturation and, for those with ADHD, these characteristics can lessen when the brain reaches full maturity by early 20s. The developmental delay in certain brain regions of approximately three years can often present as immature behaviour or lack of ability to mainstream school teachers who expect levels of academic attainment to correlate with certain chronological ages and educational key stages.

ADHD presentation in children must be evident across at least two domains – home and school. There can sometimes be conflicting views between home and school due to misconceptions of what ADHD is and is not. In 2013, the DSM5 reclassified ADHD as a neurodevelopmental condition – as distinct from a behavioural disorder, reflecting both the developmental delay typical of ADHD and

recognising that children with ADHD don't always display context inappropriate 'distress' behaviours. Subjective opinion obtained from observations by parents and teachers should be investigated further if there is divergence of presentation between home and school.

Similarly, presentation of ADHD characteristics with children who have comorbid autism – even when it is a sub threshold for a secondary diagnosis of autism – can, at times, mask certain characteristics of ADHD. This also raises questions for clinicians about how children who display sub threshold comorbidities should be treated and what advice they give to parents and teachers about how their needs are understood and supported both at home and school.

## THERE ARE THREE MAIN CHARACTERISTICS OF ADHD

### INATTENTION

Resulting in poor concentration, poor working memory, cognitive overload, resulting in problems with task initiation and learner anxiety.

### IMPULSIVITY

Presenting as impulsive actions, words, thoughts and emotions, that may cause social and communication difficulties, as well as frequent mistakes and repeating errors that the individual knows are incorrect or not contextually appropriate responses, but seems unable to control. Sadly, this is often interpreted as deliberate chosen behaviour that is inappropriate. In reality, ADHD impulsiveness is not a lack of self-awareness, or 'the rules', but a neurological impulse control that enables the child to consider the consequences until after the fact.

### HYPERACTIVITY

More common in boys than girls, and one of the reasons boys are more often referred for diagnosis than girls. Hyperactivity doesn't impair academic performance, but is viewed as disruptive – sometimes deliberately so by adults who assume incorrectly that the child has the ability to always control this instinctive need to move. Many don't understand that the natural way to utilise the neurotransmitter dopamine is 'to move'.

## SECONDARY CHARACTERISTICS

## FREQUENTLY CONSIDERED BY CLINICIANS IN THE CONTEXT OF A CLINICAL INTERVIEW

- Low emotional resilience, frustration, and rejection sensitivity
- Concerns with sleep
- Family history of neurodevelopmental conditions
- Traumatic brain injury, including trauma arising out of epilepsy and developmental delay caused by pre-term births or perinatal trauma
- Age of parents at conception and whether the child was conceived with IVF that may impact on pre-term birth
- Poor executive functioning skills, such as poor emotional regulation, difficulty with 'working memory', resulting in cognitive overload, an inability to plan and organise tasks, and task initiation or completion. Feedback from parents and schools will also offer indications of poor executive functioning skills

## ASSESSMENT AND DIAGNOSIS

Observational rating scales, such as Connors Scales, Swan Rating Scales and Vanderbilt, completed by parents and teachers, are commonly employed as part of the pre-diagnostic screening undertaken before the clinical interview. Common misconceptions and enduring myths about ADHD can skew the interpretation of the rating scales by parents and teachers and, as a consequence, there is an emerging trend of employing computer-based, objective, cognitive functioning tests, such as QB Test and QB Check, that are validated with an accuracy rate in excess of 83 per cent.

The added advantage of such tests is that QB Check can be administered by a trained teacher and form part of the initial screening before making a referral for a full clinical assessment. This also ensures that interventions can be put in place at home and school as soon as the concern is identified to avoid the traditional model of waiting for a formal diagnosis through the NHS which can take up to two years.

*A Swan Rating Scale combined with a number of questions that GPs, school nurses and School Special Educational Needs Co-Ordinators may find useful can be found here: [www.adbdfoundation.org.uk/wp-content/uploads/2019/04/ADHD-screening-with-SNAP.pdf](http://www.adbdfoundation.org.uk/wp-content/uploads/2019/04/ADHD-screening-with-SNAP.pdf).*

## MEDICATION

There are a number of different medicines for ADHD. Medicines for ADHD that are licensed in the UK are psychostimulants that regulate dopaminergic function such as, Methylphenidate, Lisdexamfetamine, and Dexamphetamine. Non-stimulant noradrenergic applications include Atomoxetine and Guanfacine.

