COVID-19: FROM THE FRONTLINE
YOUR VOICES, YOUR VIEWS

HEART FAILURE
A blueprint for change

SMOKING CESSATION
Making every contact count

MENTAL WELLBEING
Overcoming pandemic fatigue

GASTROENTEROLOGY
Dietetic contributions to care
Help them face life’s adventures

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EleCare® is the first amino acid-based formula to contain 2’-FL*,† a major component of most mothers’ breast milk:1

- Helps support the immune system in the gut and beyond1–3
- Contains 2’-FL† which has proven benefits on the gut and systemic immune responses1
- Supports healthy growth and symptom resolution‡4–7
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† 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.

EDITOR’S LETTER

Welcome to the latest edition of Northern Ireland Healthcare Review!

That feeling of being out of my depth has been as familiar a theme in my life as the whistle of a kettle boiling – seemingly inevitable.

This January marked five years since I took up the role as Editor of Northern Ireland Healthcare Review, and I can so easily flash back to the panic that consumed me during those first few months. I felt like I was trying to wade through an ever-filling pool of uncertainty and self-doubt.

I was desperate to represent this sector that I cherish so much in the best way possible, yet not deriving from a healthcare background, nor being equipped with any medical expertise – unless having a first-aid kit at the back of my kitchen cupboard counts – I simply didn’t know how.

Then a couple of weeks in I sat at my desk and dedicated hours to ringing and emailing a plethora of the region’s healthcare professionals. Although my reasoning was initially to introduce myself and my arrival to the post, these conversations soon took on a whole new meaning. You shared your backgrounds with me; what drives your hard work; and the direction in which you want our healthcare services to go. I was gripped.

As the dialogue continued, my nerves began to evaporate, and I realised that my new job wasn’t about practicing and perfecting my own voice – it was about giving you the platform to use yours. To share your ideas and innovations; to promote the causes which are ingrained on your hearts; to share the industry’s successes and signpost the dents which need mended.

So as I sit here typing one year on since the pandemic turned the tide on our normal ways of working and living, and showered us in sadness and fear, it’s not my experiences that matter – yours do. Aiming to represent your voices and views, in this edition of Northern Ireland Healthcare Review we asked you to share your stories of how you have persevered through the unknown and adapted to the new normal of COVID-19 (beginning on page 16).

Also in this issue we explore how the effects of coronavirus will be seen in the dystonia community for years to come (page 44); tackle the fatigue associated with the post-COVID era (page 24); and delve into the British Heart Foundation’s new report which sets out a blueprint for heart failure change (page four).

That’s not all – Cancer Focus Northern Ireland share why now is the time for health experts to support and strengthen stop smoking measures (page 36), and the Salivary Gland Cancer UK team depict the risks of missed detection (page six). We round-up some of the latest Parkinson’s research updates too (page 32).

Take care.

Sarah Nelson Editor
sarah.nelson@medcom.uk.com
“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

UCB has a passionate, long-term commitment to help patients and families living with severe diseases lead normal, everyday lives.

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.
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Discover the devastating consequences the pandemic has posed for the dystonia community
Disjointed and unequal care, likely exacerbated by the COVID-19 pandemic, is leading to more people dying with heart failure. Harnessing the urgent need for action, the British Heart Foundation has launched a new report which sets out a blueprint for change. One of the co-authors of the report, British Heart Foundation Northern Ireland Health Systems Insight Manager, Karen McCammon, sheds light on its findings and delves into how the enhanced allocation of support can help individuals live well with heart failure for longer.

Karen McCammon

ABOUT THE REPORT
Heart failure affects nearly a million people across the UK. It’s a life-limiting condition that too often causes emergency hospital admissions, poor quality of life and ultimately early death. But it’s possible to live well with heart failure and the British Heart Foundation’s report offers a blueprint for change in the way we care for people with this condition in the future.

The report identifies four key areas that hold the potential to transform services and improve outcomes and experiences for people living with heart failure:

1. Reframing heart failure as a long-term condition
2. Focusing on people, not structures
3. Driving change with data
4. Leading across the pathway

By diagnosing people with heart failure early, getting them the specialist care they need and joining up services, it is possible to cut emergency admissions, improve quality of life and give people the opportunity to live well for longer.

The COVID-19 pandemic has stretched our health services like never before, shining a light on existing inequalities in heart failure care and support. As the NHS across the UK strives to return to delivering routine care, it’s vital that heart failure services aren’t just ‘switched back on’ but are built back better.

The British Heart Foundation’s report, supported by the British Cardiovascular Society, the British Society for Heart Failure, the Primary Care Cardiovascular Society and the Pumping Marvellous Foundation, provides a blueprint for how this can be done, so that everyone with heart failure has the opportunity to live well for longer.
CAN YOU GIVE US A GLIMPSE INTO HEART FAILURE INCIDENCE IN NORTHERN IRELAND?

There are approximately 19,000 people with heart failure in Northern Ireland but that’s only those who have been diagnosed – heart failure is very common but underdiagnosed. The data in Northern Ireland isn’t great but we know that in the UK the condition is the greatest cause of hospital admission for people over 65.

WHAT WERE THE MAIN CHALLENGES FACING THESE PATIENTS PRIOR TO THE PANDEMIC?

The challenges are variable and depend very much on whether specific areas have a local leader or champion. Some areas are doing really good work – for example, the Southern Health & Social Care Trust appointed a consultant, Patricia Campbell, a few years ago and she has really focussed on heart failure and pushed a lot of things forward. If there isn’t a champion, heart failure tends to be at the bottom of the pile of priorities so the nature of the challenges can generally differ.

HOW HAVE THESE HEART FAILURE ISSUES INTENSIFIED IN LINE WITH THE ESCALATION OF COVID-19?

One of the major healthcare issues in Northern Ireland has been the shortage of nurses and this has been exacerbated by the pandemic. Heart failure patients – the ones that we know about – are usually looked after by specialist heart failure nurses in which they monitor the patients’ drugs, help them stay out of the hospital, and help them with rehab in order to live better quality lives. A lot of these specialist nurses were taken from their wards and needed to work in other wards that were left because staff were moved from the CCU to cover COVID, or they were moved to cover the CCU. The heart failure services were therefore depleted.

Alongside this is the fact that individuals with heart failure are vulnerable and high-risk so there has been a reluctance to bring them into the hospital or for a face-to-face appointment due to fears around them contracting COVID. Telephone consultations haven’t been without their challenges as individuals are being asked to describe their own symptoms. People with heart failure collect fluid at times and one of the ways this shows up is that they become short of breath and their ankles will swell a little bit more – but this can’t be properly checked over the phone.

Also, heart failure is quite often – but not always – a disease of the elderly, and this generation may have a tendency to not want to ‘bother’ the health system after seeing on the news how there’s a huge burden on the NHS.

CAN YOU TELL US ABOUT THE ORIGINS OF THE BRITISH HEART FOUNDATION’S NEW REPORT AND THE NECESSITY OF ITS RELEASE?

The report came about through insight. We had a team of 27 people throughout the UK who worked with health leaders, such as doctors and nurses, and it became really obvious through what they were hearing that heart failure was a huge problem. There has been a lot of improvements in other areas of cardiovascular health but care for heart failure patients hasn’t moved on. Whenever we recognised that, we set out to collect more and more insights – and the report is based on that and what people in the midst of the provision of services are experiencing and what needs to happen to make things better.

HOW DID YOUR INVOLVEMENT IN THE PROCESS COME ABOUT?

I was one of the authors of the report and in our team of 27 people we divided ourselves into different groups – as a result of my professional experience I was in the group which looked at heart failure.

It was really interesting hearing the feedback from healthcare professionals, as well as patient focus groups. We found that in the different areas of the UK, a lot of the same issues arise, such as the lack of data, the fact that leadership makes a difference, and that heart failure care, like many things, is based around structures – people are made to fit into the structures that are there already.

We also have a heart helpline at the British Heart Foundation which has been very busy – particularly at the beginning of the pandemic. It’s staffed by cardiac nurses and we have all helped out on it. I remember one lady phoning in who explained that although her father had heart failure, she couldn’t make any progress in confirming a GP appointment for him or getting an ambulance to arrive. There was just no support available because everything had suddenly changed.

WHY MUST PSYCHOLOGICAL AND EMOTIONAL SUPPORT FOR HEART FAILURE PATIENTS BE IMPROVED?

Heart failure patients need emotional support to live their lives, particularly because the term ‘heart failure’ can initially be very frightening and they might not know what it means. Their symptoms, such as struggling to breathe, can be difficult for their loved ones to observe so they need support too.

Heart failure is a difficult diagnosis to receive but if patients receive a full package of support, like that which is available for other long-term health conditions, then it can feel much more manageable.

HOW CAN HEALTHCARE PROFESSIONALS HELP DRIVE CHANGE?

Healthcare professionals should be aware that if someone is presenting with a shortness of breath, then it could be heart failure, especially if the individual already has a history of heart problems. They should also be aware that there are treatments which these patients can have which do really help them.

In Northern Ireland, a cardiac network is currently being set up and within the next six months, they’ll assess heart failure services within the region. This information will be really important in telling us where we are and what we need in order to create a comprehensive package to make sure that people with heart failure don’t fall through the net, and that when they do, we catch them with the provision of proper care.

For more information about the British Heart Foundation’s report, and to access resources and support, visit www.bhf.org.uk.
SALIVARY GLAND CANCERS

SPOTLIGHT ON: SALIVARY GLAND CANCERS

0.3 per cent of all cancer cases globally are salivary gland cancers, but delays in diagnosis often mean that the disease has progressed, and more extensive treatment may be needed. In their first article, the Salivary Gland Cancer UK team further depict the risks of missed opportunities for detection, and the significance of pushing forward for the best outcomes for patients.

Salivary Gland Cancers (SGC) are some of the rarest cancers around. Often called salivary cancer, there are over 20 types in total. Adenoid Cystic Carcinoma is the most common, and around five people in every million are diagnosed with SGC every year in the UK.

There are no clearly identified risk factors and no links with gender, age, ethnicity or lifestyle. Diagnosis is often a long detective process and, as such, can come late with devastating consequences. Surgical treatment can be extensive, little is known about its biology, and there are no targeted drug therapies available. Outcomes are poor and until recently, there was limited research. Patients can often develop metastases which, as they are relentless but slow-growing, they can live with for many years.

Until recently, there was no specific patient support available in the UK. To address these unmet needs, Salivary Gland Cancer UK (SGC UK) was founded in 2019 as a unique collaboration between patient advocate, Emma Kinloch, and medical oncologist, Dr Robert Metcalf, from The Christie Hospital in Manchester.

NETWORK

SGC UK’s central purpose is to build a UK-wide information and support network for anyone affected by SGC, as well as those treating or conducting research into those affected by these rare cancers. It is working to further research into SGC, developing a community of patients and providing networking events to enable face-to-face support and information on the latest research and clinical developments.

As SGC are so rare, patients with SGC, their families and carers have often never met anyone else who has had the same experience as them. Providing information, news and opportunities for face-to-face meetings, or online networking, in order to share experiences is invaluable.

BIOBANK DATABASE

As well as focusing on patient engagement and education, one of the overarching research aims of the charity is to better understand the biology of Adenoid Cystic Carcinoma (ACC) and other rare salivary gland cancers. This will further the work towards developing new treatments and targeted therapies.

The Christie NHS Foundation Trust in Manchester has established a specialist hub that is focused on salivary gland cancers, and patients are referred from all over the UK. Dr Metcalf is building a national biobank of tumour tissue donated by patients. This invaluable resource has already shown some real traction in better understanding the disease. Results from this research, subject to appropriate consent and ethical agreements, can be shared with researchers internationally.

Patients who are having tumours removed can choose to donate the tissue to the Biobank. These donations are invaluable to Dr Metcalf and other researchers working on new treatments for these rare diseases. It also means that patients can have their tumour profiled. This means that the unique characteristics of the tumour can be revealed at a molecular level. Doctors can then better understand which treatments are most likely to deliver the best results for them.

COMMUNITY AND EVENTS

SGC UK has had a number of events since its inception in 2019 and a dedicated community that is growing all the time. Nearly 200 people have signed up to its network online from the UK and around the world. There are typically up to 30 people attending networking events three-to-four times per year. As well as online events, and a newsletter, SGC UK has launched a podcast. In the first of the series, Dr Robert Metcalf, from The Christie Hospital, Manchester, talks about scans, MRIs and their role in discovering and monitoring disease in ACC patients. He tackles questions, such as, how often should you have scans? Does an MRI scan show ACC growing on your nerves? What is a nomogram and how can it help in discussions with your clinicians?

For more information, visit www.salivaryglandcancer.uk.

Emma Kinloch is the Consumer Forum Chair for the National Cancer Research Institute and is active in many areas of patient advocacy, both in the UK and internationally. Emma is one of the ePAG representatives for the EURACAN ERN and has fostered close alliances with many international organisations. She is also a patient who was diagnosed with a rare salivary gland cancer.

Dr Rob Metcalf MB ChB PhD MRCP is a consultant head and neck cancer medical oncologist and clinician scientist. His clinical and research focus is on salivary gland cancer, seeing patients from across the UK. Most of his patients have Adenoid Cystic Carcinoma. The overall aim of his clinical and research practice is to develop new therapies for these patients.
THE FUTURE IS BRIGHT
Striving to empower leaders and foster students’ voices, the Northern Ireland Healthcare Leadership Forum continues to be a vital force for change within the healthcare sector. Sarah Rutherford, Chairperson of the forum, discusses the importance of collaboration, and how the student-led society has been adapting to the obstacles presented by the pandemic.

CAN YOU DELVE INTO THE ROLE OF THE NORTHERN IRELAND HEALTHCARE LEADERSHIP FORUM (NIHLF)?
The NIHLF is a student-led society made up of Northern Ireland healthcare students of multiple disciplines, who promote and inspire improvement in healthcare. We encourage those going into healthcare provision to recognise their leading capabilities and their ability to empower improvement, regardless of their professional title.

The NIHLF was founded in 2012 by a former medical student, Adam Dalby. Following an intercalated degree in healthcare management, he recognised the gap between management and practising clinicians. This disharmony affected and, sadly, still affects, patient care, NHS development and interdisciplinary relationships. Since then, the society has matured and is now modelling a student version of the multidisciplinary team, in order to utilise a wide range of perspectives.

Improvement has and will always be our focus. The intention is to close the gap between leadership and the workforce. We believe that the key to this is to empower healthcare professionals and students to not only recognise the need for an attitude of improvement, but to act on it.

WHY IS IT IMPORTANT FOR HEALTH STUDENTS AND PROFESSIONALS TO CONNECT AND COMMUNICATE?
Healthcare professionals and students are on the same team; we are working towards the same goal. It is vitally important that we connect and communicate because how else will we develop? Development comes from continual learning and there needs to be a shift in attitude, scrapping the underlying hierarchy, to allow us to recognise the value in learning from each other. Mutual respect for colleagues and students (who are arguably also colleagues) will result in better teamworking and consequently better patient care.

WHAT HAVE BEEN YOUR HIGHLIGHTS AS CHAIRPERSON OF THE FORUM THUS FAR?
It would undoubtedly have to be our idea generation meetings. I love seeing an idea blossom from a wide variety of perspectives and hugely ambitious visions. I do miss the in-person events and the networking opportunities that brings but I am so pleased with all that we have achieved despite the adversity of the pandemic. It is so exciting to work alongside such a wide range of students and healthcare professionals all so invested in their vocation and fired up to improve patient care!

WHAT HAVE BEEN THE GREATEST LESSONS YOU’VE LEARNED ABOUT LEADERSHIP FROM YOUR EXPERIENCES WITH THE FORUM – AND HOW MIGHT THESE TRANSLATE TO YOUR FUTURE CAREER PATH?
I used to believe that you had to be the most ‘qualified’ person in the team to be a good leader. I have always ended up in leadership positions because I like to get the job done. I am by no means the most ‘qualified’ for the job, nor do I command authority. A model of support results in an effective team – a good leader will facilitate and support their team to become the best version of itself. Resilience, mutual respect, and optimism are good character traits for a role that is, sadly, not all sunshine and rainbows. Healthcare leadership is everyone’s responsibility. As frontline healthcare professionals we need to be advocates for improvement so that we can continuously be providing an increasingly higher quality of care for our patients.

I am currently in my third year of studying Medicine at Queen’s University Belfast. I don’t know what my future career holds but I am certain that leadership skills will help me be a better doctor. I love that improvement is something that I can get involved in regardless of my professional title, but maybe I’ll run the hospital one day? Dream big.

HOW HAS COVID-19 IMPACTED THE FORUM’S PLANS? HOW HAVE YOU HAD TO ADAPT?
As with everything, we have had to adapt our plans by shifting everything to an online platform. It has been a challenge to engage attendees without the allure of free food and an opportunity to network. In other ways, our events have become more accessible, giving both attendees and speakers the ability to contribute from their own home, as well as the option to watch after the live event.

WHAT’S COMING UP FOR THE NORTHERN IRELAND HEALTHCARE LEADERSHIP FORUM?
We are currently in the middle of an evening series exploring Advance Care Planning, correlating with the development of a Department of Health policy. This evening series has been incredible and I, personally, have gained so much from it. Each year looks totally different for the forum because the committee dictates the direction, all with the goal of improving healthcare. I don’t know what the future holds, but we are going to be a part of healthcare transformation.

HOW CAN HEALTHCARE PROFESSIONALS GET INVOLVED?
We have been so grateful over the years for the support of so many of our professional colleagues, and long may it continue. We would love to get alongside you if you are pioneering an improvement, trying to raise awareness around a healthcare field, or anything else you feel aligns with our goals. As healthcare professionals (and students) we want you to recognise your capabilities and the value of your voice. If all healthcare professionals were constantly looking for ways to improve, our healthcare service would be continually transformed by small steps (but lots and lots of small steps).
The aim was to reduce the gastroenterology waiting lists and allow redistribution of consultant care to more urgent cases. Different models of care have been adopted across the region dependent on population, clinician preference and resources available.

Collaborating in a regional group has allowed gastroenterology dietitians to draw on a combined wealth of experience and benefit from shared ideas for working. Benefits of the new dietetic-led models are summarised in Box 1.

**BOX 1: BENEFITS OF THE DIETETIC-LED SERVICE**

- Reduction in Consultant caseload allowing prioritisation of other patient groups
- Consultation with an Advanced Practitioner Dietitian experienced in the area and trained specifically for the role
- Service tailored specifically to meet the needs of the patient group using evidence-based care pathways and local protocols updated with input from Consultant Gastroenterologists
- Improved information/support for patients empowering self-management of their symptoms with dietary intervention
- Improved patient journey/experience demonstrated on patient satisfaction surveys
- Improved accessibility for patients as service can be delivered in the community
- Reduction in GP/hospital appointments
- Reduce number of patients having to undergo unnecessary endoscopy procedures
- Reduce the waiting list for endoscopic procedures for other patient groups
- Allowing patients to be seen in a timely manner by the Consultant Gastroenterologist when required due to excellent communication links
- Local/regional audits of outcomes
- Cost savings in Consultant time, investigations and medical interventions
- Maintenance of local coeliac registers

**IBS**

IBS is a chronic, relapsing, and often lifelong disorder affecting 10- to 15% per cent of the population. It is characterised by the presence of abdominal pain or discomfort that may be associated with defecation and / or a change in bowel habit. Symptoms range in presentation and severity and have the potential to impact greatly on a patient’s quality of life.

Approximately one-third of patients referred to Gastroenterologists present with symptoms of IBS, allowing for significant reduction in waiting lists through redirection to Dietetic-led Services. Referrals were directed to the service through education and promotion of the care pathways across primary care, transferring suitable cases from Gastroenterology waiting lists and incorporating systems to allow Consultants to directly triage appropriate referrals to the Dietitian.

The Dietetic IBS Service is comprised of two tiers. The first line recommendations focus on establishing healthy eating habits, identifying any potential trigger foods and manipulating fibre intake. Tier 2 consists of a low FODMAP diet.

Fermentable Oligosaccharides, Disaccharides, Monosaccharides and Polyols (FODMAPs) are short-chain carbohydrates that are poorly absorbed by the body, and therefore can pass into the colon undigested and undergo fermentation by colonic bacteria.

Restricting FODMAPs in the diet can reduce the osmotic load in the small bowel and decrease gas production through fermentation. The efficacy of a low FODMAP diet for treating IBS is well-documented, with up to 86 per cent of patients finding a reduction in overall or individual gastrointestinal symptoms. The diet, however, should only be implemented under the supervision of a trained professional, raising the need for specialist clinics and services.

