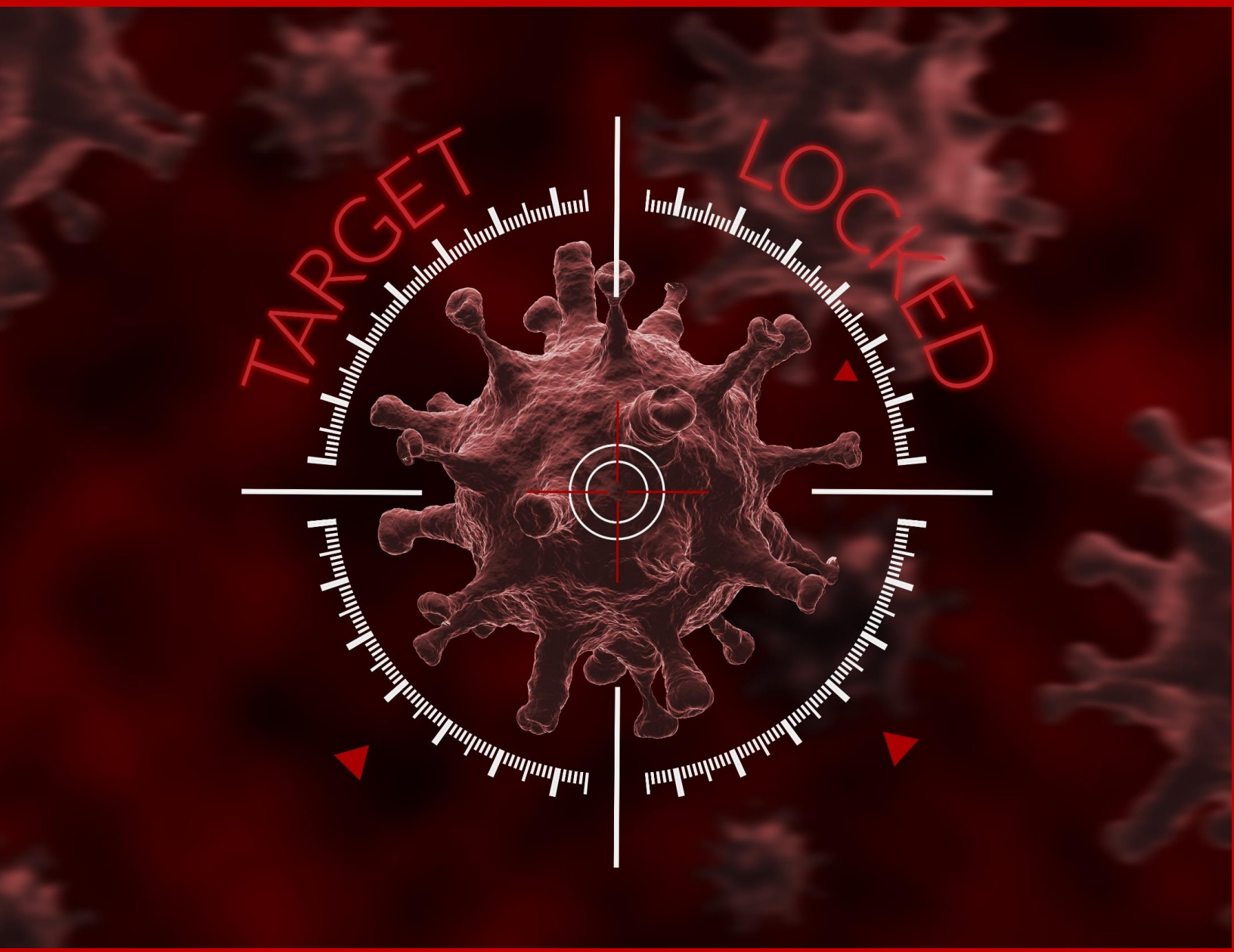
gain4all

For people affected by GBS, CIDP & the associated inflammatory neuropathies

Guillain-Barré & Associated Inflammatory Neuropathies
gain4all issue 17
Winter 2020-21 FREE



A light at the end of the tunnel

Emerging vaccines mark the beginning of the end for COVID-19, and remind us of the importance of immunisation

AGM & Annual Report 2019-20

The year in review

New kids on the block

An overview of conditions traditionally covered by the charity, plus a few related additions recently added

PLUS

Your stories of survival and recovery

Access to online physiotherapy videos

Steps to mental wellbeing in a COVID world

Easy ways to support your favourite charity

and much more

A message from GAIN Chief Executive, Caroline Morrice

A warm welcome to Issue 17 of *gain4all*.

With a difficult year behind us, the emerging SARS-CoV-2 vaccines at last give us a reason to look ahead with some sense of optimism as we can begin to see a glimmer of light at the end of a very long tunnel.

I would like to start by saying a heartfelt 'Thank You' to all our members and supporters who have responded to our appeals for help by continuing to donate throughout the pandemic, despite the challenges that so many are facing. Thank you also to everyone offering their support in other ways, from buying our Christmas cards, fundraising, providing peer support, raising awareness, taking part in our video chats, shopping online through Easy Fundraising or Amazon Smile, etc, recycling your crisp packets and stamps, or selling your stuff for us on eBay.

Because of all of you, the charity is still here in a year when many other charities and businesses have not survived.

As we look ahead, your continued support is needed more than ever, and I have no doubt that you will find even more imaginative and creative ways to ensure we are still here next year, offering help and information to people affected by GBS, CIDP and the associated neuropathies.

The world has found new ways of staying connected, and we have been delighted to see so many of our members embracing technology, some for the very first time, in order to access information online and keep in touch via face to face video chats.

Although some of you will be missing the opportunity to meet in person, it means that location, disability or cost of travel need no longer be a barrier to getting together with others who understand the issues presented by these conditions.

Knowing that Guillain-Barré syndrome is often triggered by colds and flu-like viruses, we braced ourselves for a spike in cases as the pandemic took hold across the globe. Thankfully, this threat didn't materialise, and as the months went by, and we learned more about both the short and long term impact of COVID-19, it gradually became clear that rather than seeing an increase in numbers of GBS cases, the incidence rate was actually lower than we would see in a normal year.

As 2020 drew to a close, a new study was published by Michael P Lunn et al which found no evidence of a causal association between COVID-19 and GBS, although a temporal association had been seen in a relatively low number of cases.

Key points include;

- The possibility of SARS-CoV-2 driving a global spike in GBS has been eagerly monitored with a number of published small case series already asserting a causal link. However, a surge in GBS cases after the SARS-CoV-2 pandemic has not been detected as happened in the Zika virus pandemic.
- The study shows there was no increased incidence in GBS during the first wave of COVID-19; rather, there was a decrease and therefore no causal link of COVID-19 to GBS can be made.
- The research team also tried to establish if there was any genetic or protein structure in SARS-CoV-2, the virus that causes COVID-19, which could trigger an immune response causing GBS. Unlike Campylobacter, which contains human-like antigens causing an autoimmune response, no credible link was found with SARS-CoV-2.
- Most COVID-19 vaccinations are based on the SARS-CoV-2 spike protein, which drives a complex immune response creating antibodies to fight infection. Analysis shows SARS-CoV-2 contains no additional immunogenic material known or proven to drive GBS. Concerns that COVID vaccination might cause GBS in any significant numbers are therefore almost certainly unfounded.

This is excellent news, as we continue to reinforce the message of the importance of immunisation.

Lastly, in my voluntary role as a Trustee and Treasurer of The Neurological Alliance, I am proud to report my involvement in "Restarting services for people with neurological conditions after the COVID-19 pandemic and planning for the longer term". It specifically calls for specialist neurology staff to return to their proper departments and as services resume, efforts should be made to expand the capacity for scheduling necessary in-person appointments.

The rise of remote telemedicine consultations proved instrumental throughout the pandemic, the report noted, but many patients will need choices that include alternative settings. As a result, the Neurological Alliance has been able to directly influence NHS England and NHS Improvement's rebuild strategy.

Do you have a story you would like to share with our readers? Please email submissions for the magazine or newsletter to:

gill.ellis@gaincharity.org.uk

Preferred format: Word document (text only - photographs to be emailed as separate files in jpeg or png format)

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Guillain-Barré & Associated Inflammatory Neuropathies is a registered charity, numbers 1154843 (England and Wales) & SCO39900 (Scotland)

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STOP PRESS STOP PRESS STOP PRESS

Just as we were going to press, a new study was published by Neuroscientists at University College London who have found **no significant association** between COVID-19 and Guillain-Barré syndrome.

See pages 2 & 54 for further information

Dedicated to helping people affected by Guillain-Barré syndrome, CIDP & the associated inflammatory neuropathies

Guillain-Barré & Associated Inflammatory Neuropathies

The Annual Report 2019-20

This year, to be COVID secure, the GAIN Annual Report and AGM, which took place on Saturday, 17th October, were delivered via our video conferencing facility, providing the opportunity for all members to sign in and attend remotely, regardless of physical distance from Head Office.

Vice Chair, Adam Pownall welcomed everyone to the meeting, and it was good to see 22 people joining online. Apologies were received from 13 members.

Adam outlined the Agenda and passed over to Caroline Morrice, Chief Executive to give an overview of the past year and what is coming up.

The provision of information, non-medical advice and other assistance

	2019-20	2018-19
Requested help from GAIN	314	302
Spoke to a volunteer	67	77
Visited our website	49,000	30,000
GAIN Facebook Group members	3,000	2,000
Helped with personal grants	£11,923	£27,167

We are seeing a definite shift in how people interact with GAIN and the numbers of people that access our information is huge. I want to thank ACES Marketing Ltd for helping us achieve such an increase, with their expertise in Google Ads bringing us right up the ratings, increasing our reach from 30,000 in the previous year to 49,000 during 2019-20.

I know this is always going to be a little controversial, but, as I would expect in this era of online communication, the number that make direct contact with us, by phone or email, has increased very slightly but the numbers wanting to speak to one of our peer support volunteers has dropped again.

I will come back to this when we talk about what is coming up, but I think we must continue to offer our help and support in any way that is appropriate to the person needing that help. So if they want to talk, we can do that and if they don't, we have to accept that and just let them know we are here if they change their mind.

It has been good to hear from some people that the hospital told them about GAIN, but this is something we need to improve. Maybe our volunteers could do another leaflet drop?

Facebook membership continues to grow, and we continue to monitor the content and the membership. Some of the content is not allowed and we do make people aware of our house rules on joining. We spend a little time trying to bust myths about the conditions as well as ensuring that members have access to accurate information.

2019-20 saw a reduction in the number of grants being requested – this is not a concern as patients are aware of the scheme, but many do not need help. We will continue to offer grants.

The promotion of research into the causes, prevention and treatment of GBS, CIDP and associated conditions

How GAIN got involved in research	
Members have taken part in studies and trials for a number of different projects	GAIN offered funding for projects at Manchester and UCHL
GAIN commissioned a study, through Lincoln University, to help determine the future strategy for the charity	GAIN assisted pharma with pre-trial studies

During the year ending 31 March 2020, we continued with our research project with Lincoln University, and we have seen some interim results but are still awaiting the final written report.

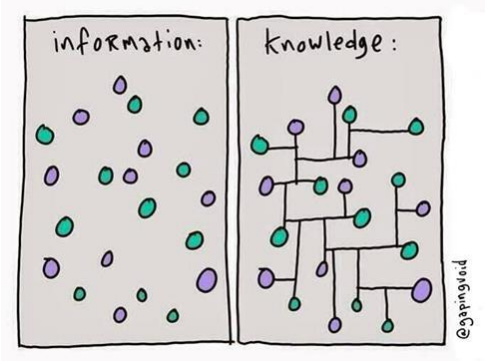
Ahead of the results, we have been working on the production of a series of home exercises and are looking at further collaborative work with universities, health providers and social enterprise. Although we were not successful in a bid at the beginning of 2020, it is hoped that we can revisit this in the future. Any collaborative work is to the benefit of our patients and would enable participation by them – we just have to get the funding!

There were still a number of studies and trials being planned, although most were postponed as the pandemic started. We are hopeful that these will resume in 2020-21 and talks are to take place to see how we can move the trials forward.

As with all research, studies and trials, I am not in a position to give any details of what the project is or who we are talking to until results are published. But everything we are in discussion about will be for the benefit of the patient whether that be for treatment or rehabilitation or something longer term. Indeed I am quite excited about the outcomes and how they could make a difference if all goes well.

The Manchester and UCLH studies were delayed due to the pandemic so we are hoping that they complete in 2020-21.''

Throughout the year, I have been involved in a number of NHS meetings, again to help the patients. This is great news for the charity as we are being recognized as a source of expertise and can represent the patient voice with the knowledge we have built up from you, our members. Again I have a confidentiality agreement on most of what is discussed, but I can tell you that the clinical pathway for autoimmune conditions has been published – hoping this will ensure an equity of treatment to all patients throughout the whole pathway from diagnosis to returning to normal life (or as near as you can get).



I have visited a few hospitals and rehab units to talk to the multidisciplinary teams involved in the care of the patients, and it is always interesting to see how they vary, but rest assured we are bringing them up to speed on best practice!

In 2018-19 we received some help from a marketing company to enhance our Instagram profile. This campaign by Precision Effect was put forward for an award in the medical marketing world, and on your behalf, I attended the award dinner in London – we came second which I thought was an amazing achievement.

We have now engaged a team at ACES Marketing Ltd to manage all our social media and google ads – and as you have seen this was a good move. We are making changes to the way we engage with our members, with monthly newsletters and an annual journal (to be published after the AGM). This will keep you better informed in a timely manner. For those that have an email address, newsletters will be sent by email and for those that don't we will post them.

Advancing the awareness of the charity and conditions to the public and healthcare professionals

How did we achieve this?	
Involvement with the NHS in developing clinical pathways	Direct contact with hospitals providing information packs for staff and patients
Greater engagement through Facebook, Twitter and Instagram	Patient stories published in magazines, newspapers and on the GAIN website

A few more facts

Chief Executive engages with:		
Specialized Healthcare alliance	Neurological Alliance (CE is a trustee)	NHS
Rare Disease UK	National Voices	

GAIN has a Silver Bond in the London Marathon, guaranteeing one place every 5 years

GAIN has a nationwide free will writing partnership with McClure Solicitors

So last year I spent a reasonable amount of time travelling between here and London to meet with the various committees and alliances that we are part of. The Neurological Alliance have now appointed me as their Treasurer, so I spend my free time working with them to the benefit of GAIN and other neurological charities – a good strength in our numbers to get neurology on the NHS agenda.

NHS committees have me participating in discussions on a whole range of topics affecting our patient group so it's an interesting time to be part of what is happening. Rest assured I am keeping the interests of our patients very much in the forefront of all my interactions at these meetings.

As we all continue to work in this new COVID era, going to digital meetings is more productive than face to face. No travelling time, balancing a laptop and papers on the square foot of table space on the train. Just top up the coffee and off you go. Meetings are more focused, and decisions seem to require less chat!

A few challenges

- **A decreasing number of voting members**
- **The age profile of voting members**
- **People not wanting to join Local Branches**

Possible solutions

- **Virtual branches**

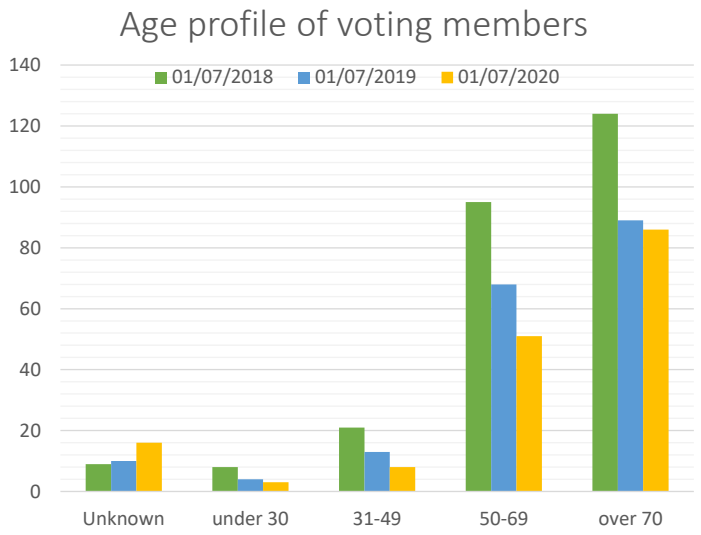
I am revisiting the age profile as it is obvious that the membership and the way people interact with the charity is changing. As you saw earlier 314 people contacted us directly with 77 asking to speak to a recovered patient, compared to the 49,000 people that used the website and the 1,000 new people that joined Facebook.