Optimising medication requires gradual titration and sometimes employing stimulant and non-stimulant medications to meet the need of the unique neurology of the child. This should then be reviewed every six months and adjusted in line with physical and psychological development.

Many parents remain concerned about medication, but their efficacy and safety are proven. Clinicians are advised to listen to parents' concerns and take the time to explain that such medication is not meant to be used in isolation from other interventions and that they are not a 'morality pill' that teaches children how to behave, rather they simply improve cognitive functioning which in turn reduces anxiety, which is the main cause of context inappropriate behaviour.

*NICE Guidelines 2018 on the diagnostic criteria and treatment of ADHD in England and Wales can be accessed via [www.nice.org.uk/guidance/ng87](http://www.nice.org.uk/guidance/ng87).*

## CONCLUSION

Given that research in neuroscience suggests that one-in-five of the population have neurodevelopmental conditions, there is now a movement toward viewing such disorders as part of the natural variation in human neurocognitive capacity.

That prevalence is so high, from an evolutionary perspective, perhaps it is time we began to change the language derived from a deficit-based research paradigm that labels those on the edge of the standard distribution curve as 'abnormal' or 'disordered' and instead adopt a more strength-based approach, while also acknowledging and treating the impairment to wellbeing across both health, education and socio-economic wellbeing.

Our 19th Century concept of intelligence and how we measure this in education is being redefined by modern industry and commerce. This is especially true of those major growth industries of the 21st Century that are influencing culture and commerce, such as technology, bioscience and compute-driven creative design, who have been actively recruiting neurodivergent employees for over a decade.

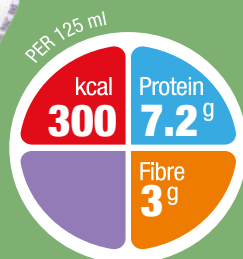
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# TAKING A STAND AGAINST STOMACH DISEASES

PROFESSOR TAMARA MATYSIAK-BUDNIK, HÉPATO-GASTROENTÉROLOGIE & ONCOLOGIE DIGESTIVE, INSTITUT DES MALADIES DE L'APPAREIL DIGESTIF, HIGHLIGHTS THE IMPORTANCE OF WIELDING AWARENESS OF THE GLOBAL BURDEN OF GASTRIC DISEASES, AND THE NEED FOR FURTHER RESEARCH IN THE FIELD, AS WELL AS IMPROVED PREVENTION AND TREATMENT STRATEGIES.

## THE ROLE OF THE STOMACH WITHIN THE DIGESTIVE SYSTEM

The stomach is a vital organ within the digestive system; it's responsible for the chemical breakdown of ingested food before it continues its journey into the small intestine. The stomach is also involved in the absorption of a number of crucial compounds and vitamins, such as vitamin B12, necessary for the production of red blood cells and the functioning of the nervous system. Additionally, the stomach's acidic environment protects against potentially harmful microbes that may enter the body with food and liquids.

## GASTRIC DISEASES

Gastric diseases range in prevalence and severity, from common short-term occurrences of dyspepsia (indigestion), to more harmful and severe chronic disorders.

These include a variety of widespread functional disorders, such as irritable bowel syndrome (IBS), which can have a devastating and life-altering impact on the lives of sufferers. Gastric diseases also affect society as a whole, placing significant pressures on over-burdened healthcare systems. IBS, which currently affects one-in-10 people globally, is estimated to cost €3.2 billion per year in Germany alone.

## GASTRIC CANCER

As one of the most life-threatening forms of gastric disease, gastric cancer is estimated

to be the fifth most frequently diagnosed cancer and third most common cause of cancer-related death in the world. In 2018, there were 80,000 new diagnoses of stomach cancer and nearly 60,000 attributable deaths in Europe. Due to the generalised nature of the symptoms, gastric cancer is often only detected at a later stage, leading to comparatively lower survival rates than many other cancers.