Over 3,300 patients with IBS were treated in dietetic-led clinics across the region between June 2019 – June 2020, with over 3,400 total patient contacts recorded. Between 91 – 95.5 per cent of dietetic outcomes measured across different trusts were achieved and patient feedback has been overwhelmingly positive (Figure 3).
Coeliac disease is an immune illness, triggered by dietary gluten, which causes a broad range of gastrointestinal and extra-intestinal manifestations. Untreated disease reduces quality of life, increases healthcare use, and is associated with substantial morbidity. Early diagnosis, and treatment with a gluten-free diet, is imperative to prevent long-term complications e.g. malabsorption and anaemia, osteoporosis and neurological issues. Mortality is increased because of lymphoproliferative malignancy, sepsis and refractory disease. Adherence to a gluten-free diet is difficult for patients and evidence shows that this chronic condition needs long-term follow-up with National Institute for Health and Care Excellence and British Society of Gastroenterology guidelines, both recommending annual clinical review.

Although the percentage of undiagnosed patients varies across Northern Ireland, the Western Health & Social Care Trust has a robust coeliac register with 2,200 patients currently diagnosed. These patients were historically reviewed in secondary care by a Consultant Gastroenterologist but this was unsustainable and the majority of these patients have been discharged for follow-up at the DLCC. A protocol was developed in collaboration with the Consultant Gastroenterologists and training was undertaken.

Figure 6 shows that 98 per cent of all patients were reviewed by an advanced practitioner dietitian in a recent audit of the service in the Western Health & Social Care Trust.

The ongoing success of these new pathways of care will hopefully provide further opportunities for experienced dietitians to contribute to the ongoing evolution of Gastroenterology Services in the future.

REFERENCES

The future
Dietitians play an integral role in the management of gastrointestinal conditions. Dietetic-led Gastroenterology Services are proving effective in managing these patient groups and are essential in providing cost-effective solutions to maintain high standards of care within the NHS.

In the Belfast Health & Social Care Trust improvement in overall symptoms was reported in 70 per cent of patients following Tier 1 dietary recommendations and 84 per cent of patients following completion of Tier 2, a low FODMAP diet (Figures 4 and 5).

This audit also showed further benefits of engaging with patients who were lost to follow-up. 60 per cent were found to have abnormal blood results (Figure 7), and of those that had never had a bone scan carried out previously, 50 per cent were abnormal when checked (Figure 8). Better monitoring of blood results can reduce the risk of nutrient deficiencies and associated symptoms and improved bone health leads to less possibility of undiagnosed osteopenia / osteoporosis.
A MEETING OF MINDS

Biosimilar adalimumab is a test of shared decision-making in the NHS.

This article has been written for healthcare professionals on the topic of switching to biosimilars and how important it is for decisions to be made together between doctors and patients.

The entry of new biosimilars and the creation of an NHS ‘local market of treatment options’ will see significant numbers of patients switched from the originator product, Humira, to one of four biosimilar alternatives.

Adalimumab is one of several biological drugs used in the treatment of autoimmune inflammatory diseases, including rheumatoid arthritis, ankylosing spondylitis, psoriasis, psoriatic arthritis, non-infectious posterior uveitis, Crohn’s and Colitis.

While some patients will take this in their stride, for others the change will be met with feelings of apprehension.

While the switch offers the potential for system savings within the NHS, from the patient perspective, it will also be a test of how patients are supported and whether shared decision-making is the norm in the NHS.

The NHS has set out a commitment to shared decision-making. Professor Alf Collins, Clinical Director, NHS England, in his 2016 blog, summed this up as the importance of patients being able to consider their options, and the risks, benefits and consequences of pursuing those options.

NHS England's biosimilar commissioning framework states 'shared decision-making between clinical prescribers and patients will be vital if the best value, clinically-effective medicines are to be used'.

On this basis, treatment decisions should always be made firstly on the basis of clinical judgement for individual patients and secondly, on the overall value proposition offered by individual medicines.

When patients are new to biologics, clinicians will want to identify which drug option is right for their disease profile and supports adherence.

Discussion will allow patients to consider whether a subcutaneous injection at home or an infusion given in hospital will work best. Conversations may also involve weighing options that reduce levels of immunosuppression or that treat concurrently a patient’s other related conditions, for example, the skin and gut.

For existing users of adalimumab, understanding what these new biosimilar drugs are, how to use them, and their safety and efficacy, will be crucial.

Important discussions need to take place between clinicians and patients about, for example, the excipients of the different biosimilars taking into account discomfort of the injection, what type of injection or pen a patient prefers and what the homecare package may include.

We hope that ‘switching’ will also generate discussions between multidisciplinary teams and their patients, as well as the trust, about how system savings can be invested to directly benefit patients in areas such as specialist nursing and service improvement.

Ensuring that patients have clear timely information is essential to delivering these changes successfully.

Our charities have worked with NHS England to produce resources to support shared decision-making and we hope that healthcare professionals will make full use of them.

Co-written by the National Rheumatoid Arthritis Society, National Ankylosing Spondylitis Society, RNIB, Birdshot Uveitis Society, Psoriasis Association and Crohn’s & Colitis UK.

For more information, support, and resources about Crohn’s and Colitis, visit www.crohnsandcolitis.org.uk and email media@crohnsandcolitis.org.uk.
Whilst many people are aware that Cancer Fund for Children support children and young people diagnosed with cancer, many people do not know about our services for children who have a parent with cancer.

When a parent has cancer, this can be a very isolating, frightening and confusing time for their children. A parent’s cancer diagnosis can bring dramatic changes to their children’s lives often affecting their experience of school, their relationships and ongoing development.

Our Cancer Support Specialists are trained in the issues facing children experiencing cancer in their family and they are here to help them cope better with their mum or dad’s cancer.

What support do we offer?
Due to current coronavirus restrictions our team is delivering individual and group support online to help connect young people develop coping skills, become more resilient and also connect them with others going through a similar experience so that they feel less isolated.

The whole family can also benefit from free therapeutic short breaks at Daisy Lodge, our residential centre in Neuchastle, 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 staff team.

Tyler’s Story
“Tyler has been such a brave boy, but I could see that he was suffering. I was put in contact with Karen from Cancer Fund for Children, and she has been amazing. Karen has been working with Tyler on zoom chats for a few weeks now and he seems to get some comfort from them. He enjoys talking to her.

Karen arranged our visit to Daisy Lodge and Tyler was so excited. Being in isolation for almost a year and then getting those few days away together was just perfect. Thanks again to everyone for making my beautiful boy happy and giving us the chance to have some quality time together.”

Jill Johnston was diagnosed with breast cancer in July 2020. She and her son Tyler (10) have benefited from Cancer Fund for Children’s support.

Cancer Fund for Children support:
• Children diagnosed with cancer (0-24)
• Children who have a parent with cancer (0-24)

Our services include:
• Individual Support
• Group Support
• Therapeutic Short Breaks
• Bereavement Support

How to Make a Referral
Referral forms are available on our website or by calling us on T: 028 9080 5599. We accept self-referrals, referrals from the family’s clinical team, allied health professional and GPs.

cancerfundforchildren.com
ALLERGY PODINAR SERIES

Tune in, sit back and relax while watching allergy experts from across Ireland having practical discussions on allergy management. There’s no formal structure, no slides, it’s all live - what could possibly go wrong?

Time: 7.30 - 8.30pm

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SAVE YOUR BREATH

Diagnosed with asthma later in life, 33-year-old Chris Nelson has had to adjust his lifestyle and hone his management regime. Here he chats to NIHR about his complex diagnosis journey, as well as his experience navigating the condition alongside fresh health fears fuelled by the onset of COVID-19.

WHEN WERE YOU FIRST DIAGNOSED WITH ASTHMA?

Ever since I was younger, I have occasionally struggled to catch my breath – however, having always experienced hay fever symptoms, I simply thought that this was just another sign of my allergies.

Throughout 2018, though, I started to notice things escalating – my chest was always tight; I was constantly coughing; and I became severely out of breath taking on simple activities, even just walking up a short flight of stairs. Things came to a head when I kept waking up at night struggling to breathe.

I visited my GP three-to-four times during this period, having my bloods taken and lung tests performed. However, everything came back clear. I was assured that I did not have asthma.

Things were still being investigated when I suddenly woke up in the early hours of a particular Monday morning unable to catch a breath at all, to the extent that I couldn’t even get the words out of my mouth to communicate to my wife that I needed to go to A&E immediately. In a panic – and in hindsight, foolishly – I jumped into my car at 4am and drove myself to Craigavon Area Hospital, with my wife following behind in her car.

Upon arrival at A&E, I was seen quickly and put on a nebuliser and given steroids in order to regulate my breathing. A variety of tests were also conducted by respiratory specialists in order to investigate things further.

After spending four nights and five days in the hospital, I was informed that I suffered from severe asthma and a plan was subsequently drawn up to help me control it.
**HOW DOES IT AFFECT YOUR DAY-TO-DAY LIFE?**

In general, my day-to-day life isn’t significantly impacted by my asthma as long as I take the medications which I’m required to and avoid triggers which I now know may set it off.

Daily, I take two puffs of my preventative steroid inhaler twice in the morning and twice in the evening before bed. When I am particularly bad, I am required to take one or two puffs in the afternoon. I also ensure that no matter where I go I have my reliever inhaler with me in case I start to struggle and experience the signs of an asthma attack. On top of this, I ensure that I take daily antihistamines because my hay fever allergies can set my asthma off quite badly.

It’s crucial that I’m organised and forward-thinking in having my inhalers ordered every month with my GP as if I run out, I could find myself in quite a dangerous situation.

In terms of asthma reviews, I receive them roughly twice-yearly – once in the winter months, as the cold weather can trigger flare-ups, and once in the summer months, as the pollen count can set off my hay fever.

These appointments take place with a respiratory nurse at my local NHS hospital.

**WHAT TRIGGERS YOUR ASTHMA FLARE-UPS AND HOW DO YOU MANAGE THESE?**

As mentioned, I need to be particularly careful during the summer and winter months. As well as hay fever, I also tested positive for quite a number of other allergies, such as cat hair, horse hair and dust so I make sure that I stay away from cats, horses and have a clean house… well my wife, Catherine, is mostly responsible for the last part!

**TO WHAT EXTENT DID FINDINGS AND COVERAGE RELATING TO COVID-19-CENTRED COMPLICATIONS IN CHRONIC LUNG CONDITIONS ELICIT CONCERN IN YOU?**

To be honest, at the beginning of the pandemic, and as its coverage became more prominent and frankly unavoidable, I became increasingly anxious – particularly as COVID was communicated as a contagious respiratory illness. I was deeply concerned that if I got COVID, my chances of surviving or maintaining my same standard of lifestyle weren’t as great as those individuals without a pre-existing underlying respiratory condition.

When lockdown was announced, I began to feel more comfortable knowing that my health would be protected to much more of a degree.

**HAS YOUR ACCESS TO ASTHMATIC SUPPORT AND CARE BEEN AFFECTED BY THE PANDEMIC?**

Yes, like everything else during COVID, my access to these services has had to adjust. My asthma reviews are now conducted over the phone, rather than in person. And while they previously would have occurred twice-yearly, they have actually been more frequent.

While I am hugely grateful to the NHS and for the fact that the provision of care has continued, I do feel that the remote consultations aren’t as effective as the previous face-to-face interactions. An example of this would be when I was struggling this previous winter. I had a phone consultation and although my asthma nurse could hear that I was struggling to breathe over the phone, she wasn’t able to listen to my chest herself and had to rely on me to check my own peak flow at home. Luckily enough I had purchased my own peak flow device when I was first diagnosed with asthma so I’m able to monitor this.

On a positive note, because of COVID, and the lack of in-person consultations available, I have been provided with an emergency pack of steroids and antibiotics which I’m able to take if I feel that my peak flow has dropped to a dangerous level.

**WHAT EXTRA PRECAUTIONS HAVE YOU TAKEN TO STAY ON TOP OF YOUR CONDITION?**

Like everyone else, I have been super careful about restricting my contact with others and cutting out any unnecessary journeys. Fortunately, my workplace has allowed me to work from home half the week, and when I am in the office, I am comfortable that sufficient precautions have been taken to protect myself and others.

I feel that it is important for me to maintain this level of cautiousness as if I let my guard down, I could end up back in the hospital – but this time I may not come out.

As well as everything else, my wife and I discovered that we are expecting our first child over lockdown so I need to be careful not just for my own sake, but for the sake of my family and my unborn child.

**A YEAR ON – AND IN LIGHT OF THE COVID VACCINE ROLL-OUT – HOW HAS YOUR CONFIDENCE AND COMFORT LEVELS CHANGED?**

One year on, and with the development of the vaccine programme, I feel much more comfortable going outdoors for my daily exercise – which mainly consists of walking my dog, Woody, and the odd visit to a local shop for groceries.

I have been fortunate enough to have recently received my first vaccine at my GP surgery due to my level of vulnerability. Although I am delighted, I must not let my guard down and ensure that I remain vigilant as many others have not yet received the vaccine, and I imagine that COVID will be around for a long time to come.

As I reflect on the last 12 months, although times have been tough, my appreciation for all those working on the frontline and behind-the-scenes of our healthcare services can’t be emphasised enough. Thinking ahead, I look forward to a time when I can reunite with my family and friends for a pint at our local pub!
Spend time with anyone from the Lupin Healthcare team and you will feel the pride in the partnerships we have developed.

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COVID-19

VIEWS FROM THE FRONTLINE

One year on since COVID-19 catapulted the population into a frenzy of panic and horror, representatives from healthcare services across the region share their stories of persevering through the unknown.

COVID-19 AT ALTNAGELVIN: A YEAR IN THE LIFE

MARTIN KELLY (MGK)1, MARGARET MC CLOSKEY (MCL)1, CIARAN KING (CKI)1, NEIL BLACK (RNB)2, PHILIP GARDINER (PVG)3, ROSE SHARKEY (RS)3

1CONSULTANT RHEUMATOLOGIST, 2CONSULTANT ENDOCRINOLOGIST & DIABETOLOGIST, 3CONSULTANT RHEUMATOLOGIST

December 2019 brought tales of an unusual, interesting and virulent illness in central China. However, images of military lorries ferrying coffins from hospitals in Northern Italy made us realise we faced an unprecedented healthcare challenge. With this came unprecedented mobilisation of services. We realised that we needed a team to oversee and coordinate. Senior clinicians such as RS and PVG volunteered to convene frequent meetings that dealt with innumerable issues – where to care for patients, staffing, infrastructure, relationships with radiology / labs / portering / estates / allied health professionals / GPs and COVID Centre among many. Meanwhile, clinicians (especially MGK, MCL and CKI – in his first week as consultant) began to see patients coming in with this new illness, regarding which we had so many uncertainties, other than its lethal capacity. A ‘coalition of the willing’ assembled, drafting other physicians such as RNB to be ‘honorary’ respiratory physicians. Rheumatologists, endocrinologists, gastroenterologists, nephrologists, neurologists and cardiologists cared for the less severely ill. Respiratory services were turned on their head.

And so, the patients arrived. They were scared. Breathlessness co-existed with fear and isolation from family and friends. Staff communicated from behind visors and layers of PPE. We had no treatments beyond oxygen and good nursing care. Honestly, we too were scared and nervous. We did not know what to expect. Would we fall sick and bring the virus home to our families? Could some of us die? The death rate among clinicians in Italy was frightening. Some of us made wills for the first time. We remember our first death. It was archetypal of COVID – all was done that could be done, but we watched helplessly as an older patient slowly died from respiratory failure. The patients and deaths kept coming. We worked long days (12 hours or more) and weekends lost meaning, delivering a consultant-led service. We strongly feel this kept the ship afloat. Many good young doctors shared the work and we all benefited from unprecedented levels of teamwork. Staff of all disciplines and grades were redistributed to provide COVID care and backfill those who were delivering it on non-COVID wards. Faces we had never known before became very familiar on the COVID wards. Many great people within portering and support services, among many, put themselves on the line to help. We recruited patients to the RECOVERY Trial – the beginnings of hope against this terrible disease. Our community respiratory nurses oversaw the discharged patients in the community. Gradually, the tide began to recede, with the first wave easing in early summer. Breath was drawn. Long overdue, much-needed and greatly appreciated breaks were taken to exotic places such as Sligo (and I was glad of it). Importantly, we tried our best to catch up with our non-COVID patients in the community. Telephone reviews soon became ‘the norm’. Terrible stories of pandemic-induced isolation, stress, depression, panic and anxiety emerged.

Suddenly, it seemed, in late August / September, numbers began to rise. With little warning, we were into a very severe second wave. For a time in October, we had the UK’s highest seven-day incidence. The eyes of the press were upon us. As intubation became a last option, we ran a 13-bed ‘Enhanced Respiratory Support’ unit with anaesthetic colleagues, equating to high dependency level care. High-tech oxygen delivery became the norm. Case numbers and deaths were much larger. The rate of rise and the sustained peak that followed came to dwarf our first wave. Morale was sapped as COVID fatigue crept in. The novelty and adrenaline of spring were gone. As numbers fell a little around Christmas, the third wave, carrying the Kent variant, broke. Pressures through Christmas into January were unparalleled. Some chinks of light brought hope – dexamethasone, tocilizumab and perhaps remdesivir proven effective. Moreover, vaccines, lovely new vaccines, provided promise of a change of fortune.

Suddenly, we are a year down the line. The numbers are somewhat in check, though we still send at least one person a week to ICU.

How did we survive? Collegiality and support were vital; those unfamiliar faces re-deployed to COVID care became the most welcome and comforting feature of the pandemic – we were in this together. There was pure stoicism at times and a strong and unbreakable sense of responsibility. This is our time, as a respiratory team. Music, walking, appreciating the small things. Lots of coffee. At times, we survived by sheer determination. A determination to do our best.

What might lie ahead? We are not sure. We see great hope from vaccination. We feel we will prevail.

Who were the real heroes? The nurses, of course, who bore the whole burden of person care and expressed compassion for and comforted the fearful, sick and the
dying. It has been an honour and privilege to work alongside people who for 12 months have given their all. Despite many dark days, they kept going for the patients and kept smiling.

MARY-CARMEL KEARNEY MPHARM PHD
Lecturer (Education), School of Pharmacy, Queen’s University Belfast

‘COVID-19 contingency planning’ was raised at a meeting I attended in January 2020. The possibility of this virus reaching our shores was becoming more probable and there was some discussion at that meeting that we might need to think about dealing with potential cases. If there were cases, then our ‘normal’ way of working might require some flexibility. We then moved to the next item on the agenda.

Reflecting on this at the time, I thought that we were very proactive. I also thought that I was unlikely to be part of any major contingency plans as I was due to begin maternity leave in March. Outside of work, COVID-19 wasn’t even the headline news story – bush fires in Australia were. Two months later and the world would be in lockdown.

Fast-forward one year and my life is very different. I have a beautiful healthy baby boy and I’ve recently returned to my job which has changed in so many ways but is very similar in others. Almost all of my teaching is now delivered virtually. Staff and students have adapted extremely well to this and I imagine that there will be many aspects of the virtual learning experience which will remain post-pandemic, such as recorded lecture series, virtual group work and remote consultations.

Although, I think we are all longing for many pre-COVID experiences to resume as soon as it safe for them to do so – such as delivery of clinical skills, face-to-face patient counselling, not to mention a coffee with colleagues. While teaching pharmacy students has changed significantly in the last year, the work ethic and effort of staff and students alike is greater than ever. I am confident that we are helping to prepare a resilient workforce who have demonstrated their commitment to contributing and advancing the profession.

On a more personal level, I’ve never been more grateful or appreciative of our health service as I have been in the last year. Each day I am thankful to the dedicated staff at Antrim Area Hospital who cared for my baby who had to spend some time in NICU when he first arrived. Having a baby during the pandemic was a difficult experience, particularly with the restrictions that were in place last April. Thankfully, some of these restrictions have eased but I think that their imposition offered a significant reminder of just how important every single element of the healthcare service is.

Going forward, I think we will have a much more integrated healthcare team, maximising the skills of all members of the multidisciplinary team to offer optimal patient benefit.

JOANNE MCCARTHY
Radiotherapy Services Manager, Belfast Cancer Centre

The radiotherapy service based in the Cancer Centre at the Belfast City Hospital has continued to provide radiotherapy treatments for between 180-and-200 patients on a daily basis throughout the pandemic.

Several key changes were introduced into the department in March 2020 to ensure the safety of both patients and staff. These changes included reducing footfall, reconfiguring waiting areas, allocating specific treatment machines to treat patients with confirmed or suspected COVID-19, and being able to carry out review appointments remotely by telephone. Some of the changes for staff included, changing working patterns of the therapeutic radiographers to allow staggered start and finish times and organising teams into groups for lunches and breaks to reduce the number of staff on-site at any one time and therefore reducing the risk of transmission between staff.

The radiotherapy department developed a robust COVID-19 Response Plan, which set out the contingency for service continuity in the event of staff shortages throughout the pandemic. This included the adoption of revised national guidelines in response to COVID-19, which provided alternative dose and fractionation regimes, with some radiotherapy patients having their treatments delivered in fewer treatments, reducing their time spent in the department.

Therapeutic radiographers’ roles are wide-ranging; they work between pre-treatment, treatment delivery, brachytherapy and specialist practice. Due to the continuous competency-based training programmes, we are proud to say that the service was able to mobilise staff to work on the treatment units when staffing shortages occurred and maintain treatment capacity throughout the last 12 months. No patient had their treatment deferred due to staffing shortages as a result of the pandemic. We have continued with our service improvement programme with the replacement of a linear accelerator, CT simulator, planning system and a refurbishing project for the brachytherapy unit.