We are living in a world of change and we have had to adapt to deal with COVID. Who would have considered Zooming to be part of daily life? Using WhatsApp to speak to a patient in hospital? Well this is how life is and we in the office have had to change to deal with this.

We have a weekly online chat and are encouraging the membership to consider joining in. The contact with others is more important than the topics you discuss, but it helps to speak to people who understand what you have or are still going through.

We have to adapt to survive and so Branches can go online. In fact, one has just recently met, and although there were a few teething problems, these are easily sorted.

Peer support will not go back to face to face – WhatsApp and similar are working well and can be done safely from home. We can also introduce condition-specific groups to meet the needs of everyone who wants our support – if you have any ideas on a group you would like to see us include, please let Simon know.



Age should not be a barrier to these necessary changes as more people are embracing this way of working – yes we have just under 10% of our membership that either have no email address or they have not provided us with it, and we interact with them by post, but given the age profile this shows just how many people now use technology.

Age needn't be a barrier to embracing new ways to keep in touch

Our plans for 2020 and beyond

COVID-19

- The challenges
- Adapting
- The long term

Growing

- Associated Inflammatory Neuropathies

GAIN*momentum*

Communication with members

As the 2019-20 came to an end, so did the way we worked!

How did we deal with COVID? We worked from home – our phones are cloud numbers, so we answer them anywhere. We collected the post, although not many people wrote to us.

We continued to raise funds reinventing the Awareness Month as #GAINmomentum, took part in the virtual fundraising 2.6 challenge when the marathon had to be postponed.

We set up and Emergency Fund to try and fill the gap from all the fundraising events that did not happen. Thank you to all the members, families and friends who dug deep and helped up plug that gap – it really was appreciated. Yes, we are still expecting a shortfall in the income and we are likely to report a deficit next year, but we are very much a going concern and will keep moving forwards to ensure that is how it stays.

We started sending out newsletters, albeit weekly at the beginning, but evolving into a monthly newsletter, mainly by email (unless you are in the 10% group without access to email), and the magazine will become an annual journal following the AGM. So you will receive information as it happens – a good way to go.

We have to adapt, and so we are adding more associated inflammatory neuropathies on the advice of the Medical Advisory Board. We already mention these in our booklet on Peripheral Neuropathies but now we are going to enhance the support we can offer people with Brachial Neuritis, Ganglionopathy and POEMS.

These are not covered by other charities although POEMS will have elements covered by others. This over time will attract more people to the charity so offering more opportunity to engage with a wider audience, without affecting the services we currently offer as so many more people take indirect support than before.

End of Annual Report

Annual General Meeting 2020

1. **Receipt and adoption of accounts**
   - The Treasurer, David Wada, proposes the adoption of the accounts for the period 2019-20
   - Seconded William Harmer
   - Postal voting results:
     For 67, Against 0, Abstain 0, Spoilt paper 2
2. **Receipt and adoption of annual report**
   - The Vice Chairman, Adam Pownall, proposes the adoption of the Trustees Annual Report for the period 2019-20
   - Seconded Glennys Sanders
   - Postal voting results:
     For 67, Against 0, Abstain 0, Spoilt paper 2
3. **Election of Trustees 2020-21**
   The GAIN Board of Trustees
   Chris Fuller, Adam Pownall, David Wada, William Harmer, Paul Waine, Robin Sheppard, Jenny Willison, Lee Raynor, Harry Rowan, Susan McAllister
   All the trustees nominated were voted in at this AGM.
   Following the AGM at the Board meeting Sally Pattinson stood down from the Board. She was thanked for input and it was hoped that she would be able to rejoin in the future.
4. **Appointment of independent examiner 2020-21**
   - The Treasurer, David Wada, proposes that Goodman Jones LLP of 29/30 Fitzroy Square, London, W1T be appointed as independent examiners for the period 1 April 2020 to 31 March 2021
   - Seconded Richard Hughes
   - Postal Voting results:
     For 66, Against 1, Abstain 1, Spoilt paper 2
5. **Date of next AGM**
   - Saturday 16 October 2021

Thank you to everyone who has been supporting our crisp packet recycling scheme over the last couple of years, earning the charity over £800 to date! Unfortunately, there have been some changes to the scheme that are outside our control.

To keep costs down, Terracycle has recently changed the rules regarding the number of shipments and maximum weight for which we can earn points. We will now only receive points for one shipment per month, weighing no more than 20kg, which equates to 2000 points (£20). This means we can no longer offer free courier labels to third party collectors.

As well as the fundraising element, a major benefit of the scheme is raising awareness of the conditions and charity, and we would of course be grateful to anyone still wishing to send us their crisp packets. Collectors can therefore still post or courier their crisp packets to us to go towards the monthly shipment we are allowed, but this does incur a cost to the sender.

The most cost-effective way to do this that we have found, is using the DPD drop-off service, which allows you to send up to 20kg for £4.79. The postal address for sending crisp packets is GAIN, Glennys Sanders House, Pride Parkway, Sleaford, NG34 8GL. Anyone within easy reach of the office is of course very welcome to drop them off with us if they are in the area, but we fully understand if neither is an option. If you are able to keep collecting for us, thank you for your ongoing efforts!

If you can't get the packets to us, then you could always look up your nearest public drop-off point, so at least someone will benefit. You can find your nearest one on the Terracycle website; https://www.terracycle.com/en-GB/brigades/crisppacket

NB: We are no longer listed for collecting Pringles tubes.

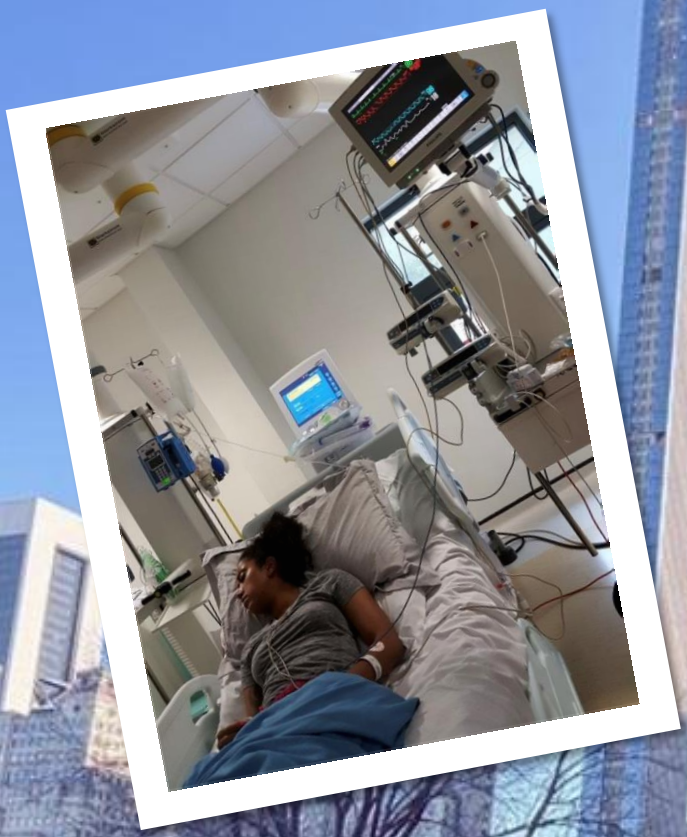
Other recycling schemes

Used stamp appeal - stamps must be totally unsorted, just as received through the mail. The stamps need to be on single paper (just the front part of the envelope), and with approximately 4-8mm of paper around each one. GAIN receives £10 per kilo. Send your collected stamps to: GAIN, Used Stamp Appeal, Fords Farm, Horsey, Norfolk, NR29 4EP.

Books and DVDs – you can turn your unwanted books and DVDs into donations to GAIN by downloading the Ziffit app or visiting www.ziffit.com

Sell unwanted items on eBay - GAIN doesn't have a retail arm like some charities, so we have no charity shop presence on the High Street. However, did you know that you can sell your unwanted stuff on eBay and choose to donate part or all of the proceeds to GAIN? Donate 10% or more and your item will feature an attention-grabbing charity ribbon, which can increase the chances of achieving a sale. Plus, you reduce your seller fees and enjoy tax savings.

Facing the unknown



As Trishna Patel recovered from a bout of 'flu in 2017, little did she imagine that the next few months would see her having to learn how to walk and talk again.

Trish's GBS Story

What is Guillain-Barré syndrome? So many of us have been asked that question, right? When I tell people I was diagnosed with GBS they immediately look confused! Guillain-Barré syndrome is not a well-known illness at all and to be honest, the first time I heard those three words was when I was being told I had it.

Something's not right

It started with a backache that I just couldn't shift; I was aching so badly that I even left a party early – which is very unlike me! I kept asking myself 'did I sleep funny?', 'move too suddenly?' or 'am I just aching from a gym workout?'

I woke up the next morning with sharp tingling in my hands and feet – the feeling was very different to the normal 'pins and needles' and so I knew something was wrong. I had caught the 'flu two weeks prior to this moment, but at the time did not think the two could possibly relate. I called 111 and was advised to go straight into A&E.

The diagnosis

Feeling very clueless walking into the hospital, the doctor told me they would need to monitor me over the next few hours to see how bad the situation became. No big deal, I was sick, the doctor would give me medicine and I would go home and be fine. My mum even put a Sunday roast on and said dinner would be waiting for me when I returned from A&E later that afternoon. Little did we know, I'd be in hospital for the next few months.

When the doctor came back to see me in the evening, my body had become weaker and my arms and legs were starting to feel numb. I am usually very ticklish, but I couldn't feel anything this time. From examinations, my reflexes had gone, which made the doctor think that I had GBS.

He asked me to walk in a straight line and noticed that my knees were starting to bend inwards and that my walk was off balance. I was very lucky that the neurologist who saw me on my first night immediately had an idea of what was going on and knew what tests to complete.

He printed off a GBS fact sheet and asked my family and I to read over it and think of any questions we had. Firstly, we couldn't even pronounce 'Guillain-Barre', so uplifted ourselves by laughter over that. Secondly, we just didn't quite understand how or why he thought my symptoms could lead to such condition. Surely, I had more chances of winning the lottery?

He began drawing a diagram which explained that there would be rapid disease progression leading to potential total paralysis within the next few days. We all were left speechless. Over the next two days, removal of spinal fluid and MRI scans (brain and body) were carried out – it was these procedures that led to my official diagnosis.

Here for the long haul

The doctors were highly concerned with the capability of my lungs as I started getting shortness of breath. After a few breathing tests, the doctor thought that my diaphragm was collapsing.

At this point I still had no idea what was going on. I was rushed in an ambulance (sirens and everything) to another hospital with an ICU/HDU as they thought I was moments away from mechanical ventilation. I had never stepped foot in this type of unit before and in my mind, this place was for really, really sick people – the doctors must have my records confused, I thought.

I was monitored at every single moment over the next week in ICU/HDU and within the space of seven days, not only did I need assistance walking, but the left side of my face had completely drooped. The doctor checked for stroke signs but gave me the all-clear.

My first night in the Intensive Care Unit

Strike a pose!

After one week of Intravenous Immunoglobulin (IVIG) treatment I was moved to the heart ward of the hospital. I remember having a physio session whereby I attempted to stand up; unlike the previous day, I completely collapsed to the floor and it was in that moment that I realised I was paralysed and had no strength to lift my own body. The deterioration that the doctor warned me of on my first day admitted, was now happening to me. I constantly felt so tired, all I wanted to do was sleep, even having a shower made me feel exhausted. I had to leave all my pride aside as I now couldn't do anything independently.

Due to the onset of facial palsy, I experienced difficulties with speech. As a result, my speech became unclear and it was harder to communicate. For a chatterbox like myself, this was really upsetting! I felt so self-conscious that at times I would refuse to look in the bathroom mirror. I just didn't see myself looking back at me and couldn't help but wonder if this were what I would look and feel like for the rest of my life.

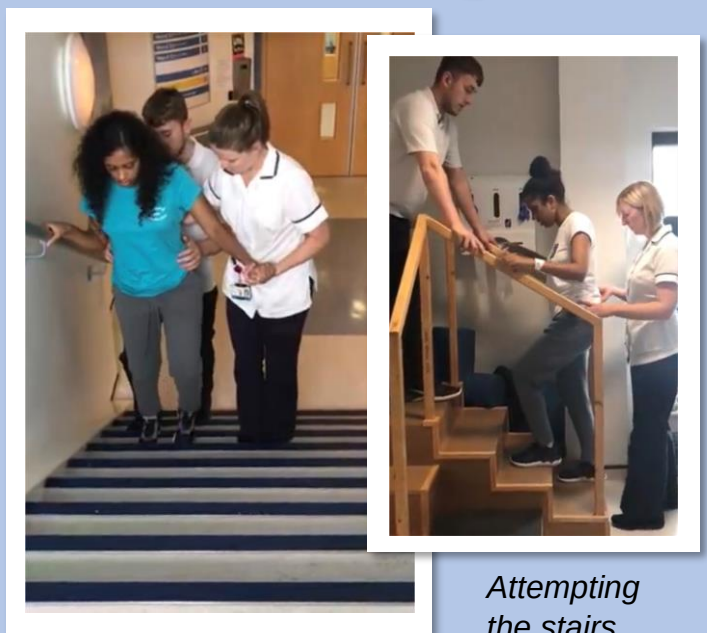
As the days went on, I found it more difficult to swallow and was informed that if my condition got any worse, they would put a tube down my throat – I was really not keen on this, so I opted for a liquid diet.

I tried to stay as emotionally strong as possibly but on many nights after my family would leave, I would cry my eyes out being physically unable to wipe the tears that streamed down my face. Every night, I kept telling myself I was in a bad dream that I would soon wake up from.

The treatment is finally working

I was administered another course of IVIG as the doctor said that the first course didn't work due to my antibodies/ immune system fighting off the treatment as it recognised that it was 'foreign'. This was mostly likely due to my young age; I was 25 at the time. Once I got my head around that, I was absolutely fuming at my own body! "Oh, now you want to protect me?" I thought to myself.

The days went by so quickly in hospital – by the time the neurologist, physios, speech therapist, critical care nurses and other staff had come to review me, I would be exhausted. I felt so lucky to have so many visitors during my time in hospital – my family and friend's support and positivity was and is a massive part of my recovery and overall journey.



Attempting the stairs

From wheelchair…

…to standing!

On the road to rehabilitation

After a few weeks, I was finally starting to show signs of improvement, I had never felt so relieved in my life! It started with gaining sensation back in my right foot, I was ticklish again – hooray! I was so determined to beat the odds; I put all my energy and effort into the exercises and activities set by the physios and occupational therapists. I continued to progress daily, setting different goals each day, stretching my arms a bit higher to the ceiling and rinsing a washcloth with more strength than yesterday. The doctors were happy for me to be transferred to the rehabilitation ward and from there, I worked even more closely with the neurophysios who helped me to take my first steps again.

The feeling was like no other, I cried with joy as my feet finally lifted off the floor and my arms began to swing. The movement was slow and definitely not smooth, but I felt as though I was prancing my way through the ward corridors. The physios continued to challenge me by including gym equipment and the dreaded stairs into my workouts. I began to pick up my walking pace and over time, I knew that my brain and body were starting to connect again – I felt so proud!

The unknown is an unsettling place

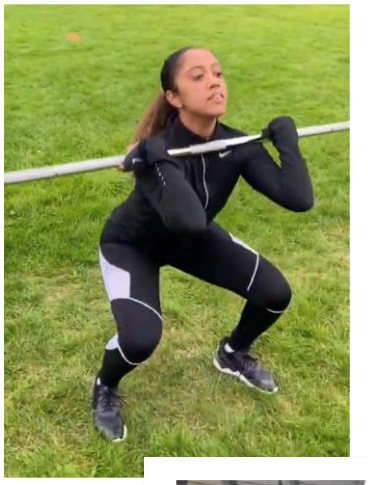
'How long will my full recovery take?', 'Will my facial palsy ever recover?', 'When do the pins and needles stop?'. I still had so many questions for my neurologist on his regular visits. He would continue to tell me how the journey is slow and that over time, I would continue to improve but he couldn't give me an exact date. This took me a while to accept. The unknown is an unsettling place and for someone like myself who is very organised and likes to have control over what I can, I really struggled to accept this.

continued overleaf

A new way of life…

My family and friends all made bets on my discharge date, it was like a fun game I'd get everyone to play when they visited me, the winner getting a good old pat on the back! I was finally discharged from hospital when my breathing results were considered normal and when I was able to walk alone. I knew that my lifestyle would look very different to how I once left it. I went back and forth with my emotions in accepting this change. I spent every week visiting the physio clinic as well as every 3 months visiting the neurologist.