Despite the general decline in gastric cancer cases globally, recent studies have uncovered a concerning link between patients with chronic autoimmune gastritis (AIG) and the development of gastric cancer. In two studies carried in America and Sweden, results showed that individuals with AIG had a three-fold increased risk of developing stomach carcinoid tumours and adenocarcinomas. Like other autoimmune diseases, AIG predominately affects females (3:1 ratio), potentially providing a link between AIG and the increasing incidence of gastric adenocarcinoma among young white females in America. The recent detection of gastric cancer among younger sectors of the population may indicate that declining levels of gastric cancer could reverse in the future.

Identifying and treating gastric cancer at an early stage can dramatically increase survival rates and treatment options. The five-year survival rate for gastric cancer is currently 31 per cent; reflecting the often late diagnosis of the condition. In comparison, the five-year survival rate for gastric cancer more than doubles (68

Continued onto next page

## STOMACH DISEASES

per cent) if the cancer is detected before spreading outside the stomach. Earlier detection of gastric cancer can also lead to a reduced need for aggressive treatment options and invasive surgery. Although not a certainty, precancerous lesions can be an indicator of future cancer progression and should be followed carefully. Recognising precancerous lesions in patients and subsequently monitoring them is an essential measure in reducing the incidence of and mortality rates associated with gastric cancer. The recent publication 'Management of Epithelial Precancerous Conditions and Lesions in the Stomach' clearly characterises the various lesions and management methods, encouraging a standardisation of treatment strategies across Europe for precancerous conditions and lesions in the stomach.

### RECENT ADVANCEMENTS IN ENDOSCOPIC IMAGING

Decreasing global mortality relies primarily on the early detection and accurate diagnosis of gastric cancer through endoscopy.

Over the last few decades, there have been a number of critical technological advancements in endoscopic imaging, improving mucosal visualisation and diagnosis. High-definition endoscopy with chromoendoscopy is currently one of the most effective diagnostic methods for identifying gastric adenocarcinoma, potentially allowing for the visualisation of gastric atrophy and intestinal metaplasia.

Despite these advances, continual improvements in endoscopic imaging are still necessary to significantly improve the prognosis of gastric cancer.

### HELICOBACTER PYLORI (H. PYLORI)

*Helicobacter pylori* (*H. pylori*) is one of the greatest risk factors for gastric cancer. Often contracted during childhood, approximately two-thirds of the world's population harbours *H. pylori* bacteria within the stomach. Although an important factor in the development of gastric cancer, evidence has shown that the successful eradication of *H. pylori* does not completely prevent the development of gastric cancer. A 2018 study suggested that *H. pylori* infection may only be an early event in the development of gastric cancer, preparing the gastric mucosa for further changes. Further research on the gastric microbiome is required to identify the precise role of *H. pylori* in the

development of gastric cancer, potentially opening up pathways to novel prevention and treatment strategies.

Important strides are continually being made in the treatment of *H. pylori* infection. Quadruple therapy is becoming increasingly common in areas with growing levels of resistance to standard triple therapy and impressive eradication rates are being achieved. More recently, vonoprazan, a potassium-competitive acid blocker, has been explored as a novel treatment strategy. A large Japanese study comparing vonoprazan to proton-pump inhibitors demonstrated a higher eradication rate with vonoprazan. Noticeably, the eradication rates of vonoprazan combined with amoxicillin and clarithromycin in clarithromycin-resistant patients was over 80 per cent. With a general rise in antibiotic resistance rates globally, evolving treatment options are necessary to combat *H. pylori* infections and associated gastric conditions.

Despite major advancements in the field, gastric diseases remain prominent across the globe. Concerning evidence has also suggested that a variety of gastric diseases may be increasing among the younger population. With the pathogenesis of many gastric conditions still being debated, further research is urgently required to improve patient outcomes and reduce the societal impact caused by these often burdensome and disruptive diseases.

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# HYPOGLYCAEMIA: THE LOWDOWN

Sharpen your knowledge of hypoglycaemia and diabetes – tackling the causes, impact, and avenues of treatment along the way – through the expert analysis of Gabriela da Silva Xavier, Senior Lecturer in Cellular Metabolism at the University of Birmingham.



Gabriela da Silva Xavier

## WHAT IS HYPOGLYCAEMIA?

Hypoglycaemia literally means low blood sugar and is clinically defined as a blood sugar level at or below 3 mM. In adults, severe hypoglycaemia is an episode of hypoglycaemia with cognitive impairment and requiring third-party assistance.