The radiotherapy department is also hoping to introduce a significant quality improvement programme over the next three months by becoming a paperless service – this will further streamline pathways and improve workflow. Due to high levels of adherence to infection prevention control measures and the vigilance and hard work of all the radiotherapy team, staff shortages have had minimal impact on service provision.

ANNE MCGALE
Practice Nurse

In March 2020, my colleague and I attended the Northern Ireland Healthcare Awards at the Europa Hotel. On the way into the event, we met a respiratory consultant who mentioned that the news had reported that the first case of COVID-19 had been detected in Craigavon Area Hospital. We had been made aware by TV and radio media that there had been a virus detected in China and Italy and it
was very infectious, and people were dying from it. Life went on as normal while we waited on guidance from the Department of Health as to how to manage this in the work setting. Every day we learned more information about the impact of this new virus and how it was changing the world.

The following week, life changed dramatically. We were advised to work from home where possible, stay at home unless in case of emergency, and we were allowed to leave the house once a day to get fresh air and exercise. Life as we knew it came to a halt.

As health professionals, we continued to work where possible. We were given identity badges and a letter to carry so that we could travel to and from work without issue. All clinics had been cancelled and Perspex barricades came up in every aspect of life. In a sense, it brought me back to the years of the Troubles, with tape cordonning off areas. In the surgery, doors were closed and only individuals who had been asked to come to the health centre were allowed entry.

We were advised to wear scrubs as they could be washed at a higher temperature and we were asked to not leave the building in work clothes. We all wore PPE and, eventually, masks. There was a lot of learning to do. We resorted to contact-less nursing. Online video and Zoom calls became the new way of communicating with our patients.

Shielding letters were sent to vulnerable individuals telling them to stay and work from home. The introduction of social distancing and safe practice was evident in all walks of life, including in the practice. The number of patients in the health centre was greatly reduced. Rooms had become the new way of working. We are seeing some care. But this was the new normal.

Finally, a vaccine has been developed and vaccine clinics have been moved to carparks, church halls and community centres. Through the process of vaccinating those most vulnerable and each age group getting vaccinated over the next number of months, the anticipation of life becoming a little more normal is creating a bit of hope for us all after the last 12 months of uncertainty.

My hopes for the future are that life will become a bit more normal and that we are able to manage COVID-19 just as we manage the yearly flu. We have been reminded through this experience what is important in life and I hope people appreciate good health and the excellent service we have in the NHS.

HEATHER TURKINGTON
DRAMATHERAPIST

Dramatherapy is a profession that is clinically versatile and able to work throughout all stages of the Five Stepped Model of Care. Our practitioners are able to work with those from all backgrounds, and all stages and walks of life, from childhood to those who are elderly. However, our work is generally very tangible in nature – we use objects, art materials, sensory engagement, and it’s also very ‘in the room’ – music, movements and face-to-face; working directly with tools like puppets and material where appropriate.

Until COVID-19 struck, most of our work was done in a face-to-face capacity, because of how dramatherapists generally work with clients.

When it did, dramatherapists used our creative and versatile natures to create room for their profession in the midst of the pandemic. Very quickly, discussions began, and trainings started with regards to working online, and best practice in those areas. Online professional support groups have been formed to help therapists work well in the transition, and we learned very quickly to adapt to a new way of working which we never thought was possible pre-COVID-19.

Although a lot of us can’t wait to get back to our clinical face-to-face therapeutic work, the introduction of online therapy has made dramatherapy a lot more accessible for many clients, and added a facet of clinical work that has developed very efficiently and wholly in the last 12 months. This is now added into our already diverse, person-centred, holistic and multidisciplinary repertoire of professional working options and ethos, and the profession as a whole is determined to use our learning here as a positive in post-pandemic Northern Ireland.

Dramatherapists have held many adults and children emotionally through this strange time, and are very aware that we may see a growth in the need for mental health care in the coming months as a direct result of that. We have done much work to change our ways of working to effectively prepare and respond to this, and we are a workforce who are ready and able to join and positively add clinical value to our existing fantastic mental healthcare professional teams. We hope to become an integral part of health and social care’s response to this in the near future.

SIMON FELL
COLLEGE OF PARAMEDICS LIASON

The past year has been a challenging and turbulent time for paramedics serving on the frontline. Ambulance staff had to quickly become accustomed to new methods of working, due to the various levels of personal protective equipment required at all calls. Other paramedics were assigned roles providing the fit testing of
masks for colleagues, as well as COVID triage, testing and contact tracing.

Outside of the ambulance setting, paramedics in primary care were, and continue to provide, COVID clinics or home assessments for patients, supporting GPs and reducing admissions to hospital. While other paramedics within hospital teams, as part of a virtual COVID hospital, are providing outreach assessments in patients’ homes, and delivering treatments and escalation plans in collaboration with hospital consultants. These examples display the vast scope of the paramedic role which has been harnessed by the entire healthcare setting during this pandemic.

Paramedics are renowned for being flexible and adaptable due to the nature of their traditional role. This has been clearly reinforced during this global pandemic, where paramedics have demonstrated the variety of services they can provide, to support the wider health system. It is anticipated the opportunities arising from the challenges of COVID will further elevate the paramedic profession and provide more diverse career prospects in the future.

KATE LESSLAR
POLICY OFFICER FOR THE ROYAL COLLEGE OF OCCUPATIONAL THERAPISTS

Members of the Royal College of Occupational Therapists have been delivering a breadth of support throughout the COVID-19 pandemic in Northern Ireland. As well as being seconded to critical hospital services and helping to rehabilitate and assist with the discharge process for patients on acute wards, including following intensive care treatment, they have also been providing face-to-face support to patients in their own homes, particularly those keen to avoid admission to hospital.

Occupational therapists in Northern Ireland have continued to deliver support services to patients in a variety of contexts. They have also been supporting a range of patients who have missed treatment due to shielding, needing to self-isolate or due to missed appointments, as well as adapting services and evolving new ways of providing services, such as through technology, as the pandemic continues.

RUTH BALMER
BRITISH DIETETIC ASSOCIATION POLICY OFFICER FOR NORTHERN IRELAND

Dietitians played a key role in the response to COVID-19, working in the ICU, introducing innovative digital clinics and supporting public health.

As a result of the COVID-19 pandemic, eating a healthy diet and getting sufficient physical activity has been more difficult, with indications that people of all ages have been eating less healthily. Public health dietitians in Northern Ireland have continued to provide helpful information and guidance to the public to help them make best use of the food they can access. During the pandemic they reached out to food banks and charities that work with the most vulnerable people. They provided guidance to local councils and community organisations to ensure that food parcels not only make nutritious meals, but also where possible, make the contents go further and add variety to food intake.

Public health dietitians have been working directly with volunteers to ensure that food parcels contain suitable items for those who need to follow special diets for medical conditions, such as diabetes, coeliac disease and cystic fibrosis. Such support has included developing menus and advice for families cooking on limited budgets. Digital platforms have enabled the continuation of public health nutrition messaging.

Public health dietitians in Northern Ireland have developed webinars on a range of subjects, from feeding your family for less, to lunchbox and snack ideas for kids, and updated programmes like COOK IT and Food Values to online formats. These resources are, and will continue to be, delivered regionally to their tutors and the people of Northern Ireland.

Many people have struggled to understand the COVID-19 pandemic and have sought out solutions or comfort online. Often people have been exploited with unhelpful and unevidenced ‘cures’ and solutions. Dietitians and the British Dietetic Association continue to play an important role in busting these myths, both on social media and more conventional press and TV.

RAYMOND ANDERSON
COMMUNITY PHARMACIST

For me the last year has seen the very best in our profession, from the heady days of March 2020 when there was real panic as to how to cope with this new virus and managing major supply issues and shortages of medicines, to now preparing for a full community pharmacy vaccination service, all within a period of 12 months.

The whole pharmacy team has to be congratulated. Every staff member working in community pharmacy played an essential role in keeping our services open to the public. I have been deeply impressed with the commitment of my staff, working under extreme pressure and concern for their own health and initially having little in the way of support with PPE.

I would say though the board, Department of Health and CPNI have worked together to support the network. Good communication channels were opened up and for me the emergency supply provision of medicines for patients who hadn’t got a prescription was extremely helpful and hopefully will continue in the future.

It is my hope that we can build on the work of the last 12 months and community pharmacy can look forward to a healthier future. The signs are good at present, but this needs to be maintained.

TOM SULLIVAN
THE CHARTERED SOCIETY OF PHYSIOTHERAPY POLICY OFFICER

The Chartered Society of Physiotherapy (CSP) is the professional, educational and trade union body for all physiotherapists in Northern Ireland and across the UK. The CSP firmly believes that more than...
ever physiotherapists will be required as we move forward in the current outbreak of COVID-19 and its aftermath.

Physiotherapists are critical to the recovery solution in Northern Ireland due to our unique transferrable skills as highlighted during this pandemic and in our key role in rehabilitation pre-, during and post-COVID-19. As Northern Ireland looks to rebuild healthcare services, rehabilitation must be recognised as an unmissable part of COVID-19 recovery, and leaders and policy-makers need to be taking urgent action to ensure that this is delivered.

Recent modelling and evidence suggests that a significant number of people who develop COVID-19 will require health and care input to support their recovery and that rehabilitation is central to the short and long-term management of patients with COVID-19.

In December 2020 the Office for National Statistics released survey results which revealed that:
- One-in-five of those testing positive for COVID-19 have symptoms for five weeks or longer, and that
- One-in-10 of those testing positive for COVID-19 have symptoms for 12 weeks or longer

Previous research carried out by the CSP in Northern Ireland found that of patients who have had severe COVID, whether in hospitals, care homes, or other community settings:
- 25 per cent are expected to self-manage without need for further rehabilitation input
- 45 per cent are expected to require some level of community-based rehabilitation input
- 17 per cent are expected to be admitted into an in-patient service for further rehabilitation
- 13 per cent have considerable functional deficits and / or are not medically stable

In addition to those with COVID, there are significant non-COVID rehabilitation needs as a consequence of the pandemic, including people whose health and function are now at risk due to pauses in planned care, delayed diagnosis and treatment, and deconditioning in those with long-term conditions.

The Department of Health in Northern Ireland needs to significantly increase investment in community rehabilitation services and support a ‘right to rehabilitation’ for everyone who needs it. The CSP is also calling for the Department of Health, to publish, as a matter of urgency, a Rehabilitation Framework to support service planning for the expected demand for rehabilitation and recovery of both COVID-19 and non-COVID-19 populations in adults and children.

Fiona Quigley
Community Stoma Nurse Specialist

From 23rd March 2020, our Community Stoma Nursing Service made adaptations like all healthcare facilities and services – we were anxious of the unknown but had a service to provide to stoma patients facing challenging issues. Timely intervention is essential to offer support and professional input to alleviate physical and mental impairment associated with life-changing surgery.

Over the past year it is important to note that there was an increase in new referrals to our service following a statement issued by The Association of Coloproctology of Great Britain and Ireland (2020) recommending lower risk surgical strategies based on the uncertainty of resources to manage postoperative complications, such as anastomotic leaks: stomas were formed as a safer option.

COVID-19-related bowel ischemia led to stoma formation in a few cases. The impact on our service meant we were unavailable to be fully re-deployed as our own patient group required care and specialist intervention. We did help district nurses but there were no skilled staff resources to step into our role and care for stoma patients.

All stoma patients with urgent and complex issues were reviewed at home if issue unresolved with a telephone consult, and a short questionnaire was asked regarding risk of exposure, patient contacts and health of patient and other members of the household prior to entry.

Cancer patients with active treatment and adverse side-effects on stoma management were reviewed by a weekly telephone call and a home visit was arranged if clinically indicated. End-of-life patients were seen at home to resolve any stoma-related issues. Telephone lines were open and manned to ensure patients received a prompt call back.

Younger patients used their phones to email pictures of peri-stomal skin issues which worked well as an alternative way of working. Telephone and email contacts worked well in our service and can be scaled up for service provision. Forwarding pictures to medical colleagues resulted in a more rapid response rate. Technology will not replace the need for face-to-face contact with such a diverse patient cohort and range of issues but with the right equipment there is potential for a digital upscale.

My responsibilities as a non-medical prescriber increased as patients were having issues getting prescriptions via GPs and local chemists. Additional PPE donated by a patient (who commenced manufacturing in aid to support the local community and make a contribution to the NHS frontline) was greatly appreciated!

Letters were issued to all patients scheduled for review during March, April, May 2020 explaining restrictions on service provision and IPC measures for safe home visits if clinically indicative.

Moving forward to present time, clinics have resumed although social distancing and IPC requirements will reduce the number of patient contacts possible for a clinical session. Clinic letters have a foot note to high-light IPC measures to reassure patients their safety is our main focus. Patient activity events and group support sessions have been stood down but patients are missing the social support of each other.

We have managed to the best of our ability to consider social distancing in
SONYA JOHNSTON  
ACTING ADDICTION SERVICES MANAGER

When COVID first hit I was working as team lead for a local addiction service and my first experience of the impact this would have on our service was informing service-users that we had to step down services which included a halt to highly-attended support groups that had been a regular feature of our team’s work for a number of years. It was a sombre conversation and there was a real feel of anxiety, fear and disappointment that these measures were being taken, however there was also an overall understanding that it was for the safety of everyone involved. As a nurse I felt hugely conflicted with the step down of services as the need had not altered and in fact had escalated as people struggled with isolation and fear of what was to come. Many began to relapse and struggle to maintain levels of sobriety or abstinence which I feel was as a direct result of not having face-to-face contact with a key worker allowing for conversation on a verbal and non-verbal level which is vital in mental health nursing. We continued to lose service-users to the effects of substance use as is sadly the case but attending a funeral in times such as these was particularly difficult as there was a sense of disconnect due to social distancing. Other group members expressed how they felt that this made them feel vulnerable as the previously-available support networks were restricted and staff felt frustrated that they could not provide the face-to-face support but did their best with alternative telephone support.

As a service we adapted with regular telephone contacts, and meetings went to Zoom platforms but when needed face-to-face contacts continued for those at high risk or for those that felt that they just couldn’t manage any other way. Our service has a high number requiring opiate substitution therapy (OST); this was completely reviewed to allow for safe prescribing while also ensuring that the service-user was safely going to remain in treatment. Not an easy task! There was a noted instability during COVID in this group who also carry a very high risk and take time to stabilise. Being a non-medical prescriber I worked with the team to review caseloads pooling all those prescribed between two key workers and co-working the service. We reviewed each case individually allowing for extended prescribing where possible and reduced face-to-face contact to only those at high risk. As a service we adapted and adhered to all the restrictions put in place and thankfully had very few incidents of COVID.

One year on and the team are well on their way to rebuilding the service. Our group work is developing with a combination of both face-to-face and Zooms to allow for those that have discovered the joy of technology and are developing an OST strategy for the trust. While some services continue to use telephone contact, we feel that where possible engagement will take place safely face-to-face.

DIAGNOSTIC RADIOGRAPHY REPRESENTATIVE

Radiographers provide imaging services 24 / 7 for the Emergency Department and all in-patient areas both in department and mobile x-rays.

As part of the COVID-19 response, all patients attending the hospital with suspected or confirmed COVID-19 will see a radiographer as part of their pathway, with the radiographer often the first person to know that a patient has COVID-19 based on their imaging findings.

In some cases at the start of the pandemic it was the radiographers that would have highlighted the asymptomatic COVID patients due to the appearances of their lungs on CT scans. Management and radiographers undertook a number of planning exercises and reviewed working practices to see what changes were required. Departments were changed to green and red zones to manage COVID and non-COVID patients. Risk assessments and PPE became integral to daily life. Rotas were changed in stages to increase the numbers of radiographers working overnight and to accommodate staffing of the red and green zones. New pathways were developed to ensure sustainability of the imaging service in all trusts. A concern was how we maintain a service for GPs, outpatients and fracture clinics, vital services which were sometimes based on acute sites. Outlying non-acute hospitals became the life saver for these. Patients and staff felt safe with this system and appointments were introduced in areas where it was normally a walk-in service.

Obviously workforce numbers were incredibly impacted with shielding and those radiographers that had to isolate. Radiographers stepped up and supported each other and went the extra mile covering last-minute shifts with little notice. A number of radiographers were also redeployed to other parts of the service and adapted quickly to support their colleagues in general x-ray.

In all, radiographers and radiology staff evolved and adapted to provide an effective and safe service for the population in Northern Ireland. COVID has changed the landscape of our health service and demand for imaging will be further impacted with those that have been affected by long-COVID, we need to see more resources for both increased numbers of radiographers and imaging equipment in Northern Ireland.
NEW PLATFORM WILL BENEFIT PHARMACY BUYERS

The Cambrian Alliance Group has recently launched e-CASS market, a new platform designed to enable pharmacy contractors to buy and sell stock from each other with ease.

The new platform is set to 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,’ said Nathan Wiltshire, the Group’s CEO.

Cambrian Alliance Group boasts a membership of 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 claims that 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.

‘We are really pleased to be able to bring yet another new product to the independent pharmacy market,’ Wiltshire continued.

‘When we first launched e-CASS some ten 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 regard 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,’ Wiltshire added.

‘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.’
Promotion

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“Just want to say I have used e-CASS market for the first time today and have ordered 3 products with ease. Not only have I saved £27.11 on these products, but the process of ordering was very simple and quick. I can't recommend it highly enough to other contractors. Thank you Cambrian Alliance Group for providing another fantastic solution.”

Brian Deal
Ashwell Pharmacy

e-CASS market will save you more time and money, get in touch today!
In this article, Dr Ayse Basak Cinar, Honorary Consultant Coach and Researcher; University of Dundee, tackles the necessity of overcoming pandemic fatigue, and how to reenergise and motivate ourselves and healthcare teams during the post-COVID era.

The prolonged period of the COVID-19 crisis is a physically and emotionally difficult time for healthcare team members. Not only are they feeling the strain of increased expectations, learning to work with the added discomfort, headaches, fatigue, and the increased body temperature that additional PPE creates, but they also have real health fears of contracting the virus. Some of them may be questioning their future and/or how to work in the near future with changing regulations.

Compounding this are the economic impacts of the crisis and more uncertainty about the future than many have ever experienced. Daily practices throughout the day, once easily achieved, may now feel insurmountable when tensions and stress levels are high. Many team members experience fatigue due to all these challenges, regardless of being self-aware of it or not. Fatigue ‘is when the tiredness is often overwhelming and is not relieved by sleep and rest’. (1) NICE defines fatigue as, ‘Fatigue may be defined as severe mental and physical exhaustion, which differs from somnolence or lack of motivation, and which is not attributable to exertion or diagnosable disease’. (2) Depression, lifestyle restrictions, increased number of leave/sick days from work, and social isolation are a few examples of the complications of fatigue. (1, 2) Most importantly, fatigue may bring team members one step closer to their breaking point. (3)

COVID fatigue has been taking an enormous toll on healthcare workers, as addressed by the BMJ. (4) High levels of fatigue among healthcare professionals have been a concern over the years, as discussed by Paul Greig and Rosamund Snow. (5) Several studies show that healthcare professionals working with patients during an epidemic/pandemic are at heightened risk of mental health problems in the short and longer-term, particularly: psychological distress, insomnia, alcohol/drug misuse, and symptoms of post-traumatic stress disorder, depression, anxiety, burnout, anger, and higher perceived stress. (6, 7)

A survey of over 7,000 doctors conducted by the BMA in December 2020 found that more than half of them reported symptoms of depression, anxiety, stress, burnout, emotional distress, or another mental health condition. (7) In alignment with that, the Institute for Public Policy Research has found that 50 per cent of NHS staff felt that their mental health had declined during the first two months of the pandemic while six months later, 76 per cent of almost 42,000 nurses surveyed by the Royal College of Nursing reported an increase in their stress levels since the advent of the pandemic. (8) Therefore, strategies and interventions targeted to improve the mental wellbeing of healthcare professionals should be proactive, future-oriented, and prevention-oriented.

Predictors of workplace mental wellbeing are multi-layered, referring to social, organisational, individual, psychological, and environmental. (7) The magnitude and impact of every predictor varies from person-to-person, so workplace mental wellbeing interventions and policies should be agile and person-centred. As highlighted and shown by the literature, ‘a one-size-for-all’ approach to improve mental wellbeing does not work, in other words interventions focusing on giving healthy lifestyle advice as solutions do not work.