Within 12 months of exercising regularly, sleeping, and eating well, I was able to run and feel light on my feet again. At present, my facial palsy remains slightly – many say they can't notice it, but I think it's a personal barrier for me to still overcome. Only after 3 years has my tingles in my hands and feet disappeared. I work out twice a week with my personal trainer and am now lifting heavier weights than I ever could pre-GBS. I still do have down days – which we are all allowed to have, but I have accepted that this journey is tough but by no means will it defeat me!



My advice for anyone going through this is to remain patient and willing. Healing is not an overnight process – this is something I remind myself of daily and even when you feel discouraged, remind yourself of how far you have already come. One of my favourite affirmations which I say regularly is 'Every day in every way, I am getting better and better'.

Thank you for reading my story.

Love Trish x

Continuing to exercise in my everyday life

Back to travelling and exploring

1001 reasons to say 'Thank You'

Back row; Sat Mistry, Kalpana Mistry, Harish Mistry, Nanu Mistry, Sharda Mistry, Front row; Irene Fuller (Marie Curie), Caroline Morrice (GAIN)

Back in February 2020, just before the COVID-19 pandemic got a firm foothold in the UK, we were delighted to hear some very good news from Sat Mistry (pictured above), who is the Communications Officer of the Wellingborough branch of Shree Prajapati Association (SPA).

SPA is an organisation whose members originate from the Gujarat state of India, promoting Hindu religious and cultural activities and running many other activities like sports and community based projects. Sat is a friend of Trish's mum, Anita Patel, who had suggested GAIN as one of their nominated charities for 2020.

Wellingborough is one of 14 SPA branches in the UK, and over the past 14 years has donated over £45,000 to over 40 local, national and international charities, organisations and disaster appeals. Last year's recipients were MND, Service Six and Daylight Centre, and their nominated charities for 2020 were GAIN and Marie Curie.

Funds are normally raised through three activities – the International Waendel Walk, a religious function, and an end of year themed fundraiser at Silk in Wellingborough.

Despite these major fundraising events having been cancelled this year due to the pandemic, each nominated charity was presented with a cheque for a fantastic £1,001.

Why £1,001 and not £1,000?

There is a tradition in India that a gift of money should always be for an amount ending in 1, but why is that?

It is common in India to give money for weddings and other auspicious occasions, and it is considered good luck to add a single rupee to the total. For this reason, the envelope containing the gift, known as a 'shagun envelope' will often have a single rupee attached to the outside.

There are various theories surrounding this. For some, it is a blessing, a token of love and luck. Because '0' signifies the end and '1' signifies the beginning, it might be considered the start of a new cycle. Either way, it makes the total an odd number, which is indivisible – a good omen for a married couple.

So, adding a '1' to any whole amount signifies the wish for growth for the receiver. In other words, 'let the money not stop with what the person gifts, but let it increase.'

Guillain-Barré & Associated Inflammatory Neuropathies

Guillain-Barré syndrome is the name attributed to the most common acute form of an autoimmune inflammatory neuropathy that attacks the peripheral nerves. However, we are also able to provide information and support to those affected by several associated conditions which come under the GBS umbrella. Here, we provide a brief outline of all the associated conditions.

Guillain-Barré syndrome (GBS)

Also known as: Acute Inflammatory Demyelinating Polyneuropathy (AIDP)

Guillain-Barré syndrome is thought to be caused by a malfunction of the immune system, the body's natural defence against illness and infection. Normally the immune system attacks germs, such as viral or bacterial infections, but in people who develop Guillain-Barré syndrome, something goes wrong with the immune response, and it mistakenly attacks the peripheral nerves.

This causes the myelin sheath that normally protects nerve fibres to become inflamed and may also cause axonal damage, which is the part of the nerve that conducts electrical impulses. This prevents signals from the brain travelling along the nerve fibres properly, which can cause numbness, weakness and pain in the limbs. Because many nerves are inflamed, GBS is called a 'polyneuropathy'.

GBS or AIDP is the 'classic' form of Guillain-Barré syndrome, and the most common, although the syndrome overall is rare, affecting only 1-2 people per 100,000. Patients with AIDP typically present with pins and needles, numbness and weakness in the feet and legs, which then progresses to the hands and arms and cranial (facial) muscles. Around 20-25% will be affected so severely that they will need a ventilator for a time to help them breathe.

There is no cure for GBS, but it can be treated with immunoglobulin, which is a blood product. This is administered intravenously (IVIg) over a period of 5 days, and can help to halt the progress of the syndrome earlier than if left to nature. An alternative to IVIg is either plasmapheresis or plasma exchange. Although all are equally effective, IVIg is the most common treatment, due to it being easier to administer.

Physiotherapy plays an important role in recovery, both to prevent muscle wastage during the period of partial or total paralysis, and also to rebuild muscle and body strength in the following weeks and months. Psychological support in the early stages can also help a great deal, in coming to terms with a very sudden and traumatic change in circumstances, and to cope with the uncertainties ahead.

The syndrome is monophasic in 95-98% of cases, and active for a maximum of six weeks (usually four). The majority of people recover within a year, but recovery can continue for more than 5 years.

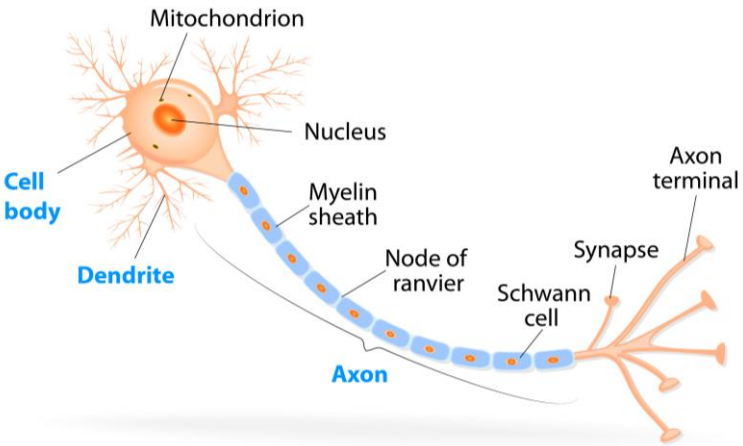
GBS does not 'relapse', and recurrence is rare. If symptoms do recur following recovery, it may be a second episode, but this could also be an indication of a chronic variant such as CIDP.

AMAN & AMSAN

With the AIDP form of GBS, the axon, which is the conducting core of the nerve, and equivalent to the copper core within electrical cables, is not damaged. However, in the **AMAN** (acute motor axonal neuropathy) and **AMSAN** (acute motor and sensory axonal neuropathy) variants, the axon is damaged and well as the myelin sheath.

As with AIDP, disease progression can be rapid, and most patients reach the worst point within two weeks. Although damage to both the myelin sheath and the axon can be repaired, recovery often takes longer and may be incomplete.

The structure of a typical neuron



Miller Fisher syndrome (MFS) & Bickerstaff's brainstem encephalitis (BBE)

Characteristics

- acute idiopathic ophthalmologic neuropathy
- syndrome of ophthalmoplegia, ataxia and areflexia

Related conditions are:

- GBS with ophthalmoplegia
- Bickerstaff's brainstem encephalitis
- acute ophthalmoparesis

MFS is characterized by abnormal muscle coordination (ataxia), paralysis of the eye muscles (ophthalmoplegia), and absence of the tendon reflexes (areflexia). Additional symptoms may include generalized muscle weakness and possible respiratory failure.

Patients described as having Miller Fisher syndrome often have a neuropathy that overlaps with GBS and demonstrate generalised weakness, sometimes paralysis, as well as additional symptoms.

Research in recent years has concentrated in identifying the antibodies that are thought to be responsible for Guillain-Barré syndrome. It has been confirmed clinically that MFS, GBS with ophthalmoplegia, BBE, and another condition called acute ophthalmoparesis (characterised by acute onset of paresis of the extraocular muscles without ataxia or areflexia) are closely related, forming a continuous range.

This is supported by immune findings with the antibody anti-GQ1b IgG being the common factor. This antibody is not found in other GBS patients, so it is thought that it is responsible for the ophthalmoplegia. It has been further noted that many BBE patients have limb weakness and this is considered an overlap with axonal GBS indicating the disorders are related.

Acute brachial neuritis

Also known as Parsonage-Turner syndrome or neuralgic amyotrophy

Brachial neuritis is a form of peripheral neuropathy that affects the chest, shoulder, arm and hand. It affects 1-2 people per 100,000 and occurs unexpectedly on its own. It is characterized by sharp, severe pain in the nerves of the brachial plexus (a network of nerves extending from the spinal cord, through the neck, over the first rib, and into the armpit), followed by weakness or numbness. The cause of acute brachial neuritis is unknown. It usually affects just one side of the body, but it can also involve other nerves and other parts of the body.

Over time, acute brachial neuritis will resolve on its own, but medication may be required to manage pain in the meantime. Symptoms typically resolve slowly over the course of a few months or a few years.

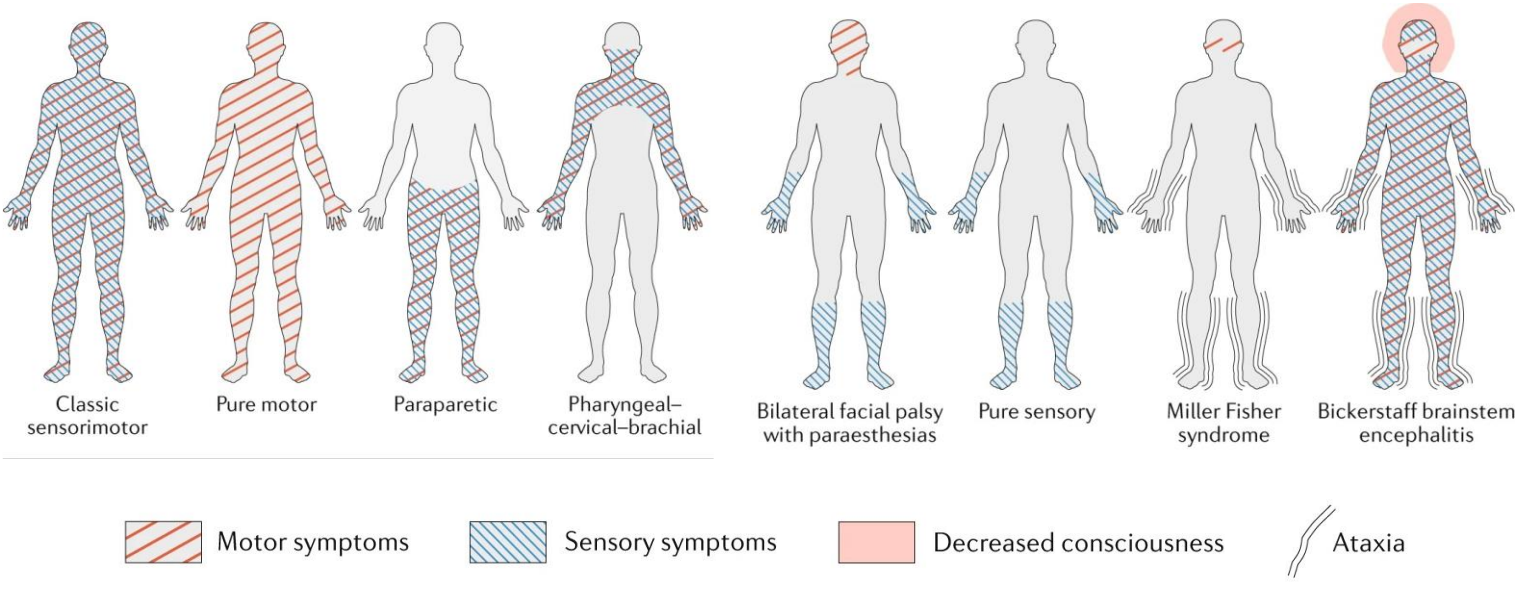
Other inflammatory neuropathies

There are several other inflammatory neuropathies which might show similar symptoms, but which are not associated with Guillain-Barré syndrome.

If you have an inflammatory neuropathy that is not listed here, please feel free to contact us, as we may be able to signpost you to another organisation who can help.

You can telephone us on 01529 469910 during office hours, or email us any time to office@gaincharity.org.uk

Pattern of symptoms in variants of Guillain-Barré syndrome



Chronic Inflammatory Demyelinating Polyneuropathy (CIDP)

Chronic Inflammatory Demyelinating Poly(radiculo)neuropathy (CIDP) is a rare autoimmune condition of the peripheral nervous system. As many as 650 people are diagnosed with CIDP each year in the UK (1-2 per 200,000)

Studies have shown that CIDP:

- has several different forms which vary in severity
- is not hereditary or infectious
- is not a psychiatric condition
- can start at any age and is slightly more common in men than women

CIDP is closely related to the acute condition, Guillain-Barré syndrome (also known as AIDP), and is distinguished from GBS by its pattern of progression. In GBS the low point is always reached within six weeks (often much sooner) whereas in CIDP the initial progressive phase generally lasts much longer.

Some patients with CIDP develop a rapid onset much the same way as patients with acute GBS, but instead of stabilising and then improving, they either remit and relapse, or continue to deteriorate for several months. A progressive course, or the emergence of a remitting and relapsing pattern may lead to an initial diagnosis of GBS being revised to the real diagnosis of CIDP.

The treatments with clinically proven efficacy in CIDP are immunoglobulin, corticosteroids, and plasma exchange. Studies have shown each of these to be equivalent, but the choice of treatment agents depends on the type of CIDP the patient is suffering, the personal situation of the patient and the patient's medical history. For example, it is felt that motor dominant types of CIDP respond better to immunoglobulin than steroids. Some CIDP is very mild and requires no treatment. All three of these treatments have associated risks and different advantages and disadvantages. Around 15% of patients do not respond to any of the three treatments available.

Intravenous immunoglobulin (IVIg) is the first treatment of choice nowadays in CIDP. If it works, there is a response quickly in a matter of weeks, with improvement in strength and function. IVIg is given in hospital and if it needs to be given long term by regular infusion typically every 6 weeks, has an impact on the patient's work which can be problematic, or if they are a main carer to other adults or children and cannot manage the time away from home. **Subcutaneous immunoglobulin** (also known as SCIg or SubCut) is increasingly available and can be administered at home, which is more convenient for patients.

Plasma exchange involves having the patient attached to a machine to remove some of their blood and replace with other blood product (eg human albumin), over 5 days. It is only available in large hospitals and is felt to be the most invasive of the 3 treatments.

Steroids are easy to administer either as daily or alternate daily treatments, or monthly oral or intravenous regimes. They can be very effective but are limited in their use by their side effects.

Around 40% of patients will go into remission after one year of treatment with either steroids or immunoglobulin.

Other chronic variants

Paraproteinaemic Demyelinating Neuropathy (PDN) is sometimes described as:

- chronic demyelinating neuropathy associated with a benign paraprotein
- CIDP associated with paraprotein
- CIDP with paraproteinaemia

Antibody-producing bone marrow cells go out of control and produce large numbers of the same antibody. The antibody (or immunoglobulin) sometimes damages nerve fibres causing a peripheral neuropathy. Some doctors regard the clinical, electrophysiological and pathological features of the demyelinating paraproteinaemic neuropathies and of CIDP as closely similar and almost indistinguishable.

These neuropathies are usually late-onset in terms of age and are a mixture of motor and sensory, although the severity of sensory loss tends to be greater compared with CIDP. There is usually more pain but less severe weakness and impairment. Most patients respond to corticosteroids, cytotoxic drugs, or plasma exchange.

Multifocal Motor Neuropathy (MMN) or MMN with Conduction Block (MMNCB)

This is sometimes thought of as a rare variant of CIDP. However, there are differences that are more prominent than the similarities. MMN patients commonly have asymmetric weakness of the distal (far) muscles, while in CIDP, proximal (near) symmetric weakness is more common.