(1) For the paediatric population, this would be an episode with severe neuroglycopenic symptoms (e.g. coma and convulsions) that requires third-party assistance. (2) It's a condition that is frequently associated with the treatment of diabetes, although it also occurs in a variety of other less common conditions

e.g. Addison's disease, insulinomas, congenital hyperinsulinism.

Hypoglycaemia is like the quiet relative to hyperinsulinaemia in the treatment of diabetes, in that the lowering of high blood glucose is usually more of the focus topic, even though hypoglycaemia is the most common complication of insulin therapy in people with diabetes and contributes to the adverse health outcomes in diabetes. For example, a recent systematic review and meta-analysis showed an association between hypoglycaemia and longer length of stay and greater in-hospital mortality. (3)

During hypoglycaemia, patients may experience palpitations, pallor, shakiness, dizziness, headaches, and feelings of fatigue, anxiety, hunger, irritability, and a tingling sensation round the mouth. As hypoglycaemia progresses, patients may also experience confusion, visual disturbances, seizures, and loss of consciousness. It's not uncommon for patients experiencing extreme hypoglycaemia to be described as if they were intoxicated. Hypoglycaemia can occur while sleeping. But what gives rise to these symptoms?

## WHAT CAUSES HYPOGLYCAEMIA?

In people with diabetes, the main cause of hypoglycaemia is taking too much glucose-lowering medication, such as insulin, sulphonylureas or glinides; delaying / skipping meals; intense exercise or activity; and excessive intake of alcohol. Other possible causes of hypoglycaemia include reactive hypoglycaemia (which may be caused when there had been an excessive intake of carbohydrates and / or alcohol, surgical procedures for gastric bypass or ulcer, inherited metabolic disorders), binge drinking, and fasting / malnutrition.

Hypoglycaemia could also be induced by the intake of certain medication (e.g. quinine).

## SO WHAT DOES EXCESSIVE LOWERING OF GLUCOSE DO?

Glucose is essential for brain metabolism and, therefore, brain function. Under normal circumstances, numerous physiological mechanisms ensure that blood glucose levels do not fall dangerously low.

Continued onto next page

# HYPOGLYCAEMIA

Glucagon is a hormone that is secreted by the pancreatic alpha cells (one of the cell types that make up the pancreatic islet) in response to low blood glucose, i.e. glucagon is the counter-hormone to insulin. Like insulin, glucagon signals to peripheral tissues. Unlike insulin, the sum total of glucagon signalling is the mobilisation of glucose stores (primarily in the liver) and de novo synthesis of glucose via gluconeogenesis to restore normal blood glucose.

Insulin secretion is suppressed when blood glucose concentrations fall below 4.4 mM (4), and glucagon secretion is activated when blood glucose is at 3.9 mM (4, 5), followed by elevation of epinephrine, growth hormone and cortisol (the sympathoadrenal response) as blood glucose continues to fall. (4 – 7) The fall in blood glucose is thus accompanied by the activation of counter-regulatory mechanisms to mobilise glucose stores and gluconeogenesis, restriction of peripheral glucose utilisation and autonomic symptoms which may result in food-seeking behaviour (excellently reviewed in (8)).

Glucagon release is suppressed in the presence of high insulin. (9) When excessive insulin is present in the blood stream due to e.g. excessive administration of insulin in type 1 diabetes or congenital hyperinsulinism, the alpha cells do not secrete glucagon, leading to a decrease in the counter-regulatory response. (9, 10) Loss of alpha cell function is observed in patients with type 1 diabetes. (11, 12) This loss of glucagon signalling, accompanied by a blunting of the sympathoadrenal response (caused by repeated exposure to hypoglycaemia) (13), over time, leads to hypoglycaemia unawareness, and the occurrence of persistent episodes of low blood glucose.

Postprandial hypoglycaemia has been reported in c. 75 per cent of patients that have undergone gastric bypass surgery. (14) This may be due to the exaggerated insulin and glucagon-peptide like one response from altered nutrient transit following the bypass surgery (15, 16), followed by subsequent blunting of the sympathoadrenal responses to hypoglycaemia. (8)

## HOW IS HYPOGLYCAEMIA TREATED?

Treatment usually involves attempting to restore blood glucose levels to the normal range through the intake of high sugar foods / drinks, or with medication, depending on the cause and severity of the hypoglycaemia. The ability of glucagon to induce elevations of blood glucose means that exogenous glucagon lends itself to counter insulin-induced hypoglycaemia in patients with type 1 diabetes or insulinomas, and reactive hypoglycaemia.