The Lancet Commission on Mental Health has mentioned that mental health improvement needs certain pillars and two of them briefly explain why a ‘one-size-for-all’ approach will not work: 1 – Mental health problems exist along a continuum from mild, time-limited distress to chronic, progressive, and severely disabling conditions (e.g. from stress, anxiety to post-traumatic stress); 2 – ‘the mental health of each individual is the unique product of social and environmental influences, in particular during the early life course, interacting with genetic, neurodevelopmental, and psychological processes and affecting biological pathways in the brain’. (9)

As the British Dental Association Chair, Mick Armstrong, mentions, there is a need for a system focused on prevention-based care, lowering stress for clinicians, and ensuring the best patient care. (10) Active engagement of both managers (10) and employees is essential in the workplace intervention development and implementation process. (11) CIPD highlights the need for placing employee wellbeing at the centre of business models and viewing it as the vital source of value creation, and the dividends for organisational health can be significant. (12)

The Five-Staged Resilience and Agility Model (Figure 1) stems from the successful outcomes of our international and local projects.
Both projects have shown that the model’s person-centered and proactive approach improves self-management skills for wellbeing (self-efficacy, self-esteem, resilience) and decreases the stress levels of the participants. (13-15) The model is originally a self-leadership development framework that integrates self-management and self-reflection dynamics, underpinned by resilience and agility, to social engagement and collective purpose setting. Studies have shown that self-leadership is the ground for effective stress management and social communication, and successful performance. (16) We propose that the model can serve as a guideline to design and execute wellbeing interventions for healthcare teams and organisations. The key feature of the model is to improve systematically personal wellbeing and team wellbeing through a tailored ‘one-size-for-all’ approach. Tailored methodology in every stage of the model provides customised tools and methodologies to enhance individual wellbeing and to strengthen agile and resilient growth of teams. Thereby, it provides a flexible, proactive and tailored methodology to build a positive workplace wellbeing culture. Wellbeing is not just for employees; it is for company leaders and CEOs as well. Creating a culture of wellbeing starts at the top and is strengthened by the active participation of the employees. Studies show that employees who feel cared for and valued by their leaders and company have higher performance and less absenteeism at work. A Deloitte study identifies five pillars a workplace must constitute to deem itself ‘a Simply Irresistible Organisation’ – meaningful work, supportive management, positive work environment, growth opportunity, and trust in leadership. (17) It also highlighted that employees look for employee wellbeing programmes focusing on the employee, their families, and their entire experience at work and life. All that may highlight the need to design and execute wellbeing interventions through collaborative participation of the managers and the employees. Those interventions also need to highlight the personal and professional growth of each individual, thus referring to the self-leadership journey of each employee and manager.

Such interventions are more important than ever for healthcare teams, in particular, if we think about their communication with and service provision for patients. Healthcare services pitched as ‘from healthcare teams to patients by healthcare teams with every team member’ can show how the healthy mindset of each team member is essential to enable positive communication with patients. The quality of care is directly related with the wellbeing, including mental health, of the whole team.

At the post-COVID-era many patients will have high levels of anxiety and stress about dental visits, and every member of the healthcare team will serve as a leading figure for secure, safe, and compassionate communication and healthcare service, and even going beyond that. Therefore, understanding the dynamics of self-leadership and improving wellbeing, inclusive of mental wellbeing, seems to be one of the cornerstones of the sustainable future of healthcare services.

At the post-COVID-era there is an emerging need for healthcare teams to feel reenergised and motivated and to feel stronger, together. Positive and enhanced wellbeing, in particular mental wellbeing, is the key driver for that state of greater achievement and fulfilment. Healthcare team culture, where everyone’s self-leadership practice for wellbeing is supported and valued, will be the key for successful delivery of healthcare services of the future.

CONFLICT OF INTEREST
The authors declare no conflict of interest.

THANK YOU
To Dr Stephanie Bilodeau for his support for promoting and working with the model.

REFERENCES
The authors declare no conflict of interest.
INTRODUCTION

Cardiovascular disease (CVD) is a leading cause of morbidity and mortality across the globe. Although policies and strategies such as smoking bans have resulted in a decline in mortality, the overall CVD burden continues to increase with resulting escalating healthcare cost. In the UK, chest pain remains a significant cause of hospital presentations and admissions. In 2017/18, there were 1.7 million inpatient episodes in the UK of which 4.4% of these were diagnosed with angina. This figure continues to rise year on year. In the absence of an acute coronary syndrome (ACS), most patients can be safely discharged with optimisation to medications however, in practice patients are admitted without optimisation.

Chronic Coronary Syndrome (CCS) is not a benign condition as 1 in 30 patients will have a significant cardiovascular event. Comorbidities and polypharmacy affect prescribing habits with resulting impact on patient outcome. Recent CCS guidelines published in 2019 by the European Society of Cardiology (ESC) have recognised the syndrome of Myocardial Ischaemia without Obstructive epicardial Coronary Arteries (INOCA). This change represents a fundamental shift in paradigm from a plaque centred focus to an overall ischaemia focused condition expanding the clinical syndrome classifications.

The goal of CCS management includes improving survival, reducing cardiovascular events as well as symptom improvement and QoL. Although the guidelines provide a consensus to patient management, the issue remains around the wide variation in practice. This has resulted in poor achievement of Optimal Medical Therapy (OMT), leaving patients vulnerable to CV events and symptomatic with significant health care costs.

Optimal Medical Therapy (OMT) encompasses a combination of medications against pathophysiology (slowing disease progression) and anti-anginals for symptom control. OMT has been shown to reduce the morbidity and mortality impact of this chronic disease with the addition of revascularisation in the appropriate patient.

Landmark studies published over the several decades, if implemented on a large scale, would have a significant positive impact on cardiovascular outcome and QoL. However, adoption of these results has been slow globally. A European study found only 57.8% of patients with CCS were on guideline recommended combination of disease modifying drugs. The FORGET study found only 32% of patients in the UK were on 2 antianginal medication prior to revascularisation. There is limited explanation for the low percentages seen in real world data compared to clinical trials but this falls far short of the 97.5% of patients on 2 or more antianginals achieved in the ORBITA trial. Even on symptom recognition, there appears to be significant discordance between patient reported and cardiologist estimated burden of angina in as much as 52% of cases.

A robust implementation of CCS management is therefore needed and a rethink of current delivery methods to improve the fundamental goals of treatment. In this article, we describe our practice in secondary care to address this issue. A practice that can be readily adopted across healthcare systems.

IMPROVING SERVICES FOR CHRONIC CORONARY SYNDROMES

Many institutions struggle with the number of chest pain attendances to the Emergency Department and resulting admission with troponin negative chest pains despite early rule out biomarkers for ACS. It is therefore necessary for pathways to be implemented that prevents the revolving door experiences of CCS patients which leads to significant related costs and poor patient satisfaction.

The opinion that cardiac drugs including anti-anginals are daunting or confusing hinders optimisation. An evidence based structured approach for patients with CCS directed at the non-cardiologist aids patient management whilst delivering significant savings to the healthcare system by avoiding unnecessary bed days.

The haemodynamic centred algorithm on the opposite page (fig 1) was developed with the acute physicians and instituted at my Trust resulting in a decreased admission and increased confidence in prescribing by non-cardiology colleagues. This simple algorithm loosely based on the work of Manolis et al, can be extended to general practice to enable General Practitioners to optimise medication therapy to minimise symptoms or identify patients that would benefit from revascularisation.

IMPLEMENTATION OF THE GUIDELINES

A truly collaborative effort is required between cardiologists and other specialties that see a significant number of CCS patients to make a significant impact to patient management and healthcare costs. A haemodynamic evidenced based algorithm has been shown to be the most logical approach to improve adoption as physicians are guided by parameters they use frequently and understand. Patient characteristics such as diabetes, co-administered medications and cardiac rhythm should also be taken into consideration to personalise management with safety considerations.

An optimisation clinic to aid up titration and evaluation of adverse effects has demonstrated significant success. Significant reductions in admissions and improving patient’s satisfaction are just some of the benefits. The use of standardised patient questionnaires such as the Seattle Angina Questionnaire can help reduce the disparity between patient and physician’s perception of symptom burden.
Clinical perspective

NEW
The shifting paradigm of Chronic Coronary Syndrome

CHALLENGE
Poor optimisation of medications- OMT

SOLUTION
A three-pronged approach
- Step wise prescribing algorithm
- Optimisation clinics/Patient empowerment
- Routine use of Patient questionnaire for angina frequency

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References:
1. Ranexa® (ranolazine) Summary of Product Characteristics.

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FOOD FOR THOUGHT

It’s common for people with a terminal illness to encounter changes in the way they eat and drink – be it a reduced appetite or shifts in taste. The team at Marie Curie tackle the common questions and concerns which they and their carers may pose.

CHANGES IN EATING AND DRINKING

Eating and drinking are a big part of life for most people. As well as providing the nutrition we need, food can be comforting and pleasurable. Sharing meals can be a way to connect with family and friends.

The patient’s illness or treatment might cause changes in the way in which they eat and drink, including:

- Changes in taste and smell – this can make some foods seem less attractive than before
- Loss of appetite
- Mouth problems
- Feeling sick and vomiting
- Constipation
- Difficulty swallowing – this can be caused by illnesses, such as head and neck cancer, motor neurone disease and dementia
- Weakness and fatigue – this can make it harder for the individual to cook and prepare meals
- Depression, anxiety or stress – this can lower their appetite
- Losing interest in eating and drinking in the last few days of life as the body slows down

Not being able to eat and drink in the same way as before can cause problems, including losing weight and feeling tired. It can also be hard to feel that they’re missing out on sharing meals with friends and family.

PRACTICAL TIPS FOR EATING AND DRINKING

If the patient has a low appetite or changes in taste they might find some of the following useful:

- Try lots of small meals or snacks throughout the day instead of having large meals
- If they notice that they have more energy at a particular time of day, they should plan their meals for when they have the most energy
- They should have foods that they want to eat – their favourites might change over time
- Adding foods, such as extra cheese, cream, fats and oils, can help to make sure that the individual is getting lots of energy even if they can’t manage big portions
- Make sure that they’re sitting upright in bed or in a chair when they eat
- Taking good care of their mouth can make it easier to eat and drink

GETTING SUPPORT WITH EATING AND DRINKING

If the individual is feeling sick or has a sore mouth, they should speak to their doctor as they might give them
Making a decision about whether or not to have tube feeding can be difficult. The patient should try and get as much information as they can before they decide. Some people are less able to make decisions about their care as their illness progresses. Making their wishes known in advance can help to make sure that they get the type of care and treatments they want.

There are different types of tubes:
- A nasogastric tube (NG tube) is inserted through one of the nostrils and straight into the stomach
- A gastrostomy tube is inserted through the abdomen (tummy) into the stomach or intestine. They need a small operation to be inserted. There are different types of gastrostomy tubes and the doctor will discuss which one might be best for the patient

They can have enteral feeding at home. A nurse or other health professional will visit to make sure that everything is working properly. The patient will need extra equipment and they or their carer will need training on how to use it.

The myTube website has videos for people with motor neurone who are considering enteral feeding, but it could be useful for people with other illnesses too.

**Parenteral Feeding**

This is when liquid feed is given through a vein (intravenously). Liquid feed is usually given through a central line or PICC line (peripherally inserted central catheter). These are lines that go straight into a vein so that liquid feed, fluids or medicines can be given through a drip. A small short procedure is needed to insert them. Parenteral feeding is rarely used at a person’s home but might be used in hospice, hospitals or care homes.

**Subcutaneous Fluids**

Subcutaneous fluids are sometimes given when someone can’t drink to keep them hydrated. This is when fluids are given through a drip into a small needle or cannula under your skin. There isn’t enough evidence to say whether this makes people feel better or not.

**Making Decisions About Eating and Drinking**

Some people find it helpful to think about what kind of support they would like with their eating and drinking if they become more unwell in the future. Making these decisions in advance can be helpful if the individual becomes too unwell to express their wishes later. They should talk to their doctor or nurse if they would like more information about this.

Amino acid solution with electrolytes 250ml, Glucose 0.60g, 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 2-16 is 12-24 hours. The recommended maximum daily dose is 150mg/kg bw/day. Additional information is available upon request.

Undesirable effects: NC

Additional information is available upon request.

References

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As crucial Parkinson’s-centred research rolls on, possessing the potential to translate into the clinic and positively impact individuals living with the condition, NIHR rounds up some of the latest updates.

**PARKINSON’S: ON THE HORIZON**

Inflammation is a common feature of Parkinson’s, and rheumatoid arthritis is an autoimmune disorder with heightened levels of inflammation commonly occurring in the tissue surrounding joints in the body. Recently, researchers have asked whether there is an association between Parkinson’s and rheumatoid arthritis: could people with rheumatoid arthritis be at higher risk of developing Parkinson’s? Now, two recent reports have explored this question.

The first, from a team of researchers – including iLCT Committee Chairman, Professor Patrik Brundin – who used the medical records of 3.6 million people in Sweden, found that people previously diagnosed with rheumatoid arthritis had a 30-to-50 per cent reduced risk of developing Parkinson’s. They found that the effect was strongest in females.

The second study, conducted by researchers in China, found a similar result: that people with rheumatoid arthritis had a reduced risk of developing Parkinson’s. Both studies suggest that a better understanding of the inflammatory processes in Parkinson’s could help with the development of new therapies for the condition.

Research into the inflammatory processes involved in Parkinson’s is an area of major interest at Cure Parkinson’s. They are co-funding the Azathioprine in Parkinson’s (or AZA-PD) study. Azathioprine is a drug that is used to treat inflammation by dampening down the immune system’s response. In the AZA-PD study, researchers at the University of Cambridge are hoping that by reducing levels of inflammation in people with Parkinson’s, they will be able to slow down the progression of the disease.

**COVID-19 AND THE NEED FOR REMOTE CLINICAL TRIALS**

The COVID-19 crisis has created medical, social, and economic hardship across the globe during 2020 and 2021; it has also dealt a cruel blow to current Parkinson’s research efforts. However, the pandemic has served as an opportunity for innovation and improvement, and this is particularly so in the way some clinical trials are being organised.

The closure of medical research centres across the globe, as part of the measures used to reduce the spread of the virus, has meant that some clinical trials have been postponed and ongoing trials may have missed certain data points, as mid-study clinical assessments have been cancelled.

In effect, the pandemic has exposed certain weaknesses in the way the medical research world currently conducts clinical trials and this unprecedented situation has served as an opportunity for innovation and improvement. An example of this is the Trial of Parkinson’s and Zoledronic Acid (or
TOPAZ) study which is an ongoing clinical trial. The interesting feature of this study is that it is being conducted entirely remotely – that is to say, the study participants are doing everything involved with the study from the comfort of their own homes. This includes recruitment, treatment and assessment.

The investigators conducting the TOPAZ study – being led by iLCT committee member, Professor Caroline Tanner (Weill Institute for Neurosciences, San Francisco) – are recruiting 3,500 people with Parkinson’s to take part. The study involves participants being treated with either the drug or placebo, and then monitored over time with a series of assessments focused primarily on the occurrence of fractures or falls.

Cure Parkinson’s are also focused on improving remote assessments in clinical trials. As part of the Exenatide Phase 3 trial in the UK, they are funding a sub-study that is evaluating the use of smartphone app technology to monitor changes in motor function during the trial.

The project is being led by Professor Michele Hu at Oxford University and will supplement the evaluations carried out in a clinical environment. This technology will capture real-life evidence more accurately and monitor changes throughout the day.

It’s hoped that projects like the TOPAZ study and the exenatide trial sub-study will help to make future global events to Parkinson’s clinical studies less disruptive, allowing this critical research to progress. And as Cure Parkinson’s initiate additional clinical trials focused on disease modification for Parkinson’s, sub-studies that further explore remote real-world assessment will be a key feature.

**POSITIONING PROSTATE DRUGS FOR PARKINSON’S**

Researchers have published evidence that a class of drugs commonly used for the treatment of prostate enlargement may have beneficial properties for Parkinson’s. This announcement also highlights yet another potential Parkinson’s treatment repurposing a clinically-available medication for Parkinson’s.

In 2019, scientists reported that a drug called terazosin exhibited neuroprotective properties in preclinical research of Parkinson’s. The drug was found to boost energy levels in cells and rescue models of Parkinson’s in the lab. This news caused some excitement, because it was quickly noted that this clinically-available medication that is used for treating enlarged prostates could have potential to be repurposed for treating Parkinson’s. A clinical trial is currently being completed at the University of Iowa, assessing how safe terazosin is in 20 people with Parkinson’s, and we await the announcement of these results.

Additional research is being conducted on terazosin to build a picture around how this drug may affect Parkinson’s, and the recent research report provides further evidence for use of terazosin as a potential treatment for Parkinson’s.

While these results need to be independently replicated across other large datasets, the findings also provide broader support for the concept of repurposing already-available medications. While terazosin may not be the best drug for treating Parkinson’s, if it can be rapidly used as a proof-of-principle test of efficacy, then better drugs can be developed based on this going forward.

Cure Parkinson’s have embraced this idea in their International Linked Clinical Trials programme with repurposed drugs like the diabetes drug, exenatide, the respiratory medication, ambroxol, and the gallstone treatment, UDCA. Once there is some evidence of effect, associated parties can step in and begin designing better, more effective molecules. The Neuraly diabetes molecule NLY-01, which is being trialled in people with Parkinson’s, is such an example.

**GUT FEELING ABOUT BILE ACIDS**

Researchers have reported that the ability of gut bacteria to break down fat is disrupted in people with Parkinson’s, resulting in issues with the production of bile acid (important for the breakdown and absorption of fats and vitamins from food in the gut).

In recent years, there has been accumulating evidence that the gut may be playing an influential role in Parkinson’s, but the underlying biology of that process has remained elusive.

Several years ago, researchers at Van Andel Institute, Michigan, reported – using two independent medical databases – that the removal of the appendix reduced the risk of a person developing Parkinson’s. In addition, the scientists found that the appendix from healthy (non-Parkinson’s) individuals contained a large proportion of the Parkinson’s-associated protein alpha-synuclein.

That same team of researchers has now followed up their first study, publishing the results of their research examining the populations of gut bacteria found in the appendix. They found that in people with Parkinson’s, there is an increase in levels of bacteria in the appendix that are involved with the production of bile acids. This increase is associated with a disruption in the gut bacteria’s ability to break down fat, making regulation of bile acid more difficult. That disruption could potentially lead to gut-related issues and cause inflammation which may be having a role on the progression of Parkinson’s.

This result is particularly interesting as it points towards a mechanism by which the bacteria of the gut and bile acids may be influencing the course of Parkinson’s. In addition, the data provides support for the Cure Parkinson’s-funded UDCA in Parkinson’s (or UP study) clinical trial. UDCA is a treatment that is used to treat gallstones and is being repurposed as a potential treatment for Parkinson’s. The UP study has now finished, and it’s hoped that results will be seen later this year.

For more information about The Cure Parkinson’s Trust, visit www.cureparkinsons.org.uk.
What’s the impact of epilepsy on the paediatric population in Northern Ireland, and why is access to assistance at an early stage so important for both patients and their families? Dr Deirdre Peake, a Consultant Paediatric Neurologist at Belfast Health & Social Care Trust, explains.

**HOW COMMON IS EPILEPSY AMONG CHILDREN IN NORTHERN IRELAND?**
The prevalence is 0.5-to-one per cent of the population.

**WHAT ARE THE EARLIEST SIGNS – AND HOW CAN THESE ADVANCE?**
The signs are variable and depend upon the age of presentation and the type of epilepsy. Epilepsy can start from the time of birth and anytime throughout childhood. Presentation is usually by the child having stereotypical repetitive abnormal movements, with or without changes in consciousness.

**WHY IS EARLY INTERVENTION NECESSARY?**
There is good evidence to suggest that in some forms of epilepsy, e.g., infantile spasms, the earlier we diagnose and treat, the better the neurodevelopmental outcome. In other forms of epilepsy, e.g., generalised tonic-clonic seizures and absence seizures, early detection can mean early treatment and earlier cessation of the seizures. This helps with cognition. In other less severe forms of epilepsy it is better to ensure that we have the correct diagnosis before committing to anticonvulsant drugs.

**WHAT DOES THE DIAGNOSIS GENERALLY INVOLVE?**
Epilepsy is a clinical diagnosis. The history and / or videos of the events are looked at by a clinician and the diagnosis can be made based on these if two separate events have occurred. This clinical diagnosis can be supported / confirmed by performing an EEG which may show features consistent with a particular type of epilepsy and hence guide treatment and investigation.

**HOW PROGRESSIVE HAS THE MANAGEMENT OF PAEDIATRIC EPILEPSY BEEN OVER THE YEARS?**
Huge progress has been made in understanding the genetics of the epilepsies. The identification of numerous genes has enabled us to use target-related anticonvulsant drugs, guide investigations, and offer a much clearer understanding of the conditions which we can provide families with. Advances in epilepsy surgery have enabled many children with underlying abnormalities in the brain to become either seizure-free or have a marked reduction in seizure frequency. This enhances the quality of life for both the child and the families.
Therapies, such as the ketogenic diet, modified Atkins and vagal nerve stimulation, offer a significant reduction in seizure frequency for those children with intractable epilepsy (i.e., those in whom seizures are not controlled by two anticonvulsant drugs).

There has been an expansion in the choice of anticonvulsant drugs that are now available to prescribe, and newer drug therapies (e.g., cannabinoid and fenfluramine) have been developed and used effectively in some epilepsy syndromes i.e., Dravet syndrome.