The remitting and relapsing course that may occur in CIDP is uncommon in MMN, and unlike CIDP, patients with MMN rarely have significant sensory symptoms. Increased protein level in the cerebrospinal fluid of MMN patients is rare. Treatment with IVIg or cyclophosphamide is usually effective.

Lewis-Sumner syndrome

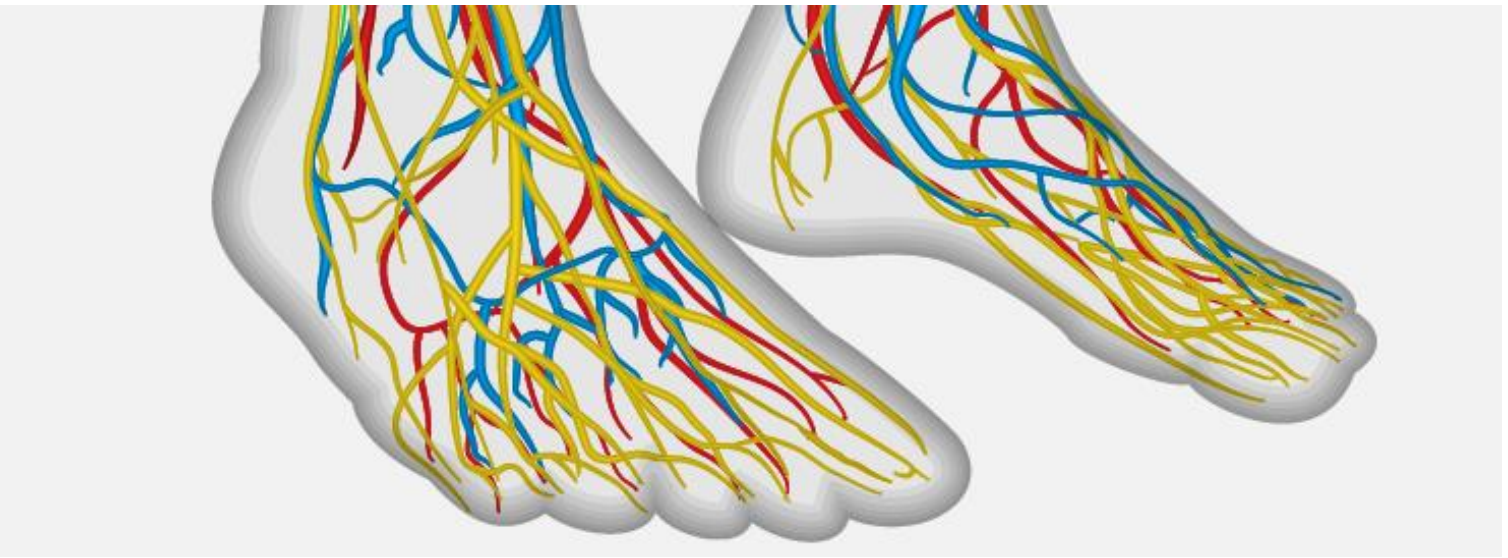
Also known as Multifocal Acquired Demyelinating Sensory and Motor neuropathy (MADSAM).

This is a chronic condition with similarities to Multifocal Motor Neuropathy but with enough differences, especially in treatment, to have acquired its own definition.

Some report it to be an asymmetrical variant of CIDP. Both MADSAM and MMN responds to IVIg. However, some MADSAM sufferers respond to prednisolone whilst most MMN sufferers do not.

Sub-acute Inflammatory Demyelinating Poly(radiculo)neuropathy (SIDP)

GBS is defined when the nadir (worst point) occurs within four weeks of first symptoms. Usually it is much less. CIDP is defined when the nadir comes after eight weeks. Usually it takes much longer. An illness peaking after four weeks but before eight weeks may be called subacute and will be treated as CIDP or GBS depending on which it best resembles.



Chronic idiopathic axonal neuropathy

If no cause for the peripheral neuropathy can be discovered, doctors call it 'idiopathic' which means 'of its own cause'. This label probably covers a number of different causes which future research may uncover. With rare exceptions, chronic idiopathic axonal neuropathy occurs in older people, only worsens very slowly (and sometimes remains stationary), and does not become disabling.

It is most commonly a sensory neuropathy causing numbness, tingling and discomfort in the feet that may gradually spread up the shins. People may become slightly unsteady and weakness of the ankles may develop. The amount of pain is variable. Some people have very little pain but more weakness. Others have little weakness but more pain.

Sensory Neuronopathy

Also known as Sensory Ganglionopathy or Dorsal Root Ganglionopathy

This is a rare subgroup of peripheral nervous system diseases with specific characteristics, such as the primary and selective destruction of the dorsal root ganglia (DRG) neuron in the spinal cord and the trigeminal ganglia neuron in the skull.

It has a typical clinical presentation, with sensory deficits that are not dependent on length and patients often report a lack of coordination of muscle movements. There are several proposed mechanisms for the pathophysiology of the condition. The diagnosis is guided by the presenting symptoms and confirmed with diagnostic tests to differentiate from other related conditions.

Treatment of sensory ganglionopathy is often difficult and patients often stabilize but fail to improve significantly. There are reports of improvement in immune-mediated and paraneoplastic sensory ganglionopathy following treatment with intravenous immunoglobulin and rituximab, respectively. Quickly treating the underlying cause, such as the underlying neoplasia, may also be helpful.

POEMS syndrome

Also known as osteosclerotic myeloma, Takatsuki syndrome and Crow-Fukase syndrome

POEMS is a rare condition caused by the body producing abnormal plasma cells (a type of blood cell which produces antibodies to fight off infections). This blood disorder affects multiple organs in the body.

It is named after the five common features of the syndrome described below.

Polyneuropathy	nerve damage leading to weakness, numbness and pain in the arms and legs
Organomegaly	an enlarged spleen and/or liver
Endocrinopathy	hormonal problems
M-protein or **Monoclonal plasma cell disorder**	an overproduction of abnormal plasma cells which lead to other multi system effects
Skin changes	darkening to skin, red spots on the body, hair growth

There are also a range of other features that may occur in POEMS syndrome. However, not every patient will have them. These include:

- Abnormal ("sclerotic") bone growth in certain parts of the skeleton.
- Swelling of the optic nerve, the main nerve in the eye
- Fluid build-up around the lungs, in the abdomen and/or the legs
- High red blood cell levels and/or high platelet levels in the blood
- Raised levels of a cytokine (chemical messenger) in the body known as vascular endothelial growth factor (VEGF) (occurs in most POEMS patients)
- Castleman disease (a type of lymph node disorder which causes a range of symptoms)

How dreaming of the open road and meeting film-maker Graham MacIver made former keen motorcyclist Kenny Smith a

Highway Star

I have been in love with motorcycling since I was 10 years old.

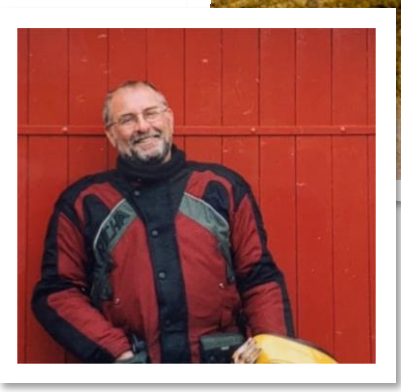
My father had an auto cycle which was a forerunner of the modern moped. My father fractured his skull one night coming home from work when the front forks broke, and he was lucky to live. Understandably he was not keen on me learning to ride.

My friend Kai, who was a couple of years older than me, wanted to try it, but it remained locked in the barn. Kai bought a paratrooper's fold up scooter, the Corgi, and taught me to ride. At the end of the Second World War there were a lot of them around. With a top speed of 40 mph it was the most exciting thing I had ever done.

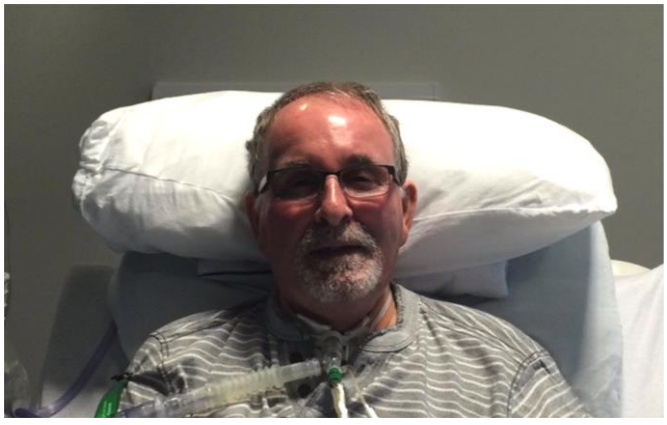
I bought my own motorcycle when I was thirteen and have had motorcycles all my life. I was only nineteen when I rode to Morocco from London with three friends in an old sidecar outfit. My wife Dolly and I had our honeymoon on a motorcycle and sidecar. We made it as far as Spain.

Guillain-Barré syndrome left me paralysed six years ago at the age of 65. I had just bought a new motorcycle for touring which is something I had always loved.

The idea of a Trike came to me after watching The Motorbike Show, it was an exhibition in Birmingham showing many trikes. With a background in engineering I could see this was the only way I was ever going to get back on the road again.



Kenny enjoying the freedom of the open road (above and left) and recovering from GBS (below)



I contacted Haydn at the Trike Shop in Cardiff who told me he had never built one before but would have a go. While Haydn and his team built The Trike there were also many trips in my van to welders, upholsters, powder coaters etc... to help with the modifications required for the wheelchair.

Taking delivery of the Trike was a very proud moment for me as it came after five months of planning, preparation and hard work. For example, taking measurements, many photographs of my wheelchair and van with its loading ramp and tie-down for the chair and myself.

I bought the original bike on eBay in the March of that year from a chap in Aberdeen. I chose a Triumph Rocket 3; 2.3 litre, which has 3 cylinders and I felt it had the power to be converted to a successful Trike. The Trike can probably do a top speed of 140 miles an hour, though this has yet to be tested!

I bought another wheelchair like my own to be sent down to Cardiff to the Trike Shop which gave them something to work with.

In the end all the hard work and months of waiting paid off. My friend Mark drove the Trike from Cardiff to Glasgow, with a pal in the wheelchair, last September. An unusual sight to see someone leaping out of a wheelchair at filling stations! The Trike required filling about six times between Cardiff and Glasgow.

As you can see my whole life has been motorcycles which came to an abrupt end on June the 7th 2014, but now at least I am back on the open road with a bike!

When film-maker, Graham MacIver heard about Kenny, he knew that it was a story he wanted to tell.

''A while back, my friend Mark Freegard suggested that I meet Kenny Smith and that his story might make for a good film project. Mark was one of Kenny's carers at the time. I met with Kenny and Highway Star is the result. It was shot over two days around the family home and out on Crow Road, near Glasgow. Kenny is a reminder to us all that we should live for each day and never take things for granted.''

Our thanks to Graham MacIver, of Studio 27 Productions, and to Mark Freegard for permission to use images from the film and taken during film-making.

You can watch this inspirational short film here; https://vimeo.com/465844535/14df9787bf

Knowing the generosity of the biking community, Kenny is determined to use his trike to raise both awareness and funds to help others affected by these conditions. To this end, the trike now bears a custom-made bumper sticker, encouraging people to text TRIKE to donate £5!

With TextGiving from Donr, donating to GAIN couldn't be easier!

Donate £5
Text GAIN
to 70085

We like to make it as easy as possible for you to support your favourite charity, so we've signed up with Donr, the Text Giving service that offers charities an affordable and flexible platform with no monthly, keyword or set-up fees.

Not only that, but we get all the Gift Aid on eligible donations!

Example:	
Donation amount	£5.00
Eligible for 25% Gift Aid?	£1.25
Minus 5% fee	£0.25
Donation worth	£6.00

We have two campaigns in place, allowing our supporters the choice of making either a one-off or a regular monthly donation.

To make a one-off donation
Text GAIN to 70085 to donate £5
(or add your own amount, e.g. GAIN10*)

To make a regular monthly donation
Text GAINAGAIN to 70085 to donate £2 per month
(or add your own amount, e.g. GAINAGAIN5)

Because we can have an unlimited number of campaigns running concurrently, we can even give our fundraisers their very own keyword campaign code!

So, if you are busy raising funds to help us through these uncertain times, and would like to encourage donations from your supporters through a personalised campaign keyword, get in touch and we'll set one up, just for you. You can then share it across social media platforms and amongst friends, family and colleagues, and even advertise it in your wider community with posters and flyers!

**The minimum donation is £1, and the maximum amount per donation is £20. Donations are limited to £30 per mobile number per day, and some operators impose monthly caps to stop users running up big mobile bills (contact your mobile phone operator for further information).*

Feeling lucky?

2021 sees the official launch of the GAIN 200 Club.

This is a nationwide extension to the 100 Club that has been run successfully for several years by the GAIN Lancashire and Cumbria branch in the North West of England.

The GAIN 200 Club is a fun and simple way to raise funds for GAIN, whilst at the same time offering members the opportunity to win monthly cash prizes.

The more people join in, the bigger the pay-out, so spread the word to family and friends and get them to buy a number too!

Please gamble responsibly
#Be Gamble**Aware**
https://www.begambleaware.org/

How does it work?

Taking part costs £20 per number for the whole year, which can be paid in one go or over two instalments of £10 each in March and September.

The takings are split 50/50, with 50% forming the prize fund and 50% supporting our charitable objectives.

Three cash prizes are awarded each month. First prize is 40% of the monthly prize fund, plus two runner-up prizes of 20% each. The remaining 20% is carried forward to a bonus draw in November.

On the 2nd Wednesday of each month (from April 2021), the winning numbers are drawn via a live video link, so anyone can dial in to see if their number comes up.

Winners will be notified, and the winning numbers will be listed on the website, on our social media platforms and in the newsletter. Participants must be 16 or over and resident in England, Scotland or Wales.*

Don't miss out! Register your interest now and make sure you sign up before the end of March 2021.

**Due to gambling regulations, this draw is not available to residents of Northern Ireland or the Republic of Ireland*

We are often asked by people for advice surrounding vaccinations, in particular the seasonal influenza vaccine, and more recently the emerging COVID-19 vaccines.

Sometimes people are advised by their doctor not to have a vaccination within 12 months of having had Guillain-Barré syndrome, as a precaution, so if your diagnosis was very recent, your doctor might advise you to give it a miss this year, **unless you are in a group considered to be at high risk from flu**.

Otherwise, the advice for people who have had GBS is the same as for anyone else regarding vaccinations. GBS is a single event acute condition that is very unlikely to recur; it doesn't 'relapse' and someone who has had GBS is unlikely to get it again (recurrence rate is believed to be around 2-5%). The only caveat to this would be if you developed GBS within 6 weeks following a vaccination, in which case it would be wise to avoid that particular vaccine in the future. The seasonal flu vaccines change each year, depending on which strains are predicted by the WHO to be most prevalent: **https://www.who.int/influenza/vaccines/virus/recommendations/en/.**

The flu vaccine is also considered safe and is recommended for people with CIDP or another of the chronic variants. If you are being treated with immunoglobulins via IVIg or SubCut, you may be less likely to get viral infections, but the best protection from the flu is still to be vaccinated. If you're being treated with corticosteroids, or other immune-suppressant medication, you may be more prone to viral infections, and a serious case of flu could put you at considerable risk, so again, it would make sense to protect yourself from flu by having a vaccination.

Under normal circumstances, most people don't need a flu jab, because for them, flu is inconvenient but not life-threatening. However, if you are in an at-risk group, or you live or work closely with people for whom flu can cause severe and even life-threatening complications, then the advice is to be vaccinated, as this is the most effective way to protect yourself against getting flu, and passing it on to others. This year, things are a bit different, because anyone getting flu and COVID-19 concurrently is potentially at a heightened risk. The flu vaccination programme for 2020/21 has been extended beyond those traditionally considered to be at risk, to minimise the spread and to protect as many people as possible from the associated danger, so it's worthwhile asking your GP or pharmacist about getting vaccinated, even if you wouldn't normally be considered at risk.