A patient that is unconscious due to severe hypoglycaemia can be treated with an injection of glucagon as an emergency measure.

Various formulations of glucagon are available for use either by intramuscular, subcutaneous, intravenous, intranasal, or insulin pump administration (reviewed in (8)), many with increased stability and ease of administration. Continuous blood glucose monitoring allows the tracking of blood glucose in diabetic individuals requiring insulin and have been shown to help reduce hypoglycaemia incidence, particularly in patients with hypoglycaemia unawareness and nocturnal hypoglycaemia (reviewed in (17) and (18)). The use of glucagon and insulin in combination in a dual-hormone artificial pancreas, mimicking the function of the two hormones in vivo, may help to maintain blood glucose concentration within a target range. (19)

Glucagon acts on multiple tissue systems and the short-term side-effects of glucagon administration – nausea, vomiting, headaches – are well-known, but the long-term consequences of chronic use are still unclear. The preparation and administration of injectable

glucagon can be problematic, leading to errors in the delivery of the drug, and under-prescription and use of injectable glucagon. (20, 21) Thus, there is a requirement for better formulations for glucagon and a better understanding of the long-term effects of chronic use for the treatment of hypoglycaemia.

Severe hypoglycaemia can be life-threatening. Due attention to hypoglycaemia risk is important for good treatment outcomes and avoidance of diabetes-related complications.

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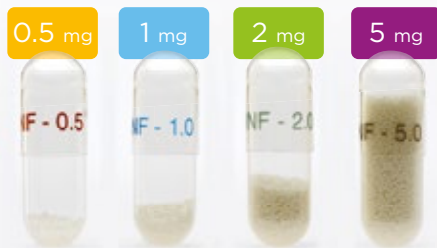
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# Alkindi® for the Individual

Individualised, accurate and flexible dosing—  
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hydrocortisone granules  
in capsules for opening



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

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

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

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

## Legal classification: POM

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

## Marketing Authorisation Holder

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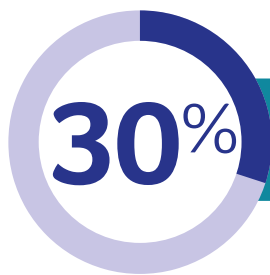
**Prescribers should refer to summary of product characteristics for full prescribing information.**

**Approval Code:** Inf EU-GB-0143

**Date of Preparation:** November 2020

**References:** 1. Diurnal. Alkindi® Summary of Product Characteristics. Available from <https://www.medicines.org.uk/emc/product/9032/smpc>;  
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**Date of Preparation:** December 2020 **Code:** Inf EU-GB-0150  
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**Adverse Events** should be reported. Reporting Forms and information can be found at [www.mhra.gov.uk/yellowcard](http://www.mhra.gov.uk/yellowcard)  
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of infants experience symptoms of regurgitation<sup>1</sup>

# WHY MEDICATE? TRY NUTRITION FIRST.

For bottle-fed infants with frequent regurgitation

## ESPGHAN\*

March 2018

RECOMMENDS  
a stepped-care approach...

REVIEW

the feeding history.

REDUCE

the feed volumes by trialling smaller, more frequent feeds (while maintaining an appropriate daily total).

TRIAL

a thickened formula.



Clinically proven to reduce infant regurgitation episodes by **78%**<sup>2</sup>

**Aptamil Anti-Reflux** is a thickened formula for the dietary management of reflux and regurgitation in bottlefed infants

**AVAILABLE IN RETAIL AND PHARMACY OUTLETS**

\* European Society for Pediatric Gastroenterology, Hepatology, and Nutrition

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**IMPORTANT NOTICE:** Aptamil Anti Reflux is a food for special medical purposes for the dietary management of frequent reflux and regurgitation. It should only be used under medical supervision, after full consideration of the feeding options available including breastfeeding. This product should not be used in combination with antacids or other thickeners and is not suitable for premature infants. Suitable for use as the sole source of nutrition for infants from birth and as part of a balanced diet from 6 months.

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December 2020