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

Over the years support for patients with epilepsy has increased. The Northern Ireland Paediatric Epilepsy Network has been running since 2010. This is a professional educational network that has ensured that all patients have access to a paediatrician with a specialist interest in epilepsy in their respective trusts. The paediatricians are supported by epilepsy specialist nurses who offer huge support to families and patients. Tertiary epilepsy services offer specialist clinics in intractable epilepsy, epilepsy surgery in conjunction with Manchester/ Liverpool i.e., NORCESS, ketogenic diet and vagal nerve stimulation. Epilepsy Action is a charity that offers information, support and help to all families with epilepsy.

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

Investment into timely access for investigations, including EEG, neuroimaging and genetics, are always required to enhance the service. The continued support of epilepsy networks locally (within Northern Ireland), nationally and internationally will enhance education, provision and management for all children in Northern Ireland.

**PATIENT SUPPORT**

Although Epilepsy Action’s groups are running virtually at the moment, it’s hoped that this will change again over the next year. In the meantime, an extensive array of resources for patients and their parents are available digitally – including a range of training courses designed to support people with epilepsy, organisations, and healthcare professionals, and a website just for children.

The child-friendly website addresses the ‘big epilepsy questions’ in an easy-to-understand way; shares stories from other children; presents short animations portraying characters and how epilepsy affects them; and includes free classroom resources which can be used on computers, tablets or interactive whiteboards.

To help support pupils with epilepsy, a downloadable toolkit is also available which covers key information, such as a checklist for school trips and an individual healthcare plan for epilepsy, as well as prompt questions.

Louise Cousins, Director of External Affairs at Epilepsy Action, explained the importance of access to patient support, saying, “The impact of epilepsy on a young person and their family often goes way beyond the seizures themselves. It can be a difficult condition to manage and can affect a young person’s education, social life and confidence. Having reliable, age-appropriate, resources to turn to for information and support can be invaluable, as can meeting families in the same boat. Epilepsy Action, through our helpline, online resources for children and families and support groups, help families affected by epilepsy feel confident about managing the condition. People can find out more at www.epilepsy.org.uk.”

**A STARK DISCONNECT**

New research shows that public understanding of epilepsy doesn’t always match with the reality faced by those living with the condition.

In Epilepsy Action’s new poll, nearly 1,000 people affected by epilepsy were asked for the one thing they wished the public knew about the condition. Half of them said that they wished that people knew that the impact of living with epilepsy goes far beyond seizures. Side-effects of medication, memory problems and impacted mental health are just some of the things that can affect people. One-in-five said that their biggest wish was for better awareness that there are many different seizure types. Other hopes included more understanding that not all seizures are triggered by flashing lights and that epilepsy is a fluctuating condition.

However, new figures suggest that much of the general public remains unaware of the ripple effect of the condition and are dismissive of how it affects people long-term. One-in-four people thought that epilepsy has no impact on a person’s life, aside from having seizures. A third said that the condition does not impact on a person’s mental health. In one revealing statement, two-thirds agreed with the suggestion that people ‘just need to be more positive when living with health conditions’. Yet, with a similar number of people (68 per cent) saying they would be afraid to even witness someone having a seizure, the charity says that this exposes a stark disconnect in understanding and compassion towards people with the condition.

For more information for anyone affected by epilepsy, visit www.epilepsy.org.uk or call the Epilepsy Action helpline on 0808 800 5050.
PLAYING WITH FIRE

Smoking remains a significant public health issue – representing the leading cause of preventable premature death in the UK. Bernie Neeson, Smoking Cessation Co-Ordinator at Cancer Focus Northern Ireland, outlines why stop smoking measures must continue to be a top priority during COVID-19, and how in order to reduce the burden of dependency in the UK, all healthcare professionals should provide effective advice and assistance. (1)

SMOKING AND COVID-19
COVID-19 has highlighted the risk factors for many patients who continue to smoke, in particular those with long-term conditions, e.g., COPD (Chronic Obstructive Pulmonary Disease) and asthma. Given that smokers are already at a greater risk of respiratory viruses since smoking damages the lungs and airways and weakens the immune system, making it harder to fight infection, COVID-19 continues to have adverse effects on smokers’ outcomes. (2)

The smoking habit which involves frequent hand-to-mouth action also contributes to the risk of contracting COVID-19. (1)

There is evidence that many smokers are fearful of the risks from COVID-19 and the motivation to quit is high. The pandemic provides an impetus for health professionals to seize every opportunity to support smokers to quit. While the period of self-isolation and lockdown restrictions could be used by some as an opportunity to quit smoking, many smokers may find the increased stress of a potentially fatal disease, fears over loss of employment, isolation and boredom too overwhelming to quit on their own. However, according to Public Health England, a smoker is four-times more likely to quit for good with specialist support along with medication and this is where Cancer Focus Northern Ireland (NI) Stop Smoking Support Service can make a difference.

Smoking is not a lifestyle but a dependency and supporting smokers to quit is one of the most effective ways to improve a smoker’s health. (3)

CANCER FOCUS NI OFFERS REMOTE SUPPORT TO SMOKERS THROUGHOUT THE PANDEMIC
Cancer Focus NI and its team of Stop Smoking Specialists have been supporting smokers to quit for over 50 years. The service extends to a range of settings – GP practices, community, schools and workplaces – reaching approximately 800 smokers annually across some of the most deprived areas in Northern Ireland. This service consistently has a quit success rate of 68 per cent at four weeks – well above the NICE guidelines.

Funded by the Public Health Agency, and in partnership with several GP practices in the Belfast and South Eastern area, Cancer Focus NI has adapted to government restrictions to facilitate clinics remotely via telephone or video. Feedback from smokers has been very positive and many value the convenience of accessing support at home.

Smokers are offered one-to-one weekly support over eight-to-12 weeks, tailored to the individual’s needs, including a combination of behavioural support and pharmacotherapy, which are proven to be the most effective approaches to help smokers quit. (4)

Despite the fact that most GP consultations are currently carried out via telephone, stop smoking advice should remain an important aspect of any consultation. Dr Manson, a GP at Bangor Health Centre, is in agreement, saying, ‘Smoking cessation remains an integral part of our assessment of patients. Smokers are advised that the best way to stop is to get specialist support and if they want to stop we can arrange an appointment with Melanie Patton, Smoking Cessation Specialist, with Cancer Focus NI’s weekly Smoking Cessation Clinic.’
MAKE EVERY CONTACT COUNT

Now is the time to support and strengthen stop smoking measures. The pandemic can’t be allowed to distract health professionals from addressing smoking with their patients. Smoking status should still be asked and recorded.

According to Dr Alex Bobak, a GP Specialist in Smoking Cessation, Wandsworth, London, it only takes 30 seconds to offer ‘Very Brief Advice’ (VBA) which can be very effective in triggering a response from the smoker to quit, and in turn has the power to transform the future life chances of a patient who smokes.

Dr Bobak suggests that healthcare professionals should practice VBA as part of routine care, being aware of locally available specialist support and how to refer smokers.

The VBA model has three simple steps:

• **Ask** and record smoking status – is the patient a smoker, ex-smoker or non-smoker?
• **Advise** on how to quit – the best way of stopping smoking is a combination of specialist support and pharmacotherapy. Smokers are four times more likely to quit for good
• **Act** on the patient’s response – offer support and treatment or refer to a local Stop Smoking Service

ELAINE’S STORY

Elaine is a 62-year-old patient at Kensington Medical Practice, Belfast, who is celebrating over 12 weeks smoke-free. Elaine has a history of diabetes and COPD and triggered by an exacerbation of her symptoms, she went to see her GP who offered her brief advice and referred her into the Cancer Focus NI Stop Smoking Support Service.

Elaine set a quit date for 23rd November 2020, and with the weekly support facilitated by Stop Smoking Specialist, Tina Fegan, along with Nicotine Replacement Therapy, she has successfully quit.

Elaine stated that her main motivation to quit was fear of contracting the COVID-19 virus, considering her current health conditions. She also stated that the lockdown restrictions gave her the opportunity to quit as she didn’t need to manage social situations and being around other smokers.

Now, three months later, she is already feeling the benefits of quitting with a reduction in her symptoms. She has also inspired her 33-year-old son to join the support service who is now eight weeks into his own quit journey.

For more information on our local smoking cessation clinics, you can get in touch by:

Scanning QR code to register online – www.cancerfocusni.org/cancerprevention/smoking/
Email – want2stop@cancerfocusni.org
www.stopsmokingni.info

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NUTRICIA ARE DELIGHTED TO ANNOUNCE THE LATEST FLAVOUR INNOVATION TO THE FORTINI COMPACT MULTI FIBRE RANGE – NEW CHOCOLATE-CARAMEL FLAVOUR.

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- Low volume, 2.4kcal/ml paediatric oral nutritional supplement (300kcal, 7.2g protein and 3g fibre per 125ml bottle)
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- Available to trial with your patients via the Nutricia Sampling Service

This information is intended for Healthcare Professionals only.

Fortini Compact Multi Fibre is a Food for Special Medical Purposes for the dietary management of disease-related malnutrition and growth failure in children from one year onwards and must be used under medical supervision.


50 PER CENT OF HOSPITAL-ACQUIRED INFECTIONS ARE PREVENTABLE

50 per cent of hospital-acquired infections are preventable. A 900-bed hospital takes two-to-three million temperatures per year – that’s two-to-three million unnecessary contact points with patients.

TriMedika, manufacturers of TRITEMP™, the non-contact medical thermometer, recognised an opportunity to bring improvements to reduce hospital spend by eliminating single-use plastics for routine devices.

Feedback from nurses revealed that waste from used thermometer covers represented a significant infection risk.

Nurses reported finding used plastics in patients’ beds, food trays and other hazards, including accidental swallowing in dementia patients.

As many hospital infections are spread through CONTACT the solution was a NON-CONTACT medical-grade thermometer requiring no plastic covers which would reduce costs, infection risk and eliminate plastic waste. Since launching the CE marked device in 2017, it is now on NHS Frameworks across the UK and used in hospitals and clinics in over 21 countries.

Roisin Molloy, TriMedika Co-Founder/ CEO, said, ‘TriMedika is passionate about developing smart, innovative medical devices from hospital healthcare teams’ feedback to deliver better patient care. New technology should challenge current hospital workflows and deliver savings on time, cost and most importantly today – eliminate infection spread in our hospitals.’

For more information, visit www.trimedika.com.
Among the more than 6,000 human diseases caused by single gene defects, the plasma deficiencies of coagulation proteins are of great importance to the haematologist, entailing as they do a life-long bleeding tendency with important morbidity and mortality if not adequately managed. Inherited coagulation deficiencies are rare diseases according to the definitions adopted in the United States (less than 200,000 cases nationwide) and Europe (less than five cases per 10,000 persons in the general population). The haemophilias are clinically relevant rare diseases: haemophilia A (HA), which results from the deficiency or dysfunction of coagulation factor VIII (FVIII), and haemophilia B (HB) of factor IX (FIX). Both are due to mutations in genes located on chromosome X and thus largely affect males, with bleeding symptoms roughly proportional to the degree of factor deficiency in plasma. The main sites of spontaneous bleeding are joints and muscles, which, if inadequately treated, cause chronic damage to the musculoskeletal system resulting in severe handicaps and disability. Furthermore, trauma and surgical interventions are accompanied by uncontrolled bleeding.

100 years ago there was practically no treatment for the haemophilias. Whole blood was the only treatment approach available and this was of poor clinical efficacy, such that the life-expectancy of people with haemophilia (PWH) was 10-to-15 years, even in the most favourable circumstances. The few cases that survived were compromised by severe musculoskeletal damage that confined them to bed or to a wheelchair, and ice, analgesics and splinting were the only measures that could be used to alleviate pain and other symptoms associated with joint and muscle bleeding. The Second World War and related combat casualties were triggers for the improved preparation of plasma that contains all the coagulation factors. Therefore, even until the 1960s, the life-expectancy of patients with haemophilia was no more than 20-to-30 years.

A first step forward was the demonstration in 1964 by Judith Pool that cryoprecipitation of fresh-frozen plasma was able to concentrate FVIII. Nevertheless, the most significant advance was seen in the 1970s with the industrial manufacturing and commercial availability of freeze-dried plasma concentrates of FVIII for HA and of the coagulation factors (II, VII, IX, X) of the so-called prothrombin complex (PCC) for HB and the corresponding rare coagulopathies. The main advantages of these products was storage in simple refrigerators, reconstitution in small amounts of fluid, and no need for a drip to administrate blood, plasma and cryoprecipitate. Their availability was the success story of the 1970s because they allowed home care and self-treatment. Also in Italy, demonstration in 1977 that the synthetic drug desmopressin (DDVP) was clinically efficacious as a non-transfusional form of FVIII replacement in mild HA and contributed to further progress in the field.

However, the 1980s threw a dramatic shadow on this favourable scenario when a large proportion of patients treated with factor produced from very large plasma pools developed serious or fatal blood-borne viral infections such as hepatitis and HIV/AIDS. This gloomy decade was accompanied by rapid progress in molecular medicine that not only clarified the genetic basis of the coagulation defects but also, and most importantly, led to the therapeutic production in the 1990s of recombinant coagulation FVIII and IX. There was a continuous improvement in the purity of these products, and the use of animal and human proteins during manufacturing and in the final formulation was avoided.

**A WORK IN PROGRESS**

Dr Gary Benson, Director of the Haemophilia Centre at Belfast City Hospital, assesses significant advancements in haemophilia therapy, as well as the steps which have contributed to this progress and the challenges which persist for patient care.

**RECENT PROGRESS IN HAEMOPHILIA THERAPY**

**PROPHYLAXIS AS STANDARD OF CARE**

Primary prophylaxis of bleeding episodes became the evidence-based standard of care following several randomised clinical trials which demonstrated that this preventive regimen was clearly superior to the episodic management of bleeds, because it reduced the rate of their occurrence and also achieved a marked reduction in joint damage. Prophylaxis became the undisputed standard of care in countries that could afford it. Additional and important advantages were a much-improved patient quality of life, including less hospitalisations and days lost from school and work, and an improved social life. However, the implementation of prophylaxis met some obstacles, in addition to that of affordability. The degree of adherence was often less than optimal, particularly in children and adolescents, owing to the burden created by the need of two-to-three or more weekly intravenous injections. This not only interfered with the patients’ quality of life, but also created problems of vein access, with the related frequent need to resort to ports or other central venous access devices.

**EXTENDED PLASMA HALF-LIFE COAGULATION FACTORS**

Frequent intravenous injections are necessary due to the relatively short plasma half-life of replaced coagulation factors (range 10-to-14 hours for FVIII, 18-to-22 hours for FIX). Thus, starting
HAEMOPHILIA

from the 2010s, attempts were made to engineer these factors by recombinant technology, with the goal of obtaining medications that remained in the circulation longer and thus reducing the number of intravenous injections.

NON-FACTOR THERAPIES

In spite of the progress made with the availability of EHL factors, unmet needs remained. In HA patients without inhibitors, the reduction in the frequency of intravenous injections was not considered satisfactory and therapy still based on the need for a venous access continued to be unattractive. HA patients with FVIII inhibitors remained poor candidates for prophylaxis that could only be provided by bypassing products that are very expensive and difficult to administer on a regular preventive basis. With these drawbacks in mind, therapeutic approaches that were not based on the replacement of the deficient factor were developed. This took place in two main ways: (i) for HA, by mimicking the coagulant activity of FVIII; and (ii) for both HA and HB, by increasing defective thrombin formation through the inhibition of the naturally occurring anticoagulants (antithrombin, tissue factor pathway inhibitor, and activated protein C).

For the moment, only the monoclonal antibody emicizumab that mimics FVIII activity has been licensed and marketed. The approach of quenching the anticoagulant pathways is currently undergoing an advanced stage of clinical development, but no product has been licensed yet.

EMICIZUMAB

This bispecific monoclonal antibody supports the spatial interaction between activated FIX (FIXa) and factor X, and thereby promotes thrombin formation by mimicking FVIIIa activity regardless of FVIII deficiency and the presence of FVIII inhibitors. Administered subcutaneously, this drug reaches a steady state with a long plasma half-life that allows well-spaced dosing intervals of at least every week, every two weeks or even every four weeks.

The clear main benefit of this first non-factor replacement is the feasibility of regular prophylaxis in patients with inhibitors, using the advantageous and user-friendly subcutaneous administration route at weekly intervals or even less frequently. Furthermore, the licensing of emicizumab also for HA patients without inhibitors is an important alternative to the currently available options of SHL and EHL coagulation factors, with the advantage of the subcutaneous instead of the intravenous route of administration.

OTHER NON-FACTOR THERAPIES

Medications with mechanisms of actions other than that of emicizumab, and also mainly administered subcutaneously, are currently at an advanced stage of clinical development. Conclizumab, a monoclonal antibody against the anticoagulant protein TFPI, increases the potential for thrombin generation. A trend towards lower bleeding rates was observed in patients with HA and HB with and without inhibitors, but the cases were too few to provide robust evidence of efficacy.

Fiturisan is a compound that interferes with RNA, and that decreases the plasma concentrations of antithrombin. In early clinical studies, this agent, given subcutaneously at progressively higher dosages and even at monthly intervals, was accompanied by the progressive decrease in plasma antithrombin paralleled by an increase in thrombin generation and reduction of the ABR. Phase III studies of fiturisan in patients with severe HA and HB with and without inhibitors are ongoing. A fatal thrombotic event that occurred in 2017 in a patient with severe HA during a phase II study led to the FDA temporarily stopping the study, but some protocol and guideline changes have allowed it to be restarted and to move this product forward to phase III studies. On the whole, it is still too early to truly understand the role of these additional non-factor products in the scenario of haemophilia care, but potential advantages are their use not only in HA but also in HB and other inherited coagulation disorders.

GENE THERAPY

The first vector associated with curative gene transfer in animal models of haemophilia was the adeno-associated virus (AAV), and, so far, AAV vectors are the only tools used to achieve therapeutic levels of FVIII and IX in haemophilia patients. Historically, the first study involved 10 patients with severe HB at the Royal Free Hospital in London, UK, who received single but increasing doses of an AAV8 vector, some of them with a current follow-up of nine-to-10 years. They continue to have stable expression of the transgene, with plasma levels ranging from two per cent to five per cent, and a 90 per cent reduction in bleeding episodes.

There are still important problems and issues that need to be resolved before licensing procedures and availability of gene therapy for the haemophilias can be carried forward. Only adult patients have been enrolled in studies so far, because in paediatric patients, the active dividing hepatocytes of children mean that there is no guarantee of achieving a persistent expression of a non-integrating vector, such as AAV.

Once these challenges to gene therapy in the haemophilias are resolved, for a number of reasons, this is likely to become the treatment of choice. Despite the major advances in prophylaxis obtained with EHL factor products and non-factor therapies, breakthrough bleeding has still not been fully eliminated, and treatment is still invasive, both physically and psychologically, even when the subcutaneous route of administration is used. Patients with severe haemophilia live with the risk of bleeding every day of their lives, and no repeated dosing regimen will be able to replace the advantages of a one-off lifetime cure. Finally, we should not forget that 70 per cent of patients worldwide have no treatment, because either nothing is available or because they can’t afford it; life-expectancy at birth for these patients is still only 10 years or less! The World Federation of Hemophilia has been attempting to tackle this formidable problem since its foundation in 1967, but despite great progress in medium-income countries, the great majority of low-income countries are still in the same situation they were in 100 years ago: ice, splinting, bed rest, and blood transfusions when available!
Severe haemophilia A has its challenges

Treatment of haemophilia and/or bleeding disorders. The treatment should be initiated.

Dosage and Administration:

Hemlibra can be used in all age groups.

Indications:

Hemlibra is indicated for routine prophylaxis of bleeding episodes in patients with: haemophilia A (congenital factor VIII deficiency) with factor VIII inhibitors; severe haemophilia A (congenital factor VIII deficiency, FVIII < 1%) without factor VIII inhibitors. Hemlibra can be used in all age groups.

Serious thrombotic events have been reported in patients receiving Hemlibra prophylaxis, of >100U/kg/24 hours of aPCC for 24 hours or more was administered. Patients receiving Hemlibra prophylaxis should be monitored for the development of activated Prothrombin Complex Concentrate (aPCC). In case a bypassing agent is indicated in a patient receiving Hemlibra, see SmPC for dosing guidance on the use of bypassing agents. Intrinsc pathway clotting-based laboratory test results in patients treated with Hemlibra should not be used to monitor its activity, or to determine dosing for factor replacement or anti-coagulation, or to measure factor VIII inhibitors titers. Caution should be taken if intrinsic pathway clotting based laboratory tests are used, as misinterpretation of their results may lead to under-treatment of patients experiencing bleeding episodes, which can potentially result in severe or life-threatening bleeds. There are no data in children <1 year of age. The developing hemostatic system in neonates and infants is dynamic and evolving, and the relative concentrations of pro- and anticoagulant proteins in those patients should be taken into consideration when making a benefit-risk assessment. Emicizumab increases coagulation potential, therefore the coagulation factor relative concentrations of pro- and anticoagulant proteins required while receiving Hemlibra prophylaxis. In case of thrombotic complication, consider discontinuing FVIIa or FVIII and interrupt Hemlibra prophylaxis as clinically indicated. Immunogenicity: <1% of patients developed anti-emicizumab antibodies with neutralising potential (based on declining pharmacokinetics). Pregnancy and Lactation: No data are available in humans. Women of childbearing potential receiving Hemlibra should use effective contraception during, and for at least 6 months after cessation of Hemlibra treatment. Adverse reactions: Very common: headache, injection site reaction, arthralgia. Common: pyrexia, diarrhoea, myalgia. Other serious adverse reactions: TMA and thrombotic events, including cavernous sinus thrombosis and superficial vein thrombosis contemporaneous with skin necrosis. Prescribers should consult the SmPC for a full list of adverse reactions.