Over the last couple of decades, there have been numerous studies looking at whether vaccines might act as a trigger for GBS/CIDP, and as a result, it is now widely believed that there is little, if any, causal link. As GBS/CIDP also occurs naturally in the vaccinated population, a very small number of cases are reported each year in temporal association with vaccination (for example, there were 11 reported cases out of 14 million flu vaccinations during 2019/20). This does not mean the vaccine was the cause. Although these may be true side-effects, they may also be due to concurrent diagnosed or undiagnosed illness, other medicines or they may be purely co-incidental events that would have occurred anyway. Based on current evidence, both Public Health England and the Medicines & Healthcare products Regulatory Agency (MHRA) state that a causal link has not been established.

On vaccinations in general, our Medical Advisory Board offers the following advice:

- DON'T have a vaccine that was temporally associated with your onset of GBS (i.e. within about 6 weeks)
- DON'T have unnecessary vaccines for travel but DO have all travel vaccines that are recommended for the particular area you are travelling to
- DO have all vaccines that are 'necessary'. This includes the flu vaccine (if you are in an at risk group), MMR, DTP, pneumovax, HIF etc., and will include COVID-19 vaccine when it becomes available. **There is no population link to causation in any of these - there are monitoring programmes going on so a link would be picked up if it occurred; no links have been detected since the 1970s**

Protect yourself and stay safe!

Things you need to know about vaccines

Vaccines DO

- ✓ protect you and your family from many serious and potentially deadly diseases
- ✓ protect other people in your community, by helping to stop diseases spreading to people who cannot have vaccines
- ✓ get safety tested before being introduced – they're also monitored for any side effects
- ✓ sometimes cause mild side effects that will not last long
- ✓ reduce or even get rid of some diseases, if enough people are vaccinated (herd immunity)

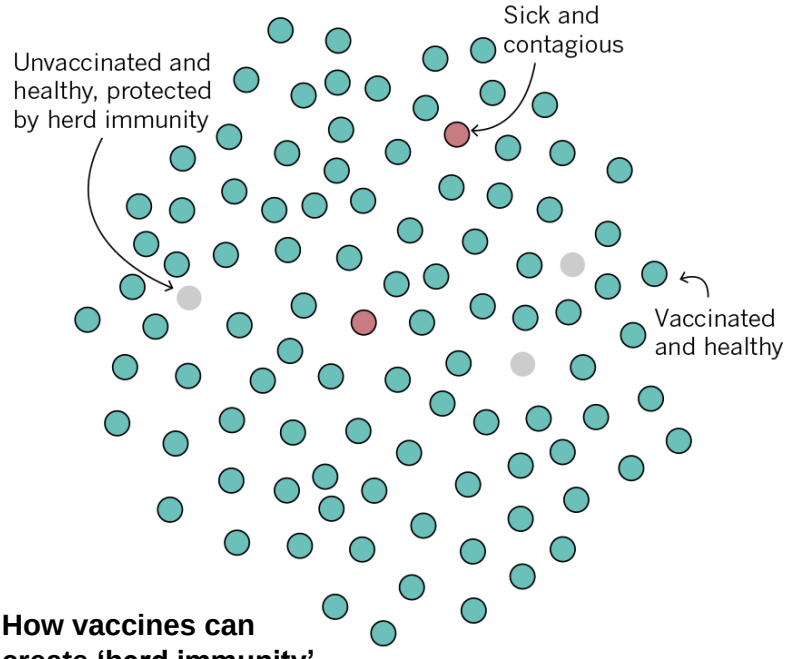
Vaccines DON'T

- ✗ cause autism – studies have found no evidence of a link between the MMR vaccine and autism
- ✗ overload or weaken the immune system – it's safe to give children several vaccines at a time and this reduces the amount of injections they need
- ✗ cause allergies or any other conditions – all the current evidence tells us that vaccinating is safer than not vaccinating
- ✗ contain mercury (thiomersal)
- ✗ contain any ingredients that cause harm in such small amounts – but speak to your doctor if you have any known allergies such as eggs or gelatine

Why vaccines are important

Vaccination is the most important thing we can do to protect ourselves and our children against ill health. They prevent up to 3 million deaths worldwide every year. Since vaccines were introduced in the UK, diseases like smallpox, polio and tetanus that used to kill or disable millions of people are either gone or seen very rarely. Other diseases like measles and diphtheria have been reduced by up to 99.9% since their vaccines were introduced.

However, if people stop having vaccines, it's possible for infectious diseases to quickly spread again. The World Health Organization (WHO) recently listed vaccine hesitancy as one of their top 10 biggest threats to global health (vaccine hesitancy is where people with access to vaccines delay or refuse vaccination).



How vaccines can create 'herd immunity'

How vaccines work and why they're safe

Vaccines teach your immune system how to create antibodies that protect you from diseases. It's much safer for your immune system to learn this through vaccination than by catching the diseases and treating them. Once your immune system knows how to fight a disease, it can often protect you for many years.

Having a vaccine also benefits your whole community through 'herd immunity'. If enough people are vaccinated, it's harder for the disease to spread to those people who cannot have vaccines.

All vaccines are thoroughly tested to make sure they will not harm you or your child. It often takes many years for a vaccine to make it through the trials and tests it needs to pass for approval.

Once a vaccine is being used in the UK it's also monitored for any rare side effects by the Medicines and Healthcare products Regulatory Agency (MHRA).

Anyone can report a suspected side effect of vaccination to the MHRA through the Yellow Card Scheme.

Source: https://www.nhs.uk/conditions/vaccinations

Rushed Hospital Discharges

IL News, November 2020 https://www.independentliving.co.uk

A study by Healthwatch England and the Red Cross has found that rushed hospital discharges have left significant numbers of people with their care needs neither assessed nor met.

In order to free up 15,000 beds for COVID patients, the government introduced a policy of "discharge to assess" – i.e. send people home and let their ongoing needs be assessed there, rather than keeping them in hospital until they had been assessed, and then discharging them, having put a suitable care package in place. But there have been major problems, as shown by a new study conducted by Healthwatch England, in partnership with British Red Cross.

The report found that more than four-fifths of respondents did not receive a follow-up visit and assessment from a health and care professional and nearly one in five (18%) of those who weren't visited said that they had unmet needs after leaving hospital. The study was conducted in England, but a system of discharge to assess is in place across the home nations.

Additional in-depth interviews with key staff

Eight local Healthwatch and partners around the country also carried out 61 in-depth interviews with key staff groups involved in hospital discharge processes. Nearly half of people with a disability and 20% of people with a long-term condition said they had support needs that were not being met following their discharge.

Researchers heard that one quarter of those who reported having outstanding support needs lived alone, and that three-quarters of those still needing support were between 50 and more than 80 years old, suggesting that there is a gap in the provision of post-discharge community health and social care services for those who are likely to need additional help. Some patients felt that their discharge from hospital was rushed; approximately one in five people (19%) did not feel prepared for leaving hospital.

Confusion abounds amongst discharged patients

People with outstanding needs reported that they were unsure of how to manage their condition following discharge, including how to administer medication, and who to contact for further advice and support. Only one in five patients were asked if they needed support taking medication before they were discharged. There were also issues relating to the provision of mobility aids and other equipment in the home, and a lack of consideration of people's home situation after they left hospital. Only 6% of people who had an assessment discussed equipment and mobility aids. Paid carers echoed this observation and suggested that there was a lack of support and consideration for people's home situations and living conditions.

Early hospital discharges can lead to readmissions

Care professionals also reported issues that affected their ability to prepare for their client's arrival after being discharged, with some patients being discharged too early and, sometimes, readmitted to hospital. Healthwatch England and British Red Cross have urged the Department of Health and Social Care and NHS England to investigate these issues and called for the government to increased investment in community services. The report said:

"A clear benefit would be improvements to joined-up working between hospitals, community healthcare, the voluntary and community sector and social care services, fostering a more patient-centred approach to discharge and reablement. However, the model will only be successful if these services are sufficiently resourced in the community"

Commenting on the findings, Healthwatch England chair Sir Robert Francis said:

"In March, hospitals were asked to discharge patients with little or no notice and the speed with which this took place was important but led to mistakes. We do not want to detract from the heroic efforts of those on the frontline, who often put themselves at great risk to care for their patients, but services and system leaders have now had more time to prepare.

It's essential that we learn from what people have shared with us about the impact that a poorly-handled discharge can have on them and their loved ones. Taking action now will not only reduce the risk to patients but will also help improve the way people leave hospital in the future."

Go to the Healthwatch website to share your experience of hospital discharge since the COVID-19 pandemic began: https://www.healthwatch.co.uk/report/2020-10-27/590-peoples-stories-leaving-hospital-during-covid-19

Community physiotherapy

Rehabilitation and engagement in activity are now widely recognized as critical components of long-term mental and physical health, and this is reflected in policy commitments across the UK as part of improvements to community and primary care.

These commitments are set out in the NHS Long Term Plan for England, 'A Healthier Wales', 'A Health and Care Delivery Plan in Scotland' and the 'Transformation Programme in Northern Ireland'.

However, **access to rehabilitation services continues to be a significant barrier for many of the people who could most benefit from them**. Those recovering from injury, or acute conditions, or living with long term conditions, often struggle to access the services they need.

These gaps are particularly evident outside of acute hospital settings. That is, services in community hospitals and intermediate care, in people's homes and for residents in care homes. Expanding access to quality rehabilitation, delivered in community settings, therefore has a key role to play.

The Chartered Society of Physiotherapy (CSP) is working with members and key stakeholder organisations to make the case for improved access and increased capacity for community rehabilitation. They want to ensure that policy commitments and new resources are translated into effective action. Delivering these changes will take several years and will need sustained and collective commitment.

As part of their campaign, the CSP has produced a short film to highlight the importance of physiotherapy in recovery.

To watch it, and find out how you can support the campaign to improve access to rehabilitation services across the UK, type the following URL into your browser;

https://www.csp.org.uk/campaigns-influencing/campaigns/rehab-matters

So, we know there's a gap in several areas between need for and availability of community rehabilitation services, and we know that the CSP is working with the NHS, and other key stakeholders to bring about change, but it won't happen overnight.

To help bridge the gap for our members, GAIN has commissioned a series of physiotherapy videos, which can be accessed online, in the comfort of your own home, and at a time to suit you.

Who is it for?

If you are recovering from GBS or an acute variant, and have been recently discharged from hospital, or if you are living with a chronic variant such as CIDP and are struggling to access community physiotherapy services, then let us know.

You must have an email address and access to a device suitable for viewing, such as a laptop, smart phone, smart TV, etc.

It's free of charge to our members, but there is a cost to the charity, so we need a few details from you, such as your name, contact details and diagnosis, etc.

Once we have those, we will create a log-in and send you a pack containing everything you need to get started!

If you're interested, please email Caroline Morrice at office@gaincharity.org.uk or phone 01529 469910 during office hours.

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https://www.giveasyoulive.com/charity/gain-charity

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Finding me again

Kate France shares her experience of getting her life back after a diagnosis of GBS in 2013, followed by a further diagnosis of CIDP when symptoms returned two years later.

Like most people reading this magazine, I have a significant date. Actually, I have two, March 2013 and March 2015.

2013 was when after having a sore throat my legs began to stop working and I learnt what GBS was. I have read many people's stories on the GAIN Facebook page and magazine, and realise that I was very lucky. My GP sent me to hospital, and I was diagnosed within a couple of days and started on IVIG. I was out of hospital after 3 weeks, albeit in a wheelchair with my legs not working, but feeling extremely lucky.

I was working in Human Resources, so was responsible for the working lives of my colleagues. Through my work I had supported many people dealing with a variety of illnesses and personal challenges, but when it is your turn, things are very different. It was hard to accept that I couldn't work and not know how long it would be for. As you know the inability to predict how long it will take to recover, and how good the recovery will be, is really hard mentally. My first step with this new reality was asking my boss to remove a banana from my desk drawer. I figured it was going to be in a very bad state by the time I would be back in the office!

My boss was keen to visit me, not to check up, but to reassure me that everyone was thinking of me. I had to be strong and say no. I wasn't ready to see anyone, as it took all of my energy and mental capacity to fight the illness. It was hard to say no to my boss, but I knew I had to. Thankfully, she understood.

From my experience in HR, I knew that often the people we work with, colleagues, managers, HR want to do the right thing, but don't know what the right thing is. This is understandable as everyone is different, so the right thing for me might not be the right thing for someone else. So, learning to say what support you need is essential, but very difficult.

Fast forward almost 3 months and a conversation with my husband really stands out for me. He took a deep breath and told me he was coping fine with the physical side of supporting me, but was struggling with the emotional. He missed "me", the strong minded, independent thinking person. I had lost my confidence.

Everyday things felt really scary - getting a taxi to the physio on my own felt huge. It is unbelievable now to think that such a small thing was so terrifying, but I had to do it. So, we did a trial run, to check if I could walk through the hospital on my crutches, and I did it. So, whilst I was still scared, I knew it was something I had to do. I was determined, and focused on doing my exercises and progressing physically, but clearly mentally I was not where I needed to be. We chatted this through, and I realised that I had felt like a burden physically, so had subconsciously wanted to be the least

trouble I could be, so I stopped having opinions and making decisions, not realising this just added to the pressure.

This also made me confront that I was putting obstacles in the way of returning to work.

I had a huge list of all the reasons it wasn't possible. I was still scared I wasn't the same person; would I still be able to do my job ? I gradually realised that returning to work was a key part of my mental recovery. So, we made a list of all of the physical obstacles and met with my boss to talk them through.

My office was upstairs and there was no lift, so work moved my office downstairs. I could only walk short distances on crutches, so I took my wheelchair to work and my colleagues helped wheel me around, and made sure I had cups of tea. Perhaps the hardest one, was my embarrassment at needing a frame in the bathroom to help me stand up, but again this was resolved. I had a designated cubicle ! My boss and my colleagues were amazing, no one could do enough to help.

It was incredibly hard to ask for help initially, and to accept that my needs were different, but with my husband's support I knew it was the only way I would find "me" again. I worked a couple of days a week from the office and some days from home and gradually built up my physical and mental health. The difference it made was huge. By the end of 2013 I was physically back to normal. As I said before I was very lucky ! 2014 was an uneventful year oh apart from changing jobs in the September following redundancy.

Then came March 2015, 6 months into my new job when the pins and needles/numbness started to come back in my feet, then my hands and arms, but slowly this time, just very gradually getting a bit worse. It took a few months this time to get a nerve conduction test and the diagnosis of CIDP.

I had already read the GAIN information, as I had had my suspicions, but as we know we are all different, so I had no idea what would happen to me and how it would progress. I had however learnt a lot from my GBS experience, and was able to think more clearly about work. I knew that I needed to keep my employer informed, help them understand the diagnosis and be prepared for whatever may come.

It has been very strange being on the other side, so to speak. I had many of the concerns that I am sure everyone has, but being in HR I had worked hard to create an environment where people would feel supported and could be open about their challenges, but when it was my turn it was not easy.

''I knew the stick made me stand out and I hated the attention it brought. There was no hiding the stick though, so I found one I loved.''

With GBS it was so sudden and immediately debilitating there was no option but to tell my employer, with CIDP it felt like more of a choice, and knowing it was long term I worried how it would affect how people saw me, and my ability to do my job. I thought about as a HR professional what would I say to a colleague in the same position and realised that I was going on a journey that I was going to need work to support me with. As I mentioned earlier, I also knew that work would need me to guide them in what support I needed.

I printed off the GAIN info on CIDP, gave it to my boss and my team, and when they had had a chance to read it, I talked to them about how it was affecting me, and also about the uncertainty for the future. This made it so much easier to talk about things as my needs changed. I thought I could work from home while having IVIG - I was wrong - I was exhausted.

For future sessions we were able to plan my work around it - working more flexibly. I started to need a walking stick and I was extremely self-conscious about it. I could walk without a stick but found it exhausting and the stick helped me go further and reduced how tired I was so I could focus better. I knew the stick made me stand out and I hated the attention it brought. There was no hiding the stick though, so I found one I loved, a really unusual shaped wooden one - so when people saw the stick, they commented how lovely it was - this somehow made me feel less self-conscious! It did have its downside when on holiday a large dog nearly ran off with it!

One plus side of the stick making the disability visible was I got offered seats on trains and tubes which I needed but wouldn't have asked for ! I found it hard to stand still in one place so needed to lean or sit - people at work knew this so made sure there was a chair.

I know everyone's experience is very different, I was initially taking steroids and my CIDP is now under control with azathioprine. I made sure work knew when my medication was changing so any side effects were understood. I don't need my stick at the moment, I still struggle standing still but all that means is I have to sit not stand at concerts and I've not risked a festival yet. I have strange sensations - mainly in my face when I'm tired but these just remind me how lucky I am.

I have been able to help my employers understand the support I needed and in return have had amazing support. At times I felt I had to swallow my pride and ask for help, but I just asked myself if it was a colleague or friend, what would I want them to do. And in every case, I would want the opportunity to support them to be able to be their best. As a consequence, I have been able to continue to carry out my job and as I saw in an article by Michael Rosen talking about the impact of corona virus on him **" I am different, not less"**

I understand that not everyone will have the same experience with their employer, but you don't know until you ask. Ultimately CIDP is a long term condition and for many would be classed as a disability (You are disabled under the Equality Act 2010 if you have a physical or mental impairment that has a 'substantial' and 'long-term' negative effect on your ability to do normal daily activities. Importantly, where the effect of the impairment is reduced or controlled by medication, medical treatment or an aid, its impact should be measured as it would be without such medication.) meaning that employers have a legal duty not to discriminate against you and to make reasonable adjustments. This applies when you are seeking employment as well as when you are employed.

It can be hard to recognise what a reasonable adjustment might be for you, there is some great information on the citizens advice website. Search for "Asking your employer for changes to help you if you're disabled"

Also think about who at work can you talk to - is it a manager, is it HR, do you have an occupational health person, or it could be Health and Safety. A good starting point may be to find your work policy on absence. If you are off work this will help you make sure you know what work expects and what you can expect e.g. how often you need to make contact, who to send your Fit note to, can you expect a long term sickness home visit, will they refer you to occupational health or ask for your permission to write to your doctor or neurologist. It can be hard to recognise what a reasonable adjustment might be for you, there is some great information on the citizens advice website. Search for "Asking your employer for changes to help you if you're disabled".

Chelsea Flower Show May 2013

''We had tickets booked and my friend, Sally and her Mum, Ann (in the picture) were amazing, persuading me still to go and that I wouldn't be a burden! It was a huge step mentally, but we had a brilliant day out!''

Also think about who at work can you talk to - is it a manager, is it HR, do you have an occupational health person, or it could be Health and Safety. A good starting point may be to find your work policy on absence. If you are off work this will help you make sure you know what work expects and what you can expect. eg.how often you need to make contact, who to send your Fit note to, can you expect a long term sickness home visit, will they refer you to occupational health or ask for your permission to write to your doctor or neurologist.

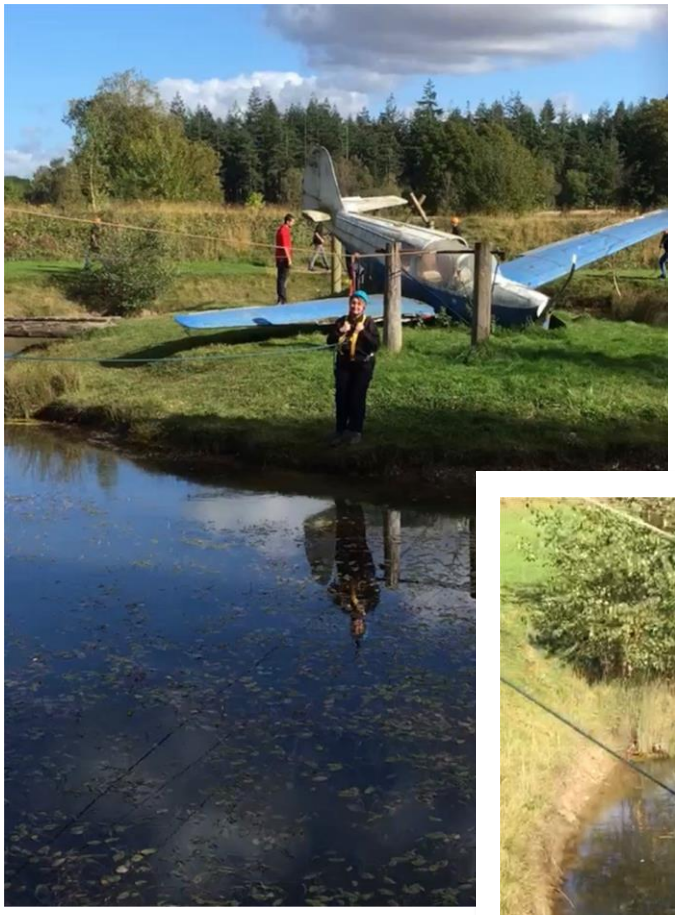
Some people may be worried that work will pressurise them into returning too soon, others may worry that work will not want them back. Either way it is important to be prepared.

Once you return to work you may need ongoing support that may change as your condition changes. At work we had a health passport that enabled people to create a record that explained their condition, what a good day looked like for them versus a bad day, and what support they needed. You created and owned your own document, and you chose who to share it with.

This meant that if you changed manager you could give them the passport, rather than having to "go through it all again"

continued overleaf

''I am different, not less''



Team building event

''I wanted to take part, so at each activity I found a part I could play. On this one I was the stranded pilot that the team had to winch over. It was a race and as an example of not being treated differently they elected that winning was the most important thing, so rather than lift me up and winch me over they just dragged me through the water!!''

Most employers will want to work with their colleagues to enable them to work to the best of their ability. Citizens Advice also gives information on what to do if you are not getting support from your employer.

I know that my experiences have made me more understanding about how difficult it can be to open up, and also that it is not a one off conversation. My needs change and sometimes people can forget that I have different needs.

I take this as a positive; they are not seeing my disability, they just see me and the work I am doing, so if I need to, I remind them. I genuinely appreciate it when people unexpectedly might just check in - wanting to know if I am OK - really wanting to know!

As I said at the start, I know I have been lucky with my condition and with my employers. If you are struggling either at work or with taking steps to get back to work you are not alone, there are people who can help, and getting in touch with GAIN is a good place to start.

For full disclosure, I'm not working at the moment but that is a conscious decision to take some time out following taking redundancy as my role relocated.

Shopping with GAIN helps raise awareness as well as funds

There are lots of gift ideas in the GAIN online shop, from cute and cuddly plushies, to tortoise-themed jewellery and keyrings.

If baking is your thing, our cake toppers and cookie cutters are perfect for a bake sale, and if you're into something a bit more energetic, a hot pink or lime green performance T-shirt is bound to get you noticed!

We're always open, so visit www.gaincharity.org.uk today to see what's in store

Introducing our brand new clothing range at GAIN Teemill!

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Visit https://gain.teemill.com/

Mental wellbeing & COVID-19

Fear, worry, and stress are normal responses to perceived or real threats, and at times when we are faced with uncertainty or the unknown.

Taking care of your mind as well as your body is really important, and there are things you can do now to help you keep on top of your mental wellbeing and cope with how you may be feeling if you're staying at home.

1. Check your employment and benefits rights

You may be worried about work and money while you have to stay home – which can have a big effect on your mental health. If you have not already, you might want to talk with your employer.

Find out about government support for businesses and self-employed people and understand your sick pay and benefits rights. Knowing the details about what the coronavirus outbreak means for you can reduce worry and help you feel more in control. Look up the latest guidance in your area.

2. Plan practical things

If you're unable to get to the shops, work out how you can get any household supplies you need. You could try asking neighbours or family friends, or find a delivery service.

Continue accessing treatment and support for any existing physical or mental health problems where possible. Let services know you are staying at home, and discuss how to continue receiving support.

If you need regular medicine, you might be able to order repeat prescriptions by phone, or online via a website or app. Contact your GP and ask if they offer this. You can also ask your pharmacy about getting your medicine delivered, or ask someone else to collect it for you.

If you support or care for others, either in your home or by visiting them regularly, think about who can help out while you are staying at home. Let your local authority (England, Scotland and Wales only) know if you provide care or support someone you do not live with. Carers UK has further advice on creating a contingency plan.

3. Stay connected with others

Maintaining healthy relationships with people you trust is important for your mental wellbeing. Think about ways to stay in touch with friends and family – by phone, messaging, video calls or social media.

4. Talk about your worries

It's normal to feel a bit worried, scared or helpless about the current situation. Remember: it is OK to share your concerns with others you trust – and doing so may help them too. If you cannot speak to someone you know or if doing so has not helped, there are plenty of helplines you can try instead.

5. Look after your body

Our physical health has a big impact on how we feel. At times like these, it can be easy to fall into unhealthy patterns of behaviour that end up making you feel worse.

Try to eat healthy, well-balanced meals, drink enough water and exercise regularly. Avoid smoking, drugs or drinking too much alcohol. If you are staying at home, you could try exercising indoors, as there are lots of free online classes. Or try an easy 10-minute home workout.

6. Stay on top of difficult feelings

Concern about the coronavirus outbreak and your health is normal. However, some people may experience intense anxiety that can affect their day-to-day life. Try to focus on the things you can control, such as how you act, who you speak to and where you get information from. It's fine to acknowledge that some things are outside of your control, but if constant thoughts about the situation are making you feel anxious or overwhelmed, there are some ideas to help manage your anxiety on the NHS website;
https://www.nhs.uk/oneyou/every-mind-matters/anxiety/

7. Do not stay glued to the news

Try to limit the time you spend watching, reading or listening to coverage of the outbreak, including on social media, and think about turning off breaking-news alerts on your phone. You could set yourself a specific time to read updates or limit yourself to checking a couple of times a day. Use trustworthy sources such as GOV.UK or the NHS website, and fact-check information from other places such as social media.

8. Carry on doing things you enjoy

If we are feeling worried, anxious, lonely or low, we may stop doing things we usually enjoy. Make an effort to focus on your favourite hobby if it is something you can still do at home. Or start a new hobby: read, write, do crosswords or jigsaws, bake, or try drawing and painting. Whatever it is, find something that works for you.

If you cannot think of anything you like doing, try learning something new at home. There are lots of free tutorials and courses online. You can still stay social at home by joining others online: book clubs, pub quizzes and music concerts are just a few of the things to try.

9. Take time to relax

This can help with difficult emotions and worries, and improve our wellbeing. Relaxation techniques can also help deal with feelings of anxiety.

10. And get good sleep

Good-quality sleep makes a big difference to how we feel, so it's important to get enough. Try to maintain your regular sleeping pattern and stick to good sleep practices.

The NHS website has lots of information that can help you help yourself.

For links to GOV.UK, Carers UK, NHS recommended helplines, 10-minute home workout, managing anxiety, relaxation and breathing exercises, sleep tips and more, go to;

https://www.nhs.uk/oneyou/every-mind-matters/coronavirus-covid-19-staying-at-home-tips/

Helping children cope with stress during the COVID-19 pandemic

Children may respond to stress in different ways such as being more clingy, anxious, withdrawn, angry or agitated, bedwetting, etc. Respond to your child's reactions in a supportive way, listen to their concerns and give them extra love and attention.

Children need to know they are loved at difficult times. Give them extra love and attention. Remember to listen, speak kindly and reassure them. Make opportunities to relax and play together. Crafting and baking sessions also work well with younger children.

Try and keep children close to parents and family, and avoid undue separation from primary caregivers. If separation occurs due to hospitalisation, for example, maintain regular contact via video chats or phone calls and offer lots of reassurance.

Keep to regular routines and schedules as much as possible, or help create new ones in a new environment, including school and learning as well as time for play and relaxing.

Provide facts about what has happened, explain what is going on now and give clear information about how they can protect themselves and prevent the spread of infection in language appropriate to their age.

The World Health Organisation has produced a book to help children and young people cope with the COVID-19 pandemic. Download free of charge;

https://www.who.int/news/item/09-04-2020-children-s-story-book-released-to-help-children-and-young-people-cope-with-covid-19

A light at the end of the tunnel

As 2020 drew to a close, the world's very first coronavirus vaccine achieved regulatory approval in the UK, and the biggest vaccination programme the country has ever seen was finally underway

Coronavirus Vaccine

At the time of writing, a coronavirus (COVID-19) vaccine developed by Pfizer/BioNTech has been approved for use in the UK and is in the process of being rolled out to the most vulnerable.

The vaccine has met strict standards of safety, quality and effectiveness set out by the independent Medicines and Healthcare products Regulatory Agency (MHRA). Other vaccines are being developed. They will only be available on the NHS once they have been thoroughly tested to make sure they are safe and effective.

Vaccine safety

Any coronavirus vaccine that is approved must go through all the clinical trials and safety checks all other licensed medicines go through. The UK has some of the highest safety standards in the world.

Vaccines will only be used if they are approved by the MHRA. The MHRA has been monitoring every stage of coronavirus vaccine development. So far, thousands of people have been given a coronavirus vaccine and no serious side effects or complications have been reported.

Who will get the vaccine

At first, the vaccine will be offered to people who are most at risk from coronavirus, before being offered more widely. You will be contacted when it's your turn, so it is important not to request a vaccination before then.

We expect the vaccine will **first** be offered to:

- people who live in care homes and care home workers
- people aged 80 and over
- health and social care workers in England

The final decision on who will get the vaccine first will follow advice from the Joint Committee on Vaccination and Immunisation (JCVI).

To read the full report by the JCVI, or for further information regarding the coronavirus vaccination programme, visit; https://www.gov.uk/coronavirus

Why you have to wait for your COVID-19 vaccine

People most at risk from the complications of COVID-19 are being offered the vaccine first.

In the UK, there are 2 types of COVID-19 vaccine to be used once they are approved. They both require 2 doses to provide the best protection. Both have been shown to be safe and effective in clinical trials.

An independent group of experts has recommended that the NHS first offers these vaccines to those at highest risk of catching the disease and of suffering serious complications or dying from COVID-19. This includes older adults in care homes and frontline health and social care workers. When more vaccine becomes available, the vaccines will be offered to other people at risk as soon as possible.

Eligible groups

You should have the vaccine when it is offered if you are:

- living in a care home for older adults
- a frontline health care worker
- a frontline social care worker
- a carer working in a care home for older residents

Then the vaccine will also be offered in age order to:

- those aged over 80 years
- those aged over 75 years
- those aged over 70 years
- adults on the NHS shielded patient list
- those aged over 65 years
- adults under 65 years with long term conditions (see list of conditions on next page)

Those aged 50 to 64 will be offered it later. Please do not contact your surgery asking for an earlier appointment.

Clinical conditions list:

- a blood cancer (such as leukaemia, lymphoma or myeloma)
- diabetes
- dementia
- a heart problem
- a chest complaint or breathing difficulties, including bronchitis, emphysema or severe asthma
- a kidney disease
- a liver disease
- lowered immunity due to disease or treatment (such as HIV infection, steroid medication, chemotherapy or radiotherapy)
- rheumatoid arthritis, lupus or psoriasis
- liver disease
- have had an organ transplant
- had a stroke or a transient ischaemic attack (TIA)
- a neurological or muscle wasting condition
- a severe or profound learning disability
- a problem with your spleen, example sickle cell disease, or you have had your spleen removed
- are seriously overweight (BMI of 40 and above)
- are severely mentally ill

At the same time as the adults under 65 years with long term conditions the vaccine will also be offered to:

- adults who provide regular care for an elderly or disabled person
- younger adults in long stay nursing and residential settings

Please wait your turn. If you are not in the groups listed, you will have to wait for a COVID-19 vaccination until more supplies are available. When more vaccine becomes available, it will be offered to more groups of the population.

200 years of progress and scepticism

COVID-19 has been a shot in the arm for vaccine research with several viable jabs in production less than a year after the disease emerged. Yet 4 in 10 Americans, and 6 in 10 French people say they will not get vaccinated against the virus, even if it is free. We look at the history of vaccines over the last two centuries, with scepticism never far away.

1796: Eureka!

Deadly and highly contagious smallpox, transmitted through open sores that scarred millions for life, ravaged populations for centuries until English doctor Edward Jenner notices that milkmaids who got cowpox never get smallpox. In 1796 he inoculates a child with the harmless version of the disease to stimulate an immune response. Despite repeated exposure, the child never falls ill. Vaccination is born.

1853: Poxy policy

The smallpox vaccine becomes mandatory for all British children in 1853, but this provokes an immediate backlash. Many object for religious reasons or see the policy as infringing of individual liberties. A conscience clause is added to the law in 1898 to allow people to opt out.

1885: Pasteur and rabies

French scientist Louis Pasteur develops a rabies vaccine from a more benign strain of the disease. Vaccine sceptics however accuse Pasteur of trying to develop "laboratory rabies" to increase his profits.