HEMLIBRA can help keep patients on track.¹

The only monoclonal antibody available for subcutaneous routine prophylaxis of bleeding episodes in patients of all ages with congenital haemophilia A, classified as severe or with Factor VIII (FVIII) inhibitors.²

Prescribing Information

Hemlibra® (emicizumab) ▼ 30 mg/ml and 150 mg/ml solution for injection

Please refer to Summary of Product Characteristics (SmPC) prior to use of Hemlibra.

Indications: Hemlibra is indicated for routine prophylaxis of bleeding episodes in patients with: haemophilia A (congenital factor VIII deficiency) with factor VIII inhibitors; severe haemophilia A (congenital factor VIII deficiency, FVIII < 1%) without factor VIII inhibitors. Hemlibra can be used in all age groups.

Dosage and Administration: Treatment should be initiated under the supervision of a physician experienced in the treatment of haemophilia and/or bleeding disorders. The recommended dose is 3 mg/kg once weekly for the first 4 weeks, followed by maintenance dose of either 1.5 mg/kg once weekly, 3 mg/kg every 2 weeks, or 6 mg/kg every 4 weeks, administered as a subcutaneous injection. Hemlibra is intended for long-term prophylactic treatment. Emicizumab has not been studied in patients with moderate or severe renal impairment or severe hepatic impairment. The safety and efficacy of emicizumab has not been established in patients receiving ongoing immune tolerance induction or in the surgical setting. Contra-indications: Hypersensitivity to the active substance or to any of the excipients.

Precautions: Cases of thrombotic microangiopathy (TMA) have been reported in patients receiving Hemlibra when on average a cumulative amount of >100U/kg/24 hours of activated Prothrombin Complex Concentrate (aPCC) for 24 hours or more was administered. Patients receiving Hemlibra prophylaxis should be monitored for the development of TMA when administering aPCC. Caution should be used when treating patients who are at high risk for TMA (e.g. have a medical or family history of TMA), or those who are receiving concomitant medications known to be a risk factor for the development of TMA. Serious thrombotic events have been reported in patients receiving Hemlibra when on average a cumulative amount of >100U/kg/24 hours of aPCC for 24 hours or more was administered. Patients receiving Hemlibra prophylaxis should be monitored for the development of thromboembolism when administering aPCC. Treatment with bypassing agents should be discontinued the day before starting Hemlibra therapy. Physicians should discuss with all patients and/or caregivers the exact dose and schedule of bypassing agents to use, if required while receiving Hemlibra prophylaxis. In case a bypassing agent is indicated in a patient receiving Hemlibra, see SmPC for dosing guidance on the use of bypassing agents. Intrinsc pathway clotting-based laboratory test results in patients treated with Hemlibra should not be used to monitor its activity, or to determine dosing for factor replacement or anti-coagulation, or to measure factor VIII inhibitors titers. Caution should be taken if intrinsic pathway clotting based laboratory tests are used, as misinterpretation of their results may lead to under-treatment of patients experiencing bleeding episodes, which can potentially result in severe or life-threatening bleeds. There are no data in children <1 year of age. The developing hemostatic system in neonates and infants is dynamic and evolving, and the relative concentrations of pro- and anticoagulant proteins in those patients should be taken into consideration when making a benefit-risk assessment. Emicizumab increases coagulation potential, therefore the coagulation factor relative concentrations of pro- and anticoagulant proteins required while receiving Hemlibra prophylaxis. In case of thrombotic complication, consider discontinuing FVIIa or FVIII and interrupt Hemlibra prophylaxis as clinically indicated. Immunogenicity: <1% of patients developed anti-emicizumab antibodies with neutralising potential (based on declining pharmacokinetics). Pregnancy and Lactation: No data are available in humans. Women of childbearing potential receiving Hemlibra should use effective contraception during, and for at least 6 months after cessation of Hemlibra treatment. Adverse reactions: Very common: headache, injection site reaction, arthralgia. Common: pyrexia, diarrhoea, myalgia. Other serious adverse reactions: TMA and thrombotic events, including cavernous sinus thrombosis and superficial vein thrombosis contemporaneous with skin necrosis. Prescribers should consult the SmPC for a full list of adverse reactions.

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Date of Preparation: June 2020

The following risk minimisation materials can be found at www.medicines.org.uk:

• Guide for healthcare professionals
• Guide for patients/caregivers
• Patient alert card
• Guide for laboratory professionals

This medicinal product is subject to additional monitoring. This will allow quick identification of any new safety information. Healthcare professionals are asked to report any suspected adverse reactions. Adverse events should also be reported to Roche Drug Safety Centre by emailing welwyn.uk_dsc@roche.com or calling +44 (0)1707 367554.

As Hemlibra is a biological medicine, healthcare professionals should report adverse reactions by brand name and batch number.
Cow’s milk allergy (CMA) can be defined as an immune-mediated response to proteins found in cow’s milk that occurs on a consistent basis whenever the child ingests cow’s milk. It is one of the most common food allergies, along with the likes of peanut allergies, occurring within a child’s formative years and can lead to a nutritional deficiency if not properly and promptly diagnosed and treated. The stress and anxiety that CMA can also present to the wider family can be extreme. Not knowing why their baby is crying constantly, continual soiled nappies and not putting on weight can be very worrying for parents of an infant.

Fatality due to CMA is rare, but in a case series of fatalities in a European population with data on 1970 children in 10 countries with anaphylaxis to food, there were a total of five fatal anaphylactic reactions and two were attributed to cow’s milk.

When cow’s milk is ingested by the baby/infant it triggers the body’s immune response to a specific milk protein. The aim of this immune response is to neutralise the causative protein and prevent any further negative effects. However, when CMA hasn’t been diagnosed and cow’s milk is again ingested, the immune system recognises this particular protein and a response is initiated resulting in the release of histamines. It is this process that causes the manifestation of the signs and systems of CMA.

It is an immune-mediated reaction to specific proteins within cow’s milk, for example, casein or beta-lactoglobulin. Within a patient’s response, three different types of inflammatory mechanisms may be present:

1. ‘Acute Onset’ Immunoglobulin E-mediated (IgE-)
2. ‘Delayed Onset’ non IgE cell-mediated
3. Mixed Type Mediated Allergies

Each patient’s onset and symptoms may vary between these

Unfortunately, as the sufferers of CMA are young, this can become even more distressing.

Acute onset (IgE-) is a type I hypersensitivity reaction in which symptoms usually occur within minutes to one-to-two hours of ingestion. Within the IgE-mediated CMA patients (typically present to school age), the early phase signs are due to the cross linking of surface bound allergen specific IgE by allergens. This interaction subsequently causes the activation of basophils and mast cells which results in the release of varying substances such as interleukin-4 (IL-4), histamines, platelet activating factor and TNF-α.

This chain of biological events can lead to symptoms such as urticaria, angioedema, throat tightness, respiratory symptoms, including difficulty breathing, coughing, and wheezing. In addition the patient may experience gastrointestinal symptoms. These symptoms can be distressing in infant patients who are unable to effectively communicate how they feel and include abdominal pain, vomiting, and diarrhoea.

Mixed and non-IgE mediated forms of CMA differ when you take into account their underlying mechanisms, symptomatic presentation and complications.

Mixed forms of CMA (both IgE and non-IgE mediated) include:
1. Atopic dermatitis
2. Allergic eosinophilic esophagitis
3. Eosinophilic gastritis

Non-IgE mediated forms of CMA include:
1. Cow’s milk enteropathy
2. Food protein induced proctitis / proctocolitis
3. Food protein induced enterocolitis syndrome (FPIES)
4. Heiner syndrome

CMA may result in a reduction of the quality of life of both the infant and parent(s) and, in some cases, impede the child’s growth. Persistent cases may also lead to the infant becoming predisposed to respiratory allergy conditions later in life such as asthma. It is important to remember when examining an infant/child who is potentially suffering from CMA, that the impact a delayed or wrong diagnosis can have on the patient and their family can be distressing and overwhelming.
Alimentum® (previously Similac Alimentum) has been upgraded to further support the immune needs of formula-fed infants with mild-to-moderate cow’s milk allergy, and other conditions where an extensively hydrolysed formula is indicated.

Contact your local Abbott Account Manager to learn more or call Freephone Nutrition Helpline on 0800 252 882

IMPORTANT NOTICE: Breastfeeding is best for infants and is recommended for as long as possible during infancy. Alimentum is a food for special medical purposes and should only be used under the recommendation or guidance of a healthcare professional.

*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.†

†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.

References.
Estimated to affect around 100,000 people, and the third most prevalent movement disorder in the UK, dystonia presents with uncontrollable and sometimes painful muscle spasms caused by incorrect signals from the brain. The severe clenching and contraction of the muscles in many cases leads to symptoms such as functional blindness, debilitating contortion of the hands, neck, and trunk, as well as difficulty walking (sometimes with near total loss of mobility due to the body jack-knifing in painful positions). Dystonia can be progressive and so may deteriorate and spread over time. Everyday tasks can be difficult and challenging.

In the Life with a Neurological Condition During COVID-19 survey (a national survey run by The Neurological Alliance (NA) in England between 9th- to 20th June 2020), over 700 people diagnosed with dystonia shared their experiences of life during the pandemic. While there are a handful of positive stories, broadly it is a negative picture with a near 70 per cent saying the pandemic had affected their condition very significantly, significantly, or moderately.

The survey also found that 80 per cent of dystonia patients had a medical appointment delayed and a further 62 per cent had a medical appointment cancelled. Many of these appointments were for botulinum toxin injections, a treatment that helps them manage their condition. Missing an injection can leave dystonia patients in pain and with more disabling symptoms that may require additional care. Many have also struggled with the reduction of physical activity while in lockdowns and have started seeing this negatively affect their symptoms too.

A patient with hemidystonia (half body dystonia) described that her new treatment was now indefinitely delayed, and the reduction in physical activity during lockdown for example to / from the shops / work was causing a significant deterioration in symptoms.

Nearly a year on, the British Neurotoxin Network estimates that only 80 per cent of clinics are running and many are unable to run at pre-pandemic capacity for a variety of reasons, including the additional time infection control takes. As such, many patients are being asked to leave longer periods between their injection cycles. While most clinics are taking on new patients, shielding patients are still unable to be seen and there is concern about how clinics will cope in the long-term once all patient groups are safely able to return.

Waiting lists for deep brain surgery were already long, but are being further delayed and patients are left unsure what to expect. Surgery is normally only considered when other treatment options have not been successful, meaning worryingly most people on the waiting lists are suffering from severely debilitating symptoms. Combining this with the obvious daunting prospect of major brain surgery and an unknown surgery date, it’s clear that the psychological toll on individuals can be significant.

One patient, who after years of suffering with cervical (neck) dystonia, finally opted for surgery in 2020. Originally scheduled for October 2020, it was delayed once and has now been delayed again and may not take place until June 2021.

Clinicians are additionally anticipating a dip in the number of new diagnoses being made during the pandemic, followed by a delayed onset increase. Diagnosing dystonia can typically take several years as it’s not a widely-recognised condition. They expect extended delays though, as many of the first symptoms of dystonia are not obvious, and at a time where we are being told to protect the NHS, people may feel the early
symptoms are not worrying enough to warrant a GP visit, especially with the heightened risk of catching COVID-19 in medical settings. A diagnosis can unlock treatment options though and help individuals manage their condition, so any delay is hugely significant.

GP referrals to neurologists are also delayed as staff are redeployed or hospitals are unable to see patients. In some cases, consultants have been able to make a new diagnosis via remote means, such as a telephone or video consultation. But dystonia is a movement disorder, and so this understandably has its challenges, and it isn’t possible in all cases.

Remote consultations are becoming far more regularly accepted across the NHS, but there are several scenarios where this is not appropriate for dystonia patients. The NA’s COVID-19 survey found that over 25 per cent of people found that the virtual appointment they had was either not very effective or very ineffective, and 50 per cent said that choosing virtual or face-to-face would depend on what their routine appointment was for, with a further 46 per cent saying that they would prefer it to be face-to-face.

There can be a number of challenges for people with dystonia in using digital access for care, from limitations with skill or equipment, to some cases where the condition itself makes it more difficult. For example, someone with laryngeal dystonia can find phone calls difficult as the spasms can distort their voice. The roll-out of digital processes has been so rapid, patient choice has not been embedded into the process, allowing groups like these to be excluded. We are concerned that as we recover from the pandemic, trusts will be left with the difficult decision of how to balance digital access with face-to-face clinics. Unless the NHS creates clear national frameworks, we expect to see an increase in variation of services across the UK, leaving people living with dystonia with further differences in their care depending on their location.

We also know that even before the pandemic, isolation is not uncommon for people with dystonia. During the pandemic, this may have been exacerbated. Dystonia UK face-to-face support groups are closed for the foreseeable future and online support networks have grown. This digital alternative will not be suitable for all though, and this concerns us that the most isolated individuals are not getting the support they need. In the NA’s COVID-19 survey, 40 per cent of people said they felt that their neurological condition had deteriorated as they had not been able to see friends and family.

We heard from one lady during the first lockdown with blepharospasm (eye dystonia) who, without her botulinum toxin injections, was now no longer able to drive, leaving her more isolated than ever.

At a time where many are facing financial hardship, we continue to hear about the difficulties people with dystonia face when applying for benefits. There are normally several challenges completing a claim, however, this process has been made even more difficult as in-person assessments have been postponed. It has also been several months since Chancellor Rishi Sunak increased Universal Credit by £20 a week, but failed to give the same increase to those on legacy benefits. This lack of financial support can hugely affect people’s independence.

Finally, all these changes have an increasingly worrying effect on mental health. The prevalence of mental health issues among dystonia patients is already high and this relationship can be two-way – the symptoms of dystonia can cause mental health issues, but also anxiety and stress can make the physical symptoms of dystonia worse. We are concerned that people with dystonia are extremely vulnerable to deterioration in their mental health. In the NA’s survey, over 38 per cent said that the COVID-19 crisis had affected their mood and sense of wellbeing, either significantly or very significantly. The survey also showed that a worrying one-in-10 people with dystonia felt helpless, and four-in-10 anxious.

We know that the pandemic has undoubtedly changed all our lives, but people with dystonia have been so greatly affected. While we are hopeful that we will start to see some normality return in 2021, the truth is that the effects of the pandemic will be seen in the dystonia community for years to come and normalcy for them will be delayed.

ABOUT DYSTONIA UK

Dystonia UK is the only UK national charity dedicated to helping people living with dystonia. Throughout the pandemic, our services have been more vital than ever, and we’ve had to rapidly shift the way we operate. No longer able to organise face-to-face events, we have found innovative ways to connect and reach our patient community at the heart of our organisation.

As part of our Reach Out, Reach All campaign we launched our first webinars reaching over 10,000 people. Our new website was launched, and we successfully held our first digital conference. 2020 also saw the dystonia community get behind our biggest dystonia awareness month campaign to date, with UK landmarks lit up in our iconic dystonia green, virtual ‘Tea with the Team’ meet-ups, a collection of personal stories, and our ‘What is Dystonia? infographic reaching over 60,000 people!'
NIHR chats to Paul Insley, Head of Bestway Medhub and Wardles, about the values which underscore the Bestway Medhub business and how they are ‘walking the walk’ when delivering them.

**Transparent**

“We strive to be honest with our customers, we will not promise something which we can’t deliver. We recently launched our Web Ordering Portal giving our customers easy and quick access to place their orders and manage invoices and statements linked to those orders. We have expanded the Buying Groups we partner with; we are listening to our customers and being transparent in the response and updates we have. We have dedicated Field Sales and Telesales Managers to support every customer with queries and work closely with our Buying Teams to be clear with customers on availability and lead times where this applies.’

**Fair**

‘Taking the mindset of working in partnership we look to be fair in our transactions at every point. Our business model can’t just work for Bestway Medhub, it needs to work for our customers and the third parties that we partner with.’

**Simple**

‘Bestway Medhub have a simple pricing structure, with no minimum spend or order quantity. We support our customers with terms and conditions that are easy to understand, with a Customer Service Team able to support queries.’

**So what’s next for Bestway Medhub?**

‘We continue to take customer feedback and review our proposition with the ever-changing needs in pharmacy. This will be especially relevant as we come out of lockdown. As the general public look towards pharmacy to manage their health more now, we have expanded our OTC range and have an electronic ordering platform for surgical lines which we believe will give customers more reasons to use Bestway Medhub, while we continue to build on the values of being transparent, fair and simple.’

For further information about opening an account with Bestway Medhub, to speak to Brendan or to find out more, call 0800 050 1055 or email Brendan.moffatt@bestwaymedhub.co.uk.
Discover the Bestway for your business

Bestway Medhub provides bespoke support for your business:
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• Simple, transparent net pricing
• Comprehensive range of Generics, PI and OTC
• Dedicated Account and Telesales Managers
• Range of ordering options, including our expert UK-based telesales team, or via e-mail
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• Payment terms of 30 days on statement
• Payment by Direct Debit, BACS, cheque, all major credit cards and Amex (with no additional charge)

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FACING THE UNKNOWN

From balancing home-school stresses with our own workloads, to attempting to maintain structure when the days are clouded with so much uncertainty, parenting in a pandemic can be both difficult and daunting. Here, Lianna Champ — who has over 40 years’ experience working with children and parents in grief counselling — provides advice as to how parents can help their child overcome death anxiety when they are exposed to floods of COVID-related sadness and scary statistics.

PARENTAL ROLE

Children learn about the world from the adults around them so as adults we have a responsibility to create confident, happy and emotionally healthy future generations. It starts when we have our babies. You can’t spoil a child with love, and this is different from giving a child anything it wants, whenever it wants. We need to create clear boundaries based on the values and morals that we want our children to have. Having children is an absolutely serious responsibility but one that brings immeasurable joy and love. We must do our part.

Many parents isolated at home are also under lots of excess stress. Parental stress has been shown to have an effect on stress reactions in their children and therefore it is more important than ever that parents manage to maintain a good level of calm and control. By managing their own stress better, parents can help to manage their children’s stress.

As parents, it’s natural to want to protect our children from the harsh realities of life, but the less we tell our children, the more they are forced to imagine. And children, no matter what age, tend to worry more when they don’t understand or aren’t told what is happening around them.

Children do pick up on their parents’ emotions, therefore we have to really monitor our parenting skills and especially at this time, be aware of our own reactions to the pandemic.

WHEN CHILDREN SUFFER WITH DEATH ANXIETY

With so many COVID deaths being reported around the globe, our reactions and behaviours directly affect how our children receive the news and therefore react themselves. Children, now more than ever, are aware of death. They hear the stories on the news and talk to their friends, also social media brings the world to our doorsteps.

Children learn their coping mechanisms from the adults around them — they may not always hear what the adults are saying, but they will always watch what they do. If you panic, struggle or keep talking about the pandemic over and over again, the chances are your child will too — it is learned behaviour. The way we teach children how to cope with traumatic events in childhood sets a pattern for the rest of their lives. Therefore, it’s important to keep our behaviours and routines as familiar as possible in the face of adversity to help give our children a feeling of safety. We can teach them to embrace all life experiences — good, bad, happy or sad — as they arise, to talk about their feelings when they feel them, and not to be made to think that there is something wrong with them when they are being emotionally honest. Also sticking to routines as much as possible helps keep a semblance of normality.

A good place to start is to find out what your child already knows about coronavirus. Watch the news with them to start the conversation. Ask them what they have learned about this illness and if they would like to ask you about it. When they talk, try not to interrupt. Let them say exactly what they want to say without comment.
HONESTY IS ALWAYS THE BEST POLICY
Answer their questions with honesty and don’t try to distract them in an attempt to try and help them ‘forget’. They won’t, and this gives you an opportunity to give them the correct information. They may have been told something or heard the adults in conversation and be worrying unnecessarily. Always answer their questions using clear and straight answers and, if you don’t know the answer to something, be honest about that too and suggest finding it out together. Above all, avoid dramatic headlines and visit official coronavirus websites. Don’t just say, ‘we all have to wear a mask’ – explain why we must all wear a mask. If you explain everything, children of all ages have a natural acceptance. If they don’t understand something, let them know that they can ask, no matter how silly it may seem. Sometimes it’s the little things that really are the big things to the young.