1920s: TB, diphtheria, tetanus

A vaccine against typhoid is developed at the end of the 19th century, followed by several crucial shots in the 1920s: the 1921 Bacille Calmette-Guerin (BCG) vaccine against tuberculosis and shots against diphtheria in 1923, tetanus in 1926 and whooping cough in 1926.

1944: Flu vaccine

The first vaccine campaign against the seasonal flu targets US soldiers fighting in Europe in 1944-45, with a new jab developed each year. In the 1970s a campaign to inoculate Americans against a supposedly devastating strain of swine flu grounds to a halt, however, when the pandemic fails to materialise and some of those vaccinated develop Guillain-Barré syndrome [subsequently found to be caused by a single faulty batch].

1980: Smallpox wiped out

The last natural case of smallpox is diagnosed in Somalia on October 26, 1977 and the World Health Organization (WHO) declares the illness officially eradicated in 1989 thanks to a global vaccination campaign. A similar campaign to eradicate polio has been hugely successful, wiping it out in Africa.

1998: Fake study, real damage

In 1998 a study published in the prestigious Lancet medical journal suggests a link between the MMR (measles, mumps and rubella) vaccine and autism. The main plank of it, however, had been falsified by its author Andrew Wakefield who was later barred from the profession. Yet the debunked study is still cited by "anti-vaxers".

https://medicalxpress.com/news/2020-12

Staying connected

People are social animals, and since the pandemic hit, we have appreciated more than ever how much we need one another.

Millions are turning to technology, many for the first time, as a means to reach out and keep in touch.

Have you given it a go yet?

The video chats we introduced during lockdown #1 have now changed from weekly to monthly, and as of January 2021 are held on the second Tuesday of the month at 2pm.

In lieu of our local branches meeting face to face, the GAIN Lancashire and Cumbria branch, as well as a group covering the Midlands are now holding virtual branch meetings, which of course, anyone is welcome to attend.

Lancashire and Cumbria usually 'meet' on the first Friday of the month (second Friday in January 2021), and the Midlands have a group chat on the third Thursday of the month. Please contact the office or check the website for details if you would like to join in.

If you are a local branch member who misses your get-togethers and would like to set up something similar, or if you would be interested in setting up a new group for people in your area, or for those with a particular variant for instance, please get in touch.

If there is sufficient interest, we may also consider holding occasional video chats based around a particular topic, If so, details will be published in the newsletter and on the website.

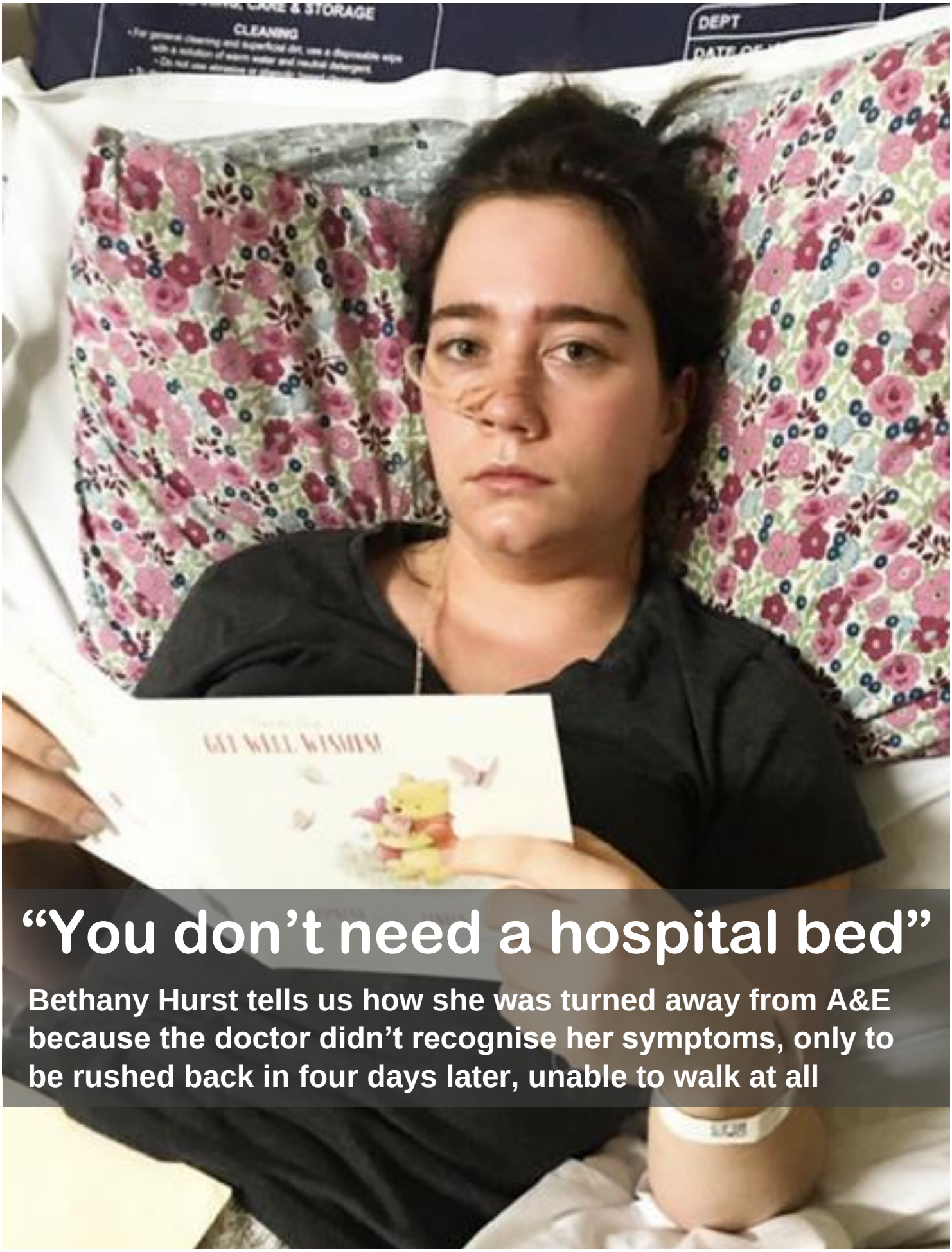
What's the point of a video chat?

This year has taught many people what it means to feel isolated, and we know that for some of our members, this was the norm even before the pandemic, due to disability, illness or age.

Getting together with others, even via a video link, allows you to share mutual support, and can help ease the feeling of being alone.

Some benefits of talking

- Talking to other people who understand what you are going through can be very liberating
- Group members can share useful tips and advice with one another
- Hearing about what other people are going through can provide a different perspective
- You can say things you might not want to share with family in case it upsets them
- Talking out loud about your worries and fears can reduce feelings of anxiety and make problems seem less unsurmountable



“You don’t need a hospital bed”

Bethany Hurst tells us how she was turned away from A&E because the doctor didn’t recognise her symptoms, only to be rushed back in four days later, unable to walk at all

Monday 30th December 2019
I woke up with a pins and needles sensation in both my feet, and a pain in the back of my neck. I had been at work the previous day and believed I had just lifted something wrong, which I thought had resulted in a trapped nerve. I didn't think it was anything serious, so I carried on as normal, and assumed in a couple of days it would go away.

Thursday 2nd January 2020
I woke in the morning and began to feel the same sensation in my hands, however rather than not being able to feel anything, everything I touched felt cold. I had developed a weakness in the left side of my body, which was affecting my balance and my ability to walk.

Friday 3rd January 2020
I decided to visit A&E because I began to become worried, rather than getting better, my symptoms were becoming increasingly worse. After a 3 hour wait, I explained my symptoms to the doctor, who then told me that I wasn't an emergency case. She told me she didn't recognise any of my symptoms. She proceeded to tell me "I don't know what you expect me to do, A&E is for emergency cases, and you don't look like you need a hospital bed. I suggest you see your GP on Monday". She concluded I was probably just experiencing extreme stress, and I was advised to go home.

Saturday 4th January 2020
Over the weekend I tried to sleep it off. I became increasingly weak.

Sunday 5th January 2020
I became extremely weak, to the point I was now unable to support myself to be able to climb the stairs. I decided I definitely needed to go to the GP, because I was scared there was something seriously wrong.

Monday 6th January 2020
One full week after experiencing the first symptoms, I was now unable to even stand without support. I had tried to get up off the sofa which had resulted in me falling on the floor, and I was unable to even push myself up. I intended going to the GP, but I was far too weak and unsteady to make it out of the house. The left side of my face had also started to feel stiff.

Tuesday 7th January 2020
Both sides of my body had become weak. Overnight, the left side of my face had also become paralysed, with my speech becoming slurred. I felt something was seriously wrong. Discouraged to go back to A&E I found the strength to visit my GP who told me needed to seek emergency medical care, hence another trip back to A&E.

I was seen immediately. Fearing I had had a mild stroke, I was given a CT scan, which showed no sign of this. Doctors were confused, and were unable to find a cause for my sudden muscle weakness. I was admitted to Rotherham Hospital that evening for further observation. By that evening, my whole face was paralysed, and I was struggling to swallow and talk properly. I now was also unable to walk at all.

Wednesday 8th January 2020
Doctors speculated I had GBS. Guillain-Barré syndrome is a rare autoimmune condition affecting the peripheral nervous system, usually leading to temporary or long-term paralysis. Around 80% of those with GBS will make a good recovery, but between 5-10% of people will not survive and the other 10-15% may be left with severe mobility or dexterity issues.

I started 5 days IVIG treatment, this is a treatment made from donated blood that contains healthy antibodies. These are given to help stop the harmful antibodies damaging my nerves.

Thursday 9th January 2020
I had an MRI scan which mainly focused on my brain and spine. The results of this confirmed that I did in fact have GBS.

Friday 10th January 2020
My breathing was now being monitored as GBS does cause problems with a patients respiratory system. I was fitted with an NG feeding tube after losing the ability to swallow, this enabled me to be fed for the next few days. I was also moved to the Hallamshire hospital in Sheffield, as I needed specialist care and there wasn't currently a neurology department at Rotherham.

Tuesday 14th January 2020
I was given an electromyography (EMG) this measures muscle response or electrical activity in response to a nerve's stimulation of the muscle. The test is used to help detect neuromuscular abnormalities. During the test, one or more small needles (also called electrodes) are inserted through the skin into the nerves.

This confirmed there was damage to my nerves, caused by GBS.

Wednesday 15th January 2020
My NG feeding tube was taken out, and I was allowed to eat a diet of puréed food.

Thursday 16th January 2020
I was now allowed to eat solid food, and started physio to be able to walk again, I struggled to get out of bed, and my energy levels were extremely low, but I was making progress. *(continued overleaf)*

Friday 17th January 2020
I was now able to walk with support of others for 5 minutes. Also, with the support of a Zimmer frame.

Monday 20th January 2020
I was moved back to Rotherham Hospital for ongoing physio, I was deemed medically fit, and my only hindrance was my mobility and my speech and paralysed face muscles.

Friday 24th January 2020
After 18 days in hospital I was back to eating solid food, and had started to regain my speech. My face was still paralysed, and my mobility was extremely limited though, I could walk (very slowly) with the support of crutches (I will need ongoing physio in order to recover fully). My energy levels were quite low, and I found myself getting fatigued extremely easily.

Thursday 5th March 2020
Just under 2 months after I was admitted to hospital, my recovery is still on going, but I feel extremely lucky that I will in fact still get better. I've regained my speech, and full control of the muscles in my face. I still have a pins and needles sensation in my feet and hands, but I can walk, I can sort of run, and I'm ready to get back to my day to day life.

Wednesday 11th March
I officially started back at university, and things are also underway for me to be able to start back at work. I have been discharged from the hospital. However, I do still have the pins and needles sensation in my hands and feet, that hasn't disappeared yet. Doctors seem to think that this might take up to a year to disappear.

2020 Asda Foundation 10k
(postponed to Sept 2021 due to COVID)

I am running the 10k for the charity GAIN, which helps people understand and manage both acute and chronic variants of the syndrome, raises awareness, and promotes clinical and non-clinical research into these conditions. Raising awareness will help doctors like the first one I visited in A&E to understand the early signs, and prevent other people from also being turned away from receiving medical assistance. I was lucky enough to get better, but not everyone does, and I want to help make a difference to that.

Bethany has smashed her target of £200, raising almost £700 including Gift Aid!

Linda Barnard tells us of her determination to beat GBS and get back to being a mum

To Hell and Back

A bit about me – in early 2019, I was about to reach my 51st birthday. As a single working mum of three, I had a busy life, two jobs, six cats, large garden, and I also loved to go out socialising.

I was active, and in good general health. In March 2019, my worst nightmare came true. As every single parent will tell you, our most dreaded situation would be to become too ill to look after our children. That exact thing happened to me.

I was having a stressful time, my bathroom was being re-fitted, and not really going to plan. I'd had a headache for two weeks. On Monday 11th March, I developed sudden numbness in my hands. I couldn't feel the temperature of the bath water that I was running for my 9-year-old son. I just thought it would wear off. Unfortunately, it didn't. The next morning, my hands, feet and tongue were tingling. I went to work (my main job is pharmacy assistant, within a GP surgery).

Although I went to work, I didn't feel 'right'. I asked for my blood pressure to be checked. It was slightly raised, and my pulse was fast. I was told that it indicated I may be coming out with a virus of some sort.

The next morning, (Wednesday 13th March, my birthday) as soon as I got up, I knew the numbness and tingling had spread. It went up my arms, and into my legs.

I nearly passed out, I managed to call my 16-year-old daughter, Amber. She called the NHS 111 helpline.

After ruling out a possible stroke, they asked me to go to A&E as soon as possible. I got a lift there, I couldn't drive. They ran some tests, including bloods. My protein levels were raised, which they wanted me to have checked in two weeks' time. Apart from that, they concluded that I was suffering from stress and anxiety. This was new to me; I had never had any kind of anxiety. Part of me didn't feel that it was a correct diagnosis. I felt so 'wrong' in myself. I didn't have much of a birthday treat!

The following day, I was worse. I couldn't eat, I felt so ill, I still had the numbness, in fact it was hard to walk. I went to see my GP, a friend drove me there, and my son Freddy had to support me walking into the surgery. My vision was blurring at times. My GP checked my reflexes – at this time they still worked. Again, I was diagnosed with stress/anxiety. I remarked that I wasn't walking too well, and promptly bumped into the wall as I left the GP's room, while she watched me. I was physically sick on the way home.

Friday 15th March. I felt awful. I nearly fainted again, and I could hardly stand up. I tried to get the duty doctor to visit me, I was told no, my only option was to get to the surgery. I promptly collapsed whilst trying to climb the stairs to go to my bathroom, I needed the toilet. After being helped upstairs, I went to the toilet, but couldn't feel myself 'going'. We called 111 again. They called an ambulance, and it came within a few minutes.

I was rushed to West Suffolk Hospital, Bury St Edmunds. I cannot remember anything of being in A&E, or AAU. Thankfully, I have now found out that an 'on the ball' A&E doctor was pretty sure I had Guillain-Barré syndrome. I was started on the IVIG treatment straight away, before having CT and MRI scans, then actual diagnosis by lumbar puncture was confirmed.

I was moved to the respiratory ward, where the Intensive Care team introduced themselves to me. They were monitoring my breathing carefully. They warned me that GBS may affect my breathing ability, as my muscle weakness progressed. They were right, on Tuesday 19th March I was admitted to ICU, and put onto a ventilator, as I could no longer breathe by myself. I was 'plugged' into various machines, tube fed, and monitored very closely for 10 days.

By now, I was totally paralysed. I couldn't even shut my eyes properly, I had double vision. I couldn't move anything from my face to my toes. I learnt to use the alphabet communication board, with someone holding the board, and my hand so I could vaguely point to each letter as I spelt out words. That in itself, was an exhausting task.

It was then time for me to try breathing unaided, so the ventilator was removed. Unfortunately, during this process, it got stuck in my throat, that was very scary. Yet again, I was unable to breathe. It was so traumatic, I don't like thinking about it.

After managing to remove it, and stabilizing me, I was moved down to a ward. After 3 days, I was back in ICU, back on a ventilator. I was taken off it too soon, I had asphyxiated, and developed double pneumonia. I was also now carrying the MRSA virus. It was touch and go for a while, I faced death yet again. I was given another 5-day course of the IVIG.