The way we teach children how to cope with major change in childhood sets a pattern for the rest of their lives. We can teach them to embrace all life experiences and to process their emotional responses – good, bad, happy or sad – as they arise. Life is not an endless series of happy moments and is always interspersed with traumas. By accepting and experiencing all life events as they occur we can live fully and meaningfully as long as we can process emotional events practically as they arise, deal with them, and move on.

CREATE A SENSE OF SECURITY
Let your children know that you are there for them. Create a safe space where they can talk about how they are feeling. Use simple words which can easily be understood. Be calm and reassuring and let them know that whatever they are feeling is okay. This is a new experience for us all and we must allow children to have their own natural responses. They are learning all the time and honest emotional expression is just as important as other skills, if not more so, as this means that children can deal with emotional issues in the moment.

KEEPING WELL AND HEALTHY
Let them know that being clean and washing their hands regularly can help stop the virus spreading to other people. Also having plenty of quality sleep, eating well and exercising can help to keep them strong and healthy. This is a good time to teach your children to take responsibility for some of their actions and the importance of self-care. Teach them how to thoroughly wash their hands, to really think about the foods they are eating – are there enough vitamins, protein etc.? This will give them some semblance of control and give them a project!

Also explain about the NHS and how the doctors and all key workers are still working and doing everything they can to keep people safe and that the scientists are working hard to ensure that the vaccine is a success.

KEEP THE SCALE OF REALITY
Explain to them that death from the virus is still rare, despite what they might hear, and let them know how so many more people survive than die.

If someone does contract the virus, you shouldn’t hide the fact from children that they may not recover. We can’t control how or when we die but we can control how we live. Introduce the idea of saying all the important things to each other and explain that we can’t always choose how or when we die, we can only make sure that we all know how important we are to each other and that we have to put our love into words. Now, more than ever, this is important as we can’t reach out and hug those we are isolated from.

KEEP THE LINES OF COMMUNICATION OPEN
Friendships, routines and social interactions are the most important factors in children’s development. Being isolated from these things may mean that they need more support than usual, so don’t be afraid to ask for help from friends and relatives and other sources, including their nursery, school or college. Never be afraid to reach out and ask for help. We are all novices in times like these.

Build into their daily routine video calls with grandparents and other relatives and friends to help reduce feelings of isolation and bring a sense of community. More than ever, our phones and computers are a lifeline.

CONTROL MEDIA TIME
Don’t keep running the news as this can block out everything else. Keep in mind that the media can influence our thoughts. Repeated reporting of COVID-19 can make it feel as if it’s going to swallow us all. It’s good to have discussions about other things that are happening too, so the coronavirus doesn’t overshadow everything. Create fun times, games, quizzes, competitions within the home, things which are a great distraction and that children of all ages can look forward to. Plan together as a family and build an activity into each day. This can really strengthen family bonds.

The internet and the speed at which news travels visually and auditorily has made the world feel like a very small place indeed. Keep the scale of reality – the world population at this date is approximately 7.6 billion. Yes, the disasters are shocking, but we can also see many good and great things happening. Everything needs a balance.

By accepting and experiencing all life events as they occur, focusing on the good which so often follows disaster – a sense of community; expressions of love; caring actions – we can teach our children to live fully and meaningfully, processing emotional events practically as they arise. We must also balance the scales – without the threats out there, there would be no value to life or thought of personal safety.

Let them know that it’s normal and natural to feel stressed sometimes. Teach them to accept that as okay. Keep an eagle eye out for any changes in their behaviour and be available for them however many times they need you.

Lianna Champ has over 40 years’ experience in grief counselling and funeral care and is author of practical guide, How to Grieve Like A Champ.
PUTTING IT ON THE MAP

Functional Neurological Disorder (FND) is a disorder relating to the way the brain sends and receives signals, in which the symptoms range from muscle spasms and movement disorders, to seizures and blackouts. With the condition having been mired in controversy, and for decades often dismissed as being of purely psychological origin, Tom Plender, a musician, pens the continuation of his journey – and the lessons which line the FND road.

Any definitive evidence to back up this idea, therefore it is little more than an unproven theory. (1)

Recent studies also don’t support this view, revealing that a significant amount of FND patients don’t have any history of psychological trauma. The Freudian view is now being challenged and superseded by a new set of ideas, the most prominent of which is the concept of the ‘Bayesian Brain’. (2) This theory suggests that FND stems from the way the brain processes data and is the result of that process going wrong.

An example of how this can be applied is the following:

You are sitting at a table about to pick up a glass of water: your brain has a pre-existing internal model or set of expectations about what will happen when you pick up that glass of water based on the fact you have done this hundreds of times before. This pre-existing model is actually stronger than the feedback you will receive through your hand, and other senses. The brain doesn’t control movement by feedback and by constantly checking the weight of the glass etc., instead it actually controls movement by making an expectation based on previous events.

In FND, it seems that the brain’s internal model of movement somehow goes wrong, setting up a kind of ‘rogue representation’. (3) These events or faulty representations take place at very low levels of the nervous system beneath the patient’s conscious control.

Tom Plender

In my previous article for Northern Ireland Healthcare Review last year, I discussed the struggles I had obtaining a FND diagnosis and getting doctors to take me seriously. I eventually had the good fortune of being referred to a leading expert in the field, Professor Mark Edwards, who was at that time practising at The National Hospital for Neurology and Neurosurgery in London, where I was successfully treated and regained my ability to function. FND research has moved forward rapidly in the last few years, and in this article I wanted to expand and go into detail about some of the new theories and treatment concepts.

A PARADIGM SHIFT

At the current time, FND is experiencing something of a paradigm shift. Previous theories were largely based on the ideas of Sigmund Freud, believing that FND is a form of ‘Conversion Disorder’ – the idea that the patient is converting psychological trauma into physical symptoms. As I stated in my previous article, there has never been any definitive evidence to back up this idea, therefore it is little more than an unproven theory. (1)

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In FND, it seems that the brain's internal model of movement somehow goes wrong, setting up a kind of ‘rogue representation’. (3) These events or faulty representations take place at very low levels of the nervous system beneath the patient's conscious control.

SO HOW DO YOU TREAT FND?

During my inpatient treatment at The National Hospital for Neurology, it was explained to me that I had a problem to do with the way my brain controlled movement and that conscious parts of my brain had become over-involved in what should be automatic movement. (4)

This often happens to patients with FND, and also people who experience long-term chronic pain. The brain's response to the pain is to distort or start ‘smudging out’ that area, possibly as a kind of survival response; it then tries to find a way round this by diverting the signals that engage movement to other parts of the brain that should not be involved.

Through physiotherapy, I had to learn how to move automatically again. For me
at that time all movement caused pain and muscle spasm that could last days and sometimes weeks. The idea was that by re-engaging my old automatic movement patterns these would then override the new faulty movement patterns in my brain. This was very challenging and hard to do as it involved many repetitions and to some extent breaking through a kind of pain barrier, but over weeks and months in a supportive environment of daily specialised neuro-physiotherapy and movement retraining it began to work. CBT or Cognitive Behavioural Therapy was also added in addition at a later stage. This can be used to alter attentional processes and expectations relating to movement and also to challenge and inhibit the faulty motor responses.

CORTICAL MAPPING

More recently I started seeing a new group of medical professionals, including a physiotherapist and a consultant who specialises in complex musculoskeletal pain. After various tests and examinations it was explained to me that their take on my FND was that I had a Cortical Mapping Disorder. This means that my brain’s internal map of my body was malfunctioning and sending signals to the wrong parts of my body, for example when I tried to do my hip strengthening exercises my neck would tighten up. My physiotherapist also pointed out that when I raise my hands above my head, my neck and shoulders overreact to this simple movement as if I am lifting weights, a clear example of the faulty movement pattern distortions I mentioned earlier.

Ideas about Cortical Mapping stem from the Australian pain researcher, Professor Lorimer Moseley. He studies pain sensitisation or central sensitisation, a condition where the brain keeps sending the signals of pain a bit like a stuck record even though the cause of the pain has subsided. Moseley’s interest began when he was walking in the outback and noticed a sharp pain in his ankle. He ignored it, kept on walking, and a few minutes later, collapsed unconscious. Upon waking in a hospital bed he was told that he had been bitten by a venomous snake and was lucky to be alive.

About five years later, after summoning the courage to go walking in the outback again, Moseley experienced a scratch on the ankle. He collapsed in absolute agony and, looking at his ankle, realised that it was just a small twig protruding from a bush that had scratched him but that his brain had sent him a colossal signal of pain as a kind of protective survival response because of previous events. This led him to realise how easily the brain can distort our perceptions of pain and how our fight or flight response can go wrong. Pain is generated in the brain, in response to signals from the injured limb, not in the actual limb itself.

As Moseley’s story demonstrates, it is the brain that makes a decision about the degree of pain you will experience depending on its perceived level of threat. He also started to notice that a lot of his central sensitisation patients went on to develop Cortical Mapping Disorders, implying that pain sensitisation can be another risk factor for developing Cortical Mapping or FND type issues.

FINDING THE RIGHT PATH

FND, FND overlay, Cortical Mapping Disorders and central sensitisation are all part of a cluster of conditions that can all feed into each other. I hope this article demonstrates how once something like this goes wrong in the brain and nervous system, if left untreated, it can over time end up triggering many more problems, leading to a downward spiral of cascading symptoms. This highlights the importance of taking these conditions seriously and getting people into targeted treatment.

Hopefully, I have also made clear why applying the Freudian paradigm has, in my view, been so damaging to patients. Spending a huge amount of time trying to root out some hidden psychological trauma really does not address the core issues. The brain is the most complex machine ever studied by man and our knowledge is minimal at best. Overly-simplistic ideas like Freudian Conversion Disorder are simply not fit-for-purpose in the 21st Century. With regards to FND, instead of seeing the brain in Freudian terms, it is much more helpful, in my view, to view it as a series of interconnected systems. It is when these different systems start to malfunction that you get conditions like FND.

It was the philosopher of science, Thomas Kuhn, who coined the term ’Paradigm Shift’. Kuhn’s view of science was that it is not ‘The Truth’, it is simply the best theory we have at the moment to describe reality. If you look at the history of science it is clear that scientific theories are continuously upgraded, refined and, in some cases, discarded and replaced with new and better ones. Science, because it is done by human beings, is often flawed and subjective; science can’t avoid subjectivity when considering evidence. Flawed ideas can be very seductive and convincing when presented in scientific language, they also often reflect cultural biases rather than scientific fact, making them harder to shift. Because of this, new paradigms are rarely accepted easily and without a fight.

The medical profession is still currently split in two about FND, with many stubbornly clinging to the old Freudian paradigm despite mounting evidence to the contrary. The Victorian scientist TH Huxley famously said, ‘Irrationally held truths may be more harmful than reasoned errors.’ Wise words, and after everything I’ve been through with FND, I suspect he was right.

For more information about FND Hope, visit www.fndhope.org.

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APTAMIL PEPTI SYNEO FOR THE DIETARY MANAGEMENT OF COW’S MILK ALLERGY IN FORMULA-FED INFANTS

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References:
1. Atwal K et al. An extensively hydrolysed synbiotic-containing formula improves gastrointestinal outcomes in infants with non-IgE cow’s milk protein allergy, already well-established on extensively hydrolysed formula. Poster Presentation. European Academy of Allergy and Clinical Immunology Food Allergy and Anaphylaxis Meeting 2020.
4. Browne et al. A new synbiotic EHF for infants with cow’s milk protein allergy is well tolerated, highly acceptable and supports good growth and intake over 28 days. Poster Presentation. British Society Allergy and Clinical Immunology Meeting 2019.

* GOS/FOS = Galacto-oligosaccharides and fructo-oligosaccharides.
† UK 4 week single split arm study1,3–5: infants with non-IgE mediated CMA, baseline non-synbiotic EHF’s vs Aptamil Pepti Syneo.
‡ subgroup of n=48 infants with IgE associated atopic dermatitis.

led to some workplaces being temporarily closed. The roll-out of workforce testing will help to prevent this by identifying asymptomatic positive cases and interrupting transmission of the virus. This will benefit employers and society as a whole as it will help to keep infection rates down across Northern Ireland.’

Individuals with positive Lateral Flow Tests will have to isolate immediately, along with their households. They should then book a PCR swab test at their closest test site to confirm the result. Community contact tracing will be initiated on PCR confirmation.

The Minister concluded, ‘Asymptomatic testing initiatives are already operating successfully for staff and pupils in schools and universities, and for staff in Translink and NI Fire and Rescue Service.

‘My officials are continuing to work closely with government departments and local government to identify and prioritise other public sector organisations and emergency services who may require access to the testing programme.

‘I am also inviting private sector organisations who may wish to access the national testing programme to contact the department to register their interest. Details of the criteria for accessing the programme, and the sectors we are prioritising in the initial phase, are available on the department’s website.’

**WORKPLACE COVID TESTING FOR KEY SECTOR EMPLOYERS**

Employers from key sectors within Northern Ireland can now access the national testing programme as part of a targeted expansion of asymptomatic testing.

Launching the programme, Health Minister Robin Swann said, ‘As COVID-19 infections continue to fall and the vaccination programme continues to deliver at scale and pace, it is important that we do not lose sight of the need to continue to control this virus.

‘In the early stages of the pandemic, the severity of some outbreaks

**LAUNCH OF YOUNG PEOPLE NI WEBSITE**

The Royal Victoria Hospital Emergency Department have unveiled a new website to help support young people with a wide range of issues they might be experiencing, including those relating to their mental health, drugs and alcohol, as well as problems at home and bullying.

Inspiration for the website struck after the team conducted a pilot scheme to introduce an assessment tool in A&E for doctors and nurses to use when a young person presents to the Emergency Department with possible mental health issues. The HEEADSSS strategy is applied to assess the risk to the young person and to help staff make decisions regarding what services they might need referred on to.

The team felt that there was a wealth of information available online, which meant that it could often be difficult for young people to locate the support that they were looking for. As a result of the new website, services available to young people on a variety of issues are detailed, offering them options for accessing support services in their home and community before they reach a crisis point.

**CROSS-DEPARTMENTAL INTERIM AUTISM STRATEGY IS PUBLISHED**

Key improvements in the provision of services and support for those with autism and their carers must be a priority for society here, Health Minister Robin Swann has asserted, following the publication of a cross-departmental interim autism strategy for action throughout 2021 and 2022.

‘We, as a society, have made significant strides in developing improved support and developing better understanding of the needs of autistic people, their families and carers but much still needs to be done,’ the Minister commented.

The Minister further explained that while the interim strategy had gained much from ongoing stakeholder engagement, this had been constrained by the emergence of the COVID-19 pandemic. He gave a commitment, however, ‘to build on the work thus far with the development of a fully co-produced autism strategy later this year.’

The interim strategy will be based around three strategic outcomes:

- A healthy life with access to services on an equal and timely basis to provide early intervention and support to best meet the needs for individuals and families
- A life with opportunities to live as an active citizen to support autistic people and their families through continued support in education and employment and as they transition through life stages
- An independent life with greater understanding and choices which provides opportunity for autistic people to live safe and independent lives within our communities and where they are met with respect and understanding.

Priorities for the strategy have been informed through extensive stakeholder engagement and a consultative process, and aim to demonstrate a societal commitment to support and understand the needs of people with autism and be used to inform planning of service provision across the wider public sector and partnerships beyond.
LISTEN TO YOUR HEART

Trudie Lobban MBE, Founder and CEO of Arrhythmia Alliance, highlights the importance of educating the public, and particularly at-risk groups, about atrial fibrillation – and the broadening access and opportunities for detecting the condition earlier.

IN THE CURRENT CONTEXT OF COVID-19, WHAT ARE SOME OF THE MAIN CONCERNS RELATING TO UNDETECTED ATRIAL FIBRILLATION (AF)?
The biggest concern is that COVID-19 restrictions will cause the detection of AF to decrease. People with symptoms of AF, such as palpitations, breathlessness, fatigue, may avoid medical contact because they think GP surgeries are ‘not open’ to people without coronavirus or because they are worried about contracting COVID-19 (particularly if they have been told to shield).

Additionally, opportunities to detect AF in people at risk of AF are limited. If people are not attending in-person check-ups, for example, healthcare professionals can’t perform pulse rhythm checks. It is important therefore to encourage the public to be aware of their pulse – is it regular or irregular and how to check. There are so many fitness apps, however it’s important that they use a NICE-approved app or device to ensure the reading is accurate from an approved device.

HOW CAN PHARMACISTS ENCOURAGE AF DETECTION FOR THEIR PATIENTS? AND IN PARTICULAR, WHICH PATIENT GROUPS SHOULD THEY BE AIMING TO KICKSTART AF-CENTRED CONVERSATIONS WITH AND WHY IS THIS SO IMPORTANT?
Pharmacists can help to detect AF by displaying AF Association’s Know Your Pulse resources, such as posters or videos, to encourage people to get into the habit of checking their pulse to know their heart rhythm and understand why this is important. If at a pharmacy, pharmacists could use a medical-grade, personal ECG device, such as AliveCor KardiaMobile, that could allow patients to check their pulse rhythm while waiting for a prescription etc. Providing the device was sanitised between use, this would be a COVID-19 secure, safe way to detect for AF.

People aged 65 or older are at increased risk of AF and, therefore, would be the target group for detection of AF. However, Arrhythmia Alliance and AF Association believes everyone should be encouraged to know their pulse, to know their heart rhythm as it could save their life. We should all be aware of our heart rhythm and the risk of AF.

CAN YOU TELL US ABOUT ANY NEW AF INITIATIVES?
Arrhythmia Alliance and AF Association has launched an opportunistic screening programme to detect AF at COVID-19 vaccination clinics. The charity has created an online resource hub for healthcare professionals working at vaccine clinics to use to detect AF (see: www.hearrhythmalliance.org/aa/uk/detection-of-af-at-vaccination-centres). This includes Know Your Pulse posters, referral letters, and What is AF factsheets — all of which can be downloaded and printed free-of-charge or ordered FOC direct from the charities in large quantities. Additionally, AF Association and its sister charity Arrhythmia Alliance has provided links to Know Your Pulse videos, which explain how to perform a simple pulse check and how this can help to detect AF, that can be played at vaccine centres, pharmacies, GP surgeries etc. We have also produced videos demonstrating how to use a mobile ECG device.

HOW HAS THE ROLE OF MOBILE ECGS TO MONITOR AF EVOLVED

IN RECENT MONTHS? WHY ARE HEALTHCARE PROFESSIONALS AND PATIENTS ALIKE EMBRACING THIS TECHNOLOGY?
A positive outcome from lockdown and the COVID-19 pandemic has been an uptake in digital technology. People welcome telemedicine and doctors’ appointments online, reducing the demand of in-person appointments. This reduces time and risk of contracting COVID-19. People are welcoming this ‘new’ service in the knowledge that if needed they can be seen physically. Both the NHS and patients are welcoming remote monitoring and apps to monitor their health – feeling more in control especially if recommended by their healthcare professional.

HAVE THERE BEEN ANY NOTABLE DEVELOPMENTS REGARDING THE SUPPLY OF REMOTE MONITORING DEVICES?
Remote monitoring for implantable devices has increased during the pandemic which has greatly reduced the need for hospital appointments to check pacemakers etc. This has reduced costs, time, potentially save lives as their risk of contracting COVID-19 is reduced.

HAVE THERE BEEN ANY NOTABLE DEVELOPMENTS REGARDING THE SUPPLY OF MOBILE ECG DEVICES?
People are able to download apps or purchase devices to monitor their ECG to check their heart rhythm for conditions such as AF. Many GP practices are also able to loan these devices and some pharmacies and surgeries have the option to use an ECG monitor while in the waiting room. More recently detection of AF has been offered in many COVID-19 vaccine hubs. It is important, however, that only officially approved apps and monitors should be used to monitor and receive the most accurate results which are then acceptable to healthcare professionals to speed up the detection and diagnosis of AF.
6 is better than 1.

Detect atrial fibrillation remotely with KardiaMobile 6L, the world’s first and only FDA-cleared, CE-marked, 6-lead personal ECG.

There are more than 37,000 people in Northern Ireland living with AF*. What if they could monitor AF from home?

With KardiaMobile 6L, you’ll receive an unparalleled view of your patients’ heart activity in just 30 seconds. Get real-time, medical-grade ECGs sent directly to you—no appointment required.

Learn more about remote patient monitoring in Northern Ireland with KardiaMobile 6L.

Please visit alivecor.com/quickstart for a complete listing of indications, warnings and precautions.

*Information on Atrial fibrillation in Northern Ireland can be found at https://nichs.org.uk/information/risk-factors/atrial-fibrillation
ULSTER UNIVERSITY LAUNCHES NEW APP FOR PEOPLE LIVING WITH DEMENTIA

The InspireD App enables people living with dementia, their carers and families to create a digital memory book to store photographs, videos and sounds; aimed at sparking conversations and providing opportunities to share experiences and maintain relationships.

For most people, the thought of a dementia diagnosis and the fear of losing their ability to recall treasured memories is devastating. However, many people living with dementia have problems with their short-term memory and find it easier to remember things about their past.

Reminiscence draws on this strength by supporting people to share their life experiences, memories and stories and, in doing so, to maintain and build connections with other people.

Free-to-download on both Apple and Android or from the health and social care App4Dementia library, the InspireD app enables users to peruse their personal photographs and videos and in doing so, share memories about past experiences and important life events. Users can also add written or voice notes about photographs, music and film clips so that family, friends and carers understand why a particular memory or time is special. This can help trigger conversations as people using the app begin to tell and hear stories that they may have never told or heard before. All of these memories are kept in an easy-to-reach place on a smartphone or tablet.

COVID-19 RAPID TESTING ROLLED OUT TO ALL SPECIAL SCHOOLS IN NORTHERN IRELAND

The non-invasive saliva-based LAMP (Loop-mediated Isothermal Amplification) test is designed to find asymptomatic and pre-symptomatic cases so that they can be isolated, along with their contacts, as quickly as possible, therefore reducing the risk of transmission of COVID-19 in schools.

The LAMP testing programme began with five pilot schools in February 2021. This has now been rolled out to all special schools and will run until June 2021. The programme is sponsored by the Department of Health and the Department of Education.

The Education Authority and the Public Health Agency (PHA) are working in partnership with Queen’s University Belfast to deliver the testing programme to all special schools. A group of principals from the Special Schools Leadership Group are co-designing the programme and representing the views of the schools in the programme management structures.

Dr Joanne McClean, Consultant in Public Health Medicine with the PHA, commented, 'The sacrifices we have all made during this lockdown are making a difference, and infection rates have dropped significantly – that combined with the roll-out of the vaccination programme provide many reasons to be hopeful, but testing and following the public health advice remains as important as ever if we are to have better times ahead. ’

‘The roll-out of testing across special schools will help find pre-symptomatic and asymptomatic cases who can then be advised to isolate at home to reduce the risk of spread in the school, so providing protection for others.’

£1 MILLION ANNOUNCED FOR AIR AMBULANCE

Health Minister Robin Swann has announced £1 million funding for Air Ambulance Northern Ireland.

Making the announcement, Minister Swann said, ‘Since this service was launched over three-and-a-half years ago, it has become a critical component of the Northern Ireland Ambulance Service’s emergency response.

‘Many people who have had life-changing injuries, and whose lives have been at risk following significant trauma, have benefited from the expertise of skilled clinicians who bring advanced critical care to the scene and rapidly transport their patient directly to the regional trauma centre for ongoing emergency care.

‘I am grateful to those individuals and businesses who have continued to support this service through charitable donations. To date this has proved to be a successful and sustainable model delivered in partnership with the Northern Ireland Ambulance Service, but I also recognise the impact that the pandemic has had on the ability of our charity partner to raise funds in its customary manner. This £1 million payment will assist Air Ambulance Northern Ireland with the challenges they are currently facing and assure the ongoing success of the funding partnership that delivers this valuable service.’

Welcoming the announcement, Ray Foran, Air Ambulance Northern Ireland Chairperson, added, ‘Air Ambulance Northern Ireland is delighted to receive a funding package to help us continue to deliver pre-hospital emergency care to those in most need. Air Ambulance Northern Ireland has experienced an increase in taskings by almost 20 per cent. We have continued to operate during these challenging times, supporting the Department of Health and Northern Ireland Ambulance Service. We would like to thank all our supporters for their continued and ongoing contribution.’

Air Ambulance Northern Ireland is a charity that raises funds to sustain the aviation side of the Helicopter Emergency Medical Service.
It’s our view that the fibromyalgia community will see this as a significant step back – both in their treatment options and their ‘legitimacy’ within the health service. In devising the guideline, the committee was looking to find best practice; yet was selective in the evidence it considered in scope. We feel that patients, with their body of first-hand evidence, are being overlooked.

There are patients who can remain in employment, maintain a good quality of life, and increase their activity levels, thanks to treatment protocols that will now be unavailable to new patients. Some of these treatments help patients to such an extent that, in time, they can reduce these medications and leave them behind.

While the committee recognises that there could be sub-groups that these medications are indeed effective for, the lack of understanding of chronic pain means that these sub-groups will be side-lined, together with everyone else.

While the committee recognises that there could be sub-groups that these medications are indeed effective for, the lack of understanding of chronic pain means that these sub-groups will be side-lined, together with everyone else.

DIVERGING VIEWS
EULAR revised guidelines for fibromyalgia gave a ‘weak for’ rating to recommendations for Amitriptyline, GABAPentinoids, SNRIs, Tramadol, acupuncture, CBT, hydrotherapy, meditation / mindfulness, and a ‘strong for’ in relation to exercise. These guidelines are now at odds with the chronic primary pain guidance from NICE.

In addition, evidence that was included in Cochrane reviews was not considered in the committee’s initial scope of evidence. A paper entitled ‘Pregabalin for Treating Fibromyalgia Pain in Adults’ said, ‘We found high quality evidence that pregabalin at daily doses of 300-600 mg produces a large fall in pain in about one-in-10 people with moderate or severe pain from fibromyalgia. Pain reduction comes with improvements in other symptoms, in quality of life, and in ability to function.’

Further, the NICE guideline has excluded large, high-quality, randomised, double-blind trials that have been used to judge evidence of pregabalin efficacy and safety in fibromyalgia – and were acceptable to the FDA, EMEA, and Cochrane reviews. This has resulted in a more limited pool of evidence and ultimately means that UK patients with fibromyalgia have fewer treatment options than if they lived in Europe, America, or other regions where that evidence pool was considered sufficient.

UNINTENDED CONSEQUENCES
Chronic pain is not an easy subject for the NHS, NICE or health professionals. We can appreciate the need to reduce the over-prescription of opioids and the need to engage in meaningful conversations with patients about their chronic pain. Patients will appreciate that conversation and being listened to!

We are grateful that people on existing treatment regimens will not, in theory, face change under this guideline, but we are sure that some will be dreading their next medication review with their GP. And we have already heard of doctors whipping treatments away from patients without any tapering or explanation.

Moreover, the service delivery in relation to chronic pain is already dreadfully under-provisioned and this guideline only reduces options even further. The guideline also favours treatments such as group exercise and acupuncture that a) can’t be provided long-term due to NHS cost pressures; and b) can’t be undertaken in the patient’s own home. Requiring patients to travel to receive treatment does not promote inclusivity or equality – some patients will not be able to afford to travel, others will not have the physical ability to travel.

THE BOTTOM LINE
People with fibromyalgia have always had an uphill struggle to be diagnosed, to be treated and to be respected for what they are going through. The fibromyalgia community believes that this guideline will be a step back in how the medical profession views them.

Of course, the guideline will certainly save some pennies on the NHS budget in the short-term, but it will also result in losses to UK plc tax revenue as patients will not have access to the treatment(s) they require to continue employment.

And while this guideline is positive in its promotion of non-drug therapies, the committee’s blanket approach to all primary chronic pain and the removal of working treatments from some within our fibromyalgia community is not helpful. In fact, we believe it will be counterproductive in the short and longer-term – for patients, their families, their healthcare providers, and the UK welfare system.

With the release of the NICE guideline on primary chronic pain, what impact may it have on patients? Fibromyalgia Action UK share their concerns.
Nearly half of the UK population have expressed scepticism towards the coronavirus vaccine as a result of media reporting, a new survey has revealed. NIHR finds out more.

According to a new nationwide survey, as many as 40 per cent of the UK population have been put off taking the COVID-19 vaccine due to what they have read in the media. This figure rises substantially to 62 per cent when considering 16-to-34-year-olds, specifically; this is in comparison to 22 per cent in the 55-plus age range. The survey was commissioned by Eskenzi PR, a Queen’s award-winning Tech PR agency and conducted by Censuswide.

However, despite the scepticism, only seven per cent have confirmed that they will not take the vaccine as a result. Other sceptics concede that they will nevertheless take the vaccine, with 26 per cent citing that it would be selfish not to do so (10 per cent) or because they recognise it is for the greater good (16 per cent). The remaining eight per cent of cynics will take the vaccine, though begrudgingly.

Remarkably, differences in attitudes are particularly stark between the younger and older generation as well as between Greater London and other regions. Indeed, those in older age groups were less likely to be swayed by the media, with 71 per cent assuring that the media did not put them off the vaccine as opposed to 27 per cent of those aged 16-to-24. Moreover, Greater London leads with the highest proportion of individuals who are put off taking the vaccine at 61 per cent. This is followed only by Wales with 46 per cent, while the East of England had the lowest proportion at 29 per cent.

Mixed Messages
These results come at a time where demand for news is skyrocketing. In fact, this survey has also found that, since the beginning of the pandemic, 60 per cent of respondents have admitted to reading more news. More precisely, nearly a quarter (24 per cent) are reading the news to find out more about COVID-19 and the vaccine. In this way, they are opening themselves up to a bombardment of information, some of which may be misleading.

‘The media has always played a pivotal role in swaying and forming people’s opinions. Since the pandemic, people have never been more hungry for information. With people digesting so much more news, not only through conventional media, but also through unconventional means, including social media, there’s going to be an element of misinformation creeping in. It comes as no surprise that they are becoming confused and cynical about having the vaccine when there are so many mixed messages,’ said Yvonne Eskenzi, Co-Founder and Director of Eskenzi PR.

‘It’s very important to keep a clear head and get a balanced viewpoint on everything in life, but especially now with something as important as whether you should take the vaccine. Still, it was good to see that even though many people didn’t really want it, they did it for the greater good of society.’
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WHAT IS GROUP B STREP?

- Group B Streptococcus (also known as Group B Strep, GBS or Strep B) is a bacterium carried by many adults, commonly in the gut or in the vagina. ‘Carriage’ is not an infection or illness, rarely causes any symptoms, and doesn’t need to be treated. Carriage should therefore be regarded as ‘normal’
- It can cause infection in newborn babies when the bacteria are transmitted to the baby around labour (in very rare cases, it can also cause infection in adults whose immune system is depressed, either through old age, other illnesses, or medical therapy)

KEY FACTS

- GBS is the most common cause of life-threatening infection in newborn babies
- It causes a range of serious infections, including sepsis, pneumonia and meningitis – it’s the most common cause of severe infection in newborn babies and of meningitis in babies under three months of age
- If left untreated, a GBS infection can kill a newborn baby within hours
- On average, two babies each day in the UK develop a GBS infection and each week, one baby dies from a GBS infection and another is left with a life-changing disability
- Most GBS infections in newborn babies can be prevented by testing during pregnancy and providing intravenous antibiotics during labour to women whose test results are positive
- The UK doesn’t routinely test for GBS, unlike America, Canada, Germany, France and Spain
- Even Bangladesh, Iran, Lithuania and Trinidad and Tobago routinely test pregnant women for GBS
- The test would cost the NHS just £11, and costs from £35 privately
**ADDRESSING THE MYTHS**

**GBS IS A SEXUALLY-TRANSMITTED DISEASE**
GBS is not a sexually-transmitted disease. It is a bacterium commonly found in the gut in healthy men and women, and in the vagina in women. It rarely causes symptoms and most carriers are unaware that they harbour GBS. Although in very rare cases it can cause infection in newborn babies, it’s the most common cause of severe infection in newborn babies.

**GBS COMES AND GOES SO IT IS NOT WORTH TESTING**
No. Research has shown that the result of the GBS-specific ECM test – positive or negative – is highly predictive of carriage status over at least the following five weeks. This is why most countries recommend testing at 35-to-37 weeks of pregnancy. Testing then is predictive of the GBS carriage status of the mother when she’s most likely to give birth – in the following five weeks.

When performed within the last five weeks before birth, research showed that a negative result is 96 per cent predictive of still not carrying GBS at delivery. Only four per cent of women acquired GBS carriage between testing and giving birth. A positive result was 87 per cent predictive of still carrying GBS at delivery (13 per cent of women lost carriage between testing and giving birth).

**TESTING FOR GBS WOULD RESULT IN MANY MORE WOMEN BEING GIVEN ANTIBIOTICS**
No. Research found that a similar number of women would be offered antibiotics if we screened women compared with the risk-based approach. The key difference is that with screening they would be offered to the women most likely to be carrying GBS in labour, rather than to women who have risk factors which are very poor at predicting GBS carriage (a recent study found that two-thirds of the newborn babies who developed GBS infection had no risk factors).

For newborn babies the consequences of their mother not having preventative antibiotics in labour if she’s carrying GBS can be catastrophic – sepsis, meningitis or pneumonia. The potential benefit of the antibiotics far outweighs the potential risk. Antibiotics have been proven to be highly effective at stopping GBS infections in newborn babies when given intravenously to the pregnant woman as soon as her waters have broken, or labour has started.

**GIVING ANTIBIOTICS IN LABOUR TO PREVENT GBS INFECTION IN NEWBORNS WOULD INCREASE ANTIBIOTIC-RESISTANT INFECTIONS**
No. This hasn’t happened in other countries, including America, where antibiotics in labour have been recommended against GBS infection in newborn babies since the mid-1990s. The recommended antibiotic is penicillin, which not only is highly effective against GBS, it also is a narrow-spectrum antibiotic so will ‘wipe out’ fewer of the ‘good’ bacteria.

**GBS IS CAUSED BY THE SAME BACTERIA THAT GIVES YOU A SORE THROAT**
No. GBS is a different bacterium – Group A Strep commonly causes strep throat. They are in the same ‘family’ of bacteria, hence the name, but cause different infections.

**THE GBS TEST IS NOT RELIABLE**
Yes it is – when done properly and at the appropriate time, the GBS-specific ECM test, recommended by Public Health England and the Royal College of Obstetricians and Gynaecologists, is very reliable.

Research has shown that whether a result is positive or negative, it is very reliable for the next five weeks. This is why the many developed countries that routinely test pregnant women for GBS carriage do so late in pregnancy, at 35-to-37 weeks gestation.

Using the right test at the right time is a highly effective way of detecting GBS. For pregnant women, this means using an enriched culture medium test between 35 weeks and 37 weeks. A woman’s GBS carriage status will stay broadly the same for the next five weeks and allows her and her midwife to consider whether taking antibiotics in labour is the right choice for her and her baby.

**WHO ARE GROUP B STREP SUPPORT?**
Group B Strep Support are a national charity, working to stop GBS infection in babies. Set up in 1996 by Jane Plumb after her newborn son, Theo, died from GBS infection aged 17 hours. They work with families affected by GBS and campaign for a proper testing regime to be introduced in the UK.

- www.gbss.org.uk: offers information about GBS infections, testing and treatment. All information is approved by an expert medical advisory panel
- Helpline: provides one-to-one support and information. Call 01444 416 176 or email info@gbss.org.uk
- Community support: where families share experiences and support others, including a Facebook community of over 35,000 people
- Campaigns: to stop GBS infection in babies through the introduction of a proper testing regime in the UK
- Awareness and education: working alongside health professionals to improve awareness and knowledge about GBS among new and expectant parents and their health professionals
An eating disorder is a very complex illness to treat, and it’s well-documented that early intervention is paramount to a person’s recovery. In light of this, the team at SEED – a voluntary organisation comprising a group of ordinary people with first-hand experience of eating disorders – discuss how the appropriate support can make a difference to those whose lives are blighted by this devastating condition.

BRIGHTER DAYS TO COME

An eating disorder is a very complex illness to treat, and it’s well-documented that early intervention is paramount to a person’s recovery. In light of this, the team at SEED – a voluntary organisation comprising a group of ordinary people with first-hand experience of eating disorders – discuss how the appropriate support can make a difference to those whose lives are blighted by this devastating condition.

TRIGGERS OF AN EATING DISORDER

We may never know what triggers an eating disorder but there is a common theme linking low self-esteem with one. It could be that things are going wrong for someone and they feel that they have no control over issues in their life – they therefore take control of something by taking control over their food, starting to evaluate themselves through body weight and shape. Below are a few of the triggers that may be the cause of someone developing an eating disorder:

- The young person not wanting to grow up. What would growing up mean? Taking responsibility, dealing with relationships, being a young person in an adult world, looking for employment, feeling the pressure to succeed, and in some cases, living up to other people’s expectations
- The pressure to be perfect is massive and nothing short of perfect will do. In truth, they are chasing the impossible because nothing will ever be good enough for them, because no-one is perfect and their standards are so high they will never be satisfied that what they have produced is good enough
- It could be the break-up of a relationship or the death of a loved one
- It could be divorce or loss of a job
- It could be money problems
- Leaving home could play a role, in which the individual starts university and experiences being independent for the first time in their life
- Often people feel that the media is the cause of an eating disorder, and perhaps people do aspire to those people of celebrity status, or the model with the ‘perfect’ stick-thin figure. Do they know that what they see is not always what you get?
- It could be bullying or not feeling like they fit in with peers
- It could be abuse, which happens in many different ways, including mental, physical and sexual
- It’s a myth that parents cause eating disorders. Yes, they may not always get things right, but parents – mothers in particular – are often made to feel that it’s somehow their fault as they are desperate to find a reason. They must not become fixated on the reason, and instead concentrate on supporting in the best possible way in which they can

HELPING PEOPLE OVERCOME EATING DISORDERS

It’s vitally important that someone suffering from an eating disorder ensures that they are getting the best possible treatment they can – that there is a network of support around them. Of that network, their GP must play a part in their recovery by monitoring the medical side of the condition.

An eating disorder is a mental health illness with physiological complications. It is vital that the psychological needs are balanced with the physical needs. If a person deteriorates to a severe or critical level, then their medical needs become the priority over their emotional needs.

It does vary in geographical areas, but if a person has a low BMI of 16.0/15.0, then that person may not be considered for therapy,
as cognitively, the brain would not be able to rationalise or process that therapy as someone of a higher BMI would.

A SOURCE OF SUPPORT
SEED was founded in 2000 in Hull, East Yorkshire, by Marg Oaten MBE and Dennis Oaten with the aim to increase awareness of eating disorders and provide more support to those who are in need.

The work that we do is focused on early intervention, prevention, and providing support to those suffering or those caring for someone with an eating disorder. Eating disorders have the highest mortality rate of any other mental illness – 20 per cent of those suffering will die as a direct result of the eating disorder or by taking their own life.

SEED’s aim is to support sufferers and carers so that they don’t feel alone in the first instance, and to signpost them quickly to professional assistance in order that early intervention may enable a better chance of full recovery.

We provide up-to-date information so people can make informed choices about their illness and strive to deal with problems in a professional manner while also ensuring strict confidentiality. This is in addition to facilitating a sympathetic and sensitive sufferers’ and carers’ monthly meeting, and wish to raise awareness of eating disorders and the devastating impact they have on people’s lives.

At our group meetings we speak openly and honestly about our personal experiences with eating disorders while being aware that no one-size-fits-all. We aim to provide information and advice in order that sufferers and carers can know what they may experience along their journey. We hope that our experiences may empower them and give them support and encouragement to know they are not alone and that during their darkest times they have someone to reach out to for advice.

THE EFFECTS OF COVID-19
Unfortunately, there has been a significant upwards trend in the numbers of children affected by eating disorders in recent years. But the COVID-19 pandemic has exacerbated the problem and children (and therefore teachers) need our support now more than ever before.

During lockdown demand for support from the charity rose significantly compared to the same period the previous year. We experienced a 29 per cent increase in new referrals, a 26 per cent increase in sufferers approaching us via our website, and a 25 per cent increase in support group attendees.

According to nationwide research we conducted, 70 per cent of respondents felt that lockdown had negatively impacted their eating habits, with 62 per cent feeling that lockdown had negatively impacted their ability to control their eating disorder.

THE EDUCATIONAL TOOLKIT
The Eating Disorder Educational Toolkit is a valuable, easy-to-use resource developed specifically to enable schools to teach responsibly, confidently, and sympathetically about eating disorders, body image and wellbeing.

The toolkit covers a range of interventions and approaches to enable young people in Key Stages 2, 3 and 4 to improve their emotional wellbeing and deal with the underlying issues causing the eating disorder and not using an eating disorder as a way of ‘control’.

It has been published by SEED to help save lives.

The Educational Toolkit comprises three main lessons followed by three optional consolidation and extension lessons to reinforce pupils’ understanding of the key issues.

Each lesson is clearly linked to statutory national curriculum objectives, including the new relationships education, relationships and sex education, and health education frameworks. The lessons lead with video content, with breaks for discussions and activities, and a range of printable resources that are included within a user guide. The core lessons are roughly an hour long, not including the optional follow-up activities.

Timings are suggested in the lesson plans, but will depend on the extent of group participation and discussion.

All proceeds from the sale of the Eating Disorder Educational Toolkit are channelled back into raising awareness of eating disorders and funding the charity’s vital supporting role to sufferers and carers alike.

For more information about SEED and the team’s services, visit www.seedeatingdisorders.org.uk. Schools can learn how they can gain access to the Eating Disorder Educational Toolkit by visiting www.toolkit.seedeatingdisorders.org.uk.
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* European Society for Pediatric Gastroenterology, Hepatology, and Nutrition

References:

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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ESPAGHAN*
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
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