During my ICU stay, my daughters visited almost daily. My eldest daughter Kyra was studying at Lincoln Uni at the time of my diagnosis, and had to sit exams before she could rush back to Suffolk to see me. She didn't recognize me at first, when she was brought over to me, she broke down sobbing. I'll never forget that heart breaking sight.

Eventually, I improved, my pneumonia eased, and the ventilator was removed successfully. The MRSA cleared, and at last my son Freddy was able to visit me. This was a very emotional first visit, three weeks after my admission to hospital.

He helped me to keep cool by putting wet tissues on my face, as my daughters had been doing too. I could only move my hands and head very slightly. I managed to croak a few words out now and again. I continued to use the alphabet communication board.

I was moved down to the Respiratory ward. I remember feeling really scared, I felt I might end up not being able to breathe by myself yet again. I had weekday visits from the physios, mainly to help me to cough productively, and sometimes to help me to move my limbs. I was still being fed with the nasal tube.

The S.A.L.T. team (Speech and Language Therapy) visited weekdays too, to help me to get my muscles moving so that I could try to talk, swallow, drink. This was an incredibly slow process. I hated the nasal tube, it fell out a few times, and eventually I refused to have it. The gagging and choking I went through each time it was re-inserted just got too much for me to cope with.

I was given vital nutrition briefly via a pick line, then I had a PEG fitted via my stomach. I needed a good amount of calories to build myself up again, I had lost over two stone in weight and I had only been nine stone before I became ill!

One day, I was turned too roughly, a muscle tore, and blood was pouring out by my PEG tube for a few hours.

I had approximately thirty minutes of physio most weekdays. I was given exercises that my children would help me with at the weekends. The physio team were great, but resources were so stretched. I knew by now, that my only chance of muscle recovery was if I had more physio. When I was told that funding to send me to Rehab had been applied for from the CCG, I was over the moon! My children were too; they needed their mum back so much.

I was often tearful, and missed my children terribly. I was stuck in the bed, for hours, days, weeks. I felt like a caged animal; I love the outdoors, and fresh air.

I was occasionally hoisted out, into a special physio chair, then into a wheelchair when I was stronger. For the first two months this was incredibly painful, but at least I could be wheeled outside by my children and friends. We could go to the adjacent park, and I had my first experiences of the big outside world again!

My daughters washed my hair for me while I was in hospital, in the bed. We did have a good giggle about how soaked we all got!

Finally, I had a visit from Karen and Pippa from Sue Ryder, The Chantry, Ipswich. They assessed me for going there for intensive rehab. I was so excited, that this may really be happening! After another couple of weeks I was told I had been accepted, the funding was going through, and a bed should be free soon. I would ask the nursing staff at hospital every day, for a month if they had heard. One day, the physio told me she had received confirmation, I would be going there soon. I was so relieved!

At this stage I was just about managing, with the help of three staff, to sit and slide from the bed to a wheelchair on a' banana board', as it was called. I arrived at The Chantry on June 3rd 2019, eleven weeks after being admitted to hospital. During this time, Amber had sat her GCSEs at school, without any parental support at home.

As soon as I was taken into The Chantry, in the wheelchair, I was so happy. The building and location were beautiful. For the first time in eleven weeks, I really did feel alive!

I met the rehab staff, nurses, physios, and occupational health therapists, over the first days. My own room was gorgeous, I had furnishings, large windows, and better still – my own bathroom. I had only been given two showers in my eleven week stay at hospital, due to lack of staffing mainly. Very quickly I progressed from the banana board to the 'Sara Steady'. Things were definitely 'on the up'.

The staff were all fantastic – they soon realised that I was strong of mind, and determined. They would praise and encourage me at every opportunity. I had insisted I would only be at rehab for eight weeks, not the usual twelve. I needed to get home for the long school summer holidays.

The whole team at Sue Ryder, Chantry, were right behind me. The physios were 'on my page'. We would set goals for me to achieve. I worked both ways – they would suggest the next thing for me to try, and I would also say what I wanted to be able to do by the end of each week. I also managed to persuade them to let me use the rehab exercise bike an extra third session each evening. This helped me to gain strength, so much more.

I had a wish of being able to walk and lay on the grass outside. The physio and rehab staff saw to it that my wish came true. One day as I walked barefoot on the grass with assistance and a frame just in front of The Chantry, the staff inside caught sight of me, and all stood at the windows cheering me on! What a fantastic feeling that gave me!

I loved to spend my rest time in the private garden. I would always 'nag' the staff to keep the bird bath filled up and water the plants! We had a great relationship, they got me to help with holding the hose pipe, we had so much fun. I needed to heal mentally as well as physically, this kind of activity did that with ease.

My children and friends were able to visit whenever they could. They frequently wheeled me round the park. It was good for my children to be able to do this. They would bring snacks to eat in the park, it was lovely.

I had sessions with the occupational health staff in the kitchen, I progressed from making a drink, to cooking a meal.

I had chats with the psychotherapist, she was very supportive.

I really wanted to see Amber go to her school prom. Thanks to the occupational health staff, rehab staff, and the physios, this was made possible. I was driven to my home; we took the necessary equipment I would need. (commode, pivot stand, wheelchair ramps). It was fantastic to get home and watch Amber. She looked breathtakingly beautiful. Then I was treated to a pizza tea, by Kyra, my eldest daughter. Kyra helped me with everything, including pushing me a long way in the wheelchair over the rough ground to get to see Amber go into her prom venue.

It was obvious that my children were happier to see me at The Chantry. They were always amazed at my progress; I would delight in showing off to them! One day, my son was due to visit, so the rehab staff kept him waiting for me at the end of the long hallway. I made my way, walking slowly with a frame, and staff beside me. It was an emotional few minute - the rehab staff shed tears too!

I visited my home a couple of times, with rehab staff and occupational health, to assess the equipment I would need, and ensure that it was ready for my final homecoming.

My ultimate goal was to walk out of rehab on my own two feet, using only a stick to help. I had arrived in a wheelchair, and I wasn't even able to stand.

Thanks to the Sue Ryder team, I achieved that goal. I walked out with a stick, on July 29th 2019, and went home.

So, that is my GBS story. It has been a hard, emotional and physical journey. In fact, it feels like I've been 'to hell and back', so that's what I'm calling it.

''My ultimate goal was to walk out of rehab on my own two feet. I had arrived in a wheelchair, and I wasn't even able to stand.''

COVID vaccine

What you need to know about vaccine safety

In any conversation about vaccine safety, there is one statistic worth holding on to: one in 1,000.

One in 1,000 of the entire UK population has already died after being infected with coronavirus during the pandemic. This is the known threat from the disease that any risks have to be balanced against.

In medicine there is an important difference between "safe" and "harmless" and between "risk" and something being "risky". And two people who were given the Pfizer vaccine had allergic reactions. So, what do we mean when we talk about Covid vaccines being "safe" to use?

"If you mean absolutely no adverse effect, then no vaccine is 'safe' and no drug is 'safe'. Every effective medicine has unwanted effects" says Prof Stephen Evans, from the London School of Hygiene & Tropical Medicine.

"What I mean by safe is the balance of unwanted effects compared with the benefit is very clearly in favour of the benefit."

The UK's medicines regulator, the MHRA, has decided the Pfizer/BioNTech vaccine has met that standard.

The bar is set really high for vaccines

There are some drugs that have truly brutal consequences on the body, but are still approved because they are considered worth the risk.

Chemotherapy drugs have a huge list of damaging effects include exhaustion, hair loss, anaemia, infertility, memory and sleep problems. Yet when those are pitted against dying from terminal cancer, nobody questions the drugs being used.

Others can have severe side-effects which are incredibly rare. The painkiller ibuprofen, which nearly all of us have at home and would take without thinking, can cause bleeding and holes to form in your stomach and intestines, difficulty breathing and kidney damage.

The risks are there, but they are far outweighed by the benefits. "Safe is not an absolute thing, it is safe in the context of the usage," Prof Evans told the BBC.

The key difference with vaccines is they are given to healthy people and that massively shifts the balance. Any risk has to be incredibly small.

A 10,000-page decision

Regulators make the assessment based on far more data than has been made publicly available, much of which has been in the form of press releases. There will be nowhere to hide - if there are safety concerns then the regulators will see them.

Companies have to hand over data from laboratory studies, animal studies, the phase one safety trials, the phase two dosing trials and the large phase three "does it work?" trials. "It will amount to at least 10,000 pages of information," said Prof Evans.

The Pfizer vaccine cuts cases of Covid by about 95%, but it does have very common side-effects including pain from the injection, headache, chills and muscle pain. These could affect more than one in 10 people. These are all symptoms of the immune system kicking into gear and can be managed with paracetamol. "The MHRA are very experienced, we can be reassured if the regulator says the benefits clearly outweigh the risks, that should be the end of it really," says Dr Penny Ward, from King's College London and the Faculty of Pharmaceutical Medicine.

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Rarer problems

It is always possible that vaccines have health consequences that have not yet become clear. There is data on about 20,000 people who were immunised in the Pfizer trial, 15,000 for the Moderna vaccine and 10,000 for the one developed by Oxford/AstraZeneca. That is enough to show the vaccines works and to detect common problems. But they may not pick up something that affects one-in-50,000 people who are immunised.

"You can't always spot them before you license without a trial of millions of people if the side-effect is vanishingly rare," says Dr Ward.

But this is true for every vaccine that gets approved. It is not a unique or new issue with the Covid jabs.

The seasonal flu jab has been linked to about a one-in-a-million chance of the nerve disorder Guillain-Barré syndrome, although even more cases are caused by the flu virus itself. And about one in 900,000 people have severe allergic reactions, known as anaphylaxis, to a vaccine.

"Not many of us think twice about driving somewhere, but the risk of a car accident is a lot higher than serious effects of a vaccine," says Dr Ward.

"There will be cases where somebody has a jab one day and then, shortly after, has a serious health problem that would have happened whether they were jabbed or not."

Don't fall for fake news

Fake news and conspiracy theories about vaccines are already spreading on social media

The danger is people falsely assume health problems that happen by coincidence are caused by the vaccine.

It is easy to predict there will be scare stories in the coming months - whether in the press or on social media, have origins that are misguided or plain malicious.

But the truth is that people get sick all the time. Every five minutes in the UK one person has a heart attack and one person has a stroke. More than 600,000 people die each year.

There will be cases where somebody has a jab one day and then, shortly after, has a serious health problem that would have happened whether they were jabbed or not.

"We could see things that happen by unhappy chance," cautions Dr Ward.

There is a real threat of repeating mistakes made when the MMR (measles, mumps and rubella) jab became falsely linked to autism and led to a drop in children being immunised.

It is why you will need to keep your wits about you as the vaccination programme kicks into gear.

And it is why safety is monitored long after a vaccine is approved to see if there are any unknown health problems. The MHRA has a Yellow Card scheme for reporting concerns and monitors anonymised data from GP surgeries for any warning signs.

https://www.bbc.co.uk/news/health-55216047

Getting back behind the wheel

A blog by Dr Nick Jenkins, Senior DVLA Doctor on the role of the Health Care Professional in assessing a person's ability to drive with a medical condition.

Around 48 million people hold a GB driving licence and individuals depend greatly upon their ability to drive for their employment, their day to day lives and socially.

There can, however, be confusion amongst clinicians as to the respective roles and responsibilities of Healthcare Professionals (HCPs) and of the Driver and Vehicle Licensing Agency (DVLA) when considering whether a patient's medical conditions may have an impact on road safety.

The Road Traffic Act (1988) places the legal responsibility on the licence holder or driving licence applicant to disclose to the Secretary of State (in practice the DVLA) any medical condition that may affect driving safety. To help drivers meet this obligation we have developed an easy to navigate, online A-Z guide of medical conditions that can be found at: www.gov.uk/health-conditions-and-driving

The DVLA is an executive agency of the Department for Transport and is responsible for licensing those who have notifiable medical conditions. The DVLA, where I am the Senior Doctor, is specifically responsible for assessing whether an individual's medical condition meets the appropriate standards for driving. In doing so we contribute to the safety of all road users.

The ongoing management of a person's medical condition involves a partnership between the individual and their clinician. Consideration of the impact of an individual's medical condition upon their ability to drive safely, and thus safeguarding both them and the wider general public, requires collaboration between the individual, their clinician and ourselves.

The DVLA received around 750,000 notifications of medical conditions in 2018. Of those, 170,000 represented the first notification of a condition to us, whilst the remainder represented the renewals of short-term licences issued for an already-declared medical condition. Approximately 4% of licence holders have told us about a medical condition, however, we do acknowledge that some people do fail to disclose their medical condition to us. The reasons for this are likely to be multi-factorial, but fear of losing their licence as a consequence of the disclosure may be a significant factor. For others, it may simply be that they do not understand the potential of their medical condition to impact on their ability to drive safely.

Health professionals can be in a unique position in knowing whether their patient has a condition that may affect driving. They play an important part in the medical notification process by advising their patients of the implications of their condition, the effect of any treatment or medication that they are receiving, and whether they need to tell the DVLA.

Clinicians may also reassure their patients that the vast majority of individuals will retain their driving licence following disclosure, either as a full-term licence or a short-term (medical review) licence.

We may issue licences of shorter duration (between one and five years) to people whose medical condition is considered to be either progressive (e.g. dementia), where we need to assess the ongoing stability of that condition or to consider the risk of recurrence of an episode being below a certain threshold. For others, adaptations to the vehicle that they drive may extend the time that they can continue to drive safely. Ideally the patient and their clinician will have discussed other means of transport/maintaining independence long before the time when a condition has progressed to a stage which is incompatible with safe driving.

Information to guide a clinician as to their patient's ability to meet the required medical standard of fitness to drive is available in the "Assessing Fitness to Drive – a guide for medical professionals" document, which is available online at: www.gov.uk/guidance/assessing-fitness-to-drive-a-guide-for-medical-professionals

As an agency we receive advice regarding the appropriate medical standards from the Secretary of State for Transport's Honorary Medical Advisory Panels which meet twice a year, and the published guidance is regularly updated as a result of that advice. Clinicians are able to sign up for email alerts to such updates.

We work in partnership with patient groups and organisations in order to increase the public's awareness of the medical standards. We also work closely with professional and regulatory bodies (e.g. General Medical Council (GMC), General Optical Council (GOC), Medical Royal Colleges) to help maintain awareness of the standards amongst the diverse group of health care professionals (HCPs) caring for patients with conditions which might impact upon driving.

There have been high profile cases where there has been a loss of life or life changing injury as a result of a medical episode and the driver had failed to notify the agency or withheld their medical history from the other health professionals involved. Fatal accident enquiries, inquests or the media often focus upon the involvement and responsibilities of HCPs and their sharing of information with the DVLA. Following one such case the GMC consulted on the issues of confidentiality and disclosure - reviewing its guidance on dealing with medical conditions, driver safety and liaising with the DVLA.

Its revised guidance *Confidentiality: good practice in handling patient information* and the accompanying explanatory guidance *Confidentiality: patients' fitness to drive and reporting concerns to the DVLA or DVA* both came into effect in April 2017. These documents clearly describe the roles and responsibilities of doctors with regard to road safety. The guidance resulted in an increase in notifications from doctors and also from other HCPs to the DVLA. Similar guidelines have also been issued by the College of Optometrists.

There have been high profile cases of loss of life or life changing injury as a result of a medical episode and the driver had withheld their medical history

The Agency has also more recently worked with the GOC to develop similar guidance and their consultation regarding that guidance was launched in March 2019. In the absence of similar guidance from other regulatory bodies many HCPs are choosing to refer to GMC guidance when deciding whether or not to disclose information to the DVLA.

The GB medical standards for driver licensing refer to Group 1 (cars and motorcycles) and Group 2 (lorries and buses). In most cases, the medical standards for Group 2 drivers are stricter than for Group 1 drivers, for example, the vision requirements. There are also stricter standards for those conditions where there may be an underlying risk of a sudden disabling episode. This reflects the size and weight of the vehicles involved and also the length of time an occupational driver typically spends at the wheel.

We appreciate that some employment-related driving involves vehicles categorised as Group 1. Some employers may choose to apply a higher medical standard for their drivers than required for the category of vehicle that they drive. For example, for drivers of emergency vehicles. Drivers of taxis or private hire vehicles are also generally subject to higher medical standards and the responsibility for any additional requirements rests with the relevant local authority or Transport for London. The Group 2 standards provide a good basis for any employer wanting to apply stricter standards for their drivers in the interests of road safety.

In writing this article I hope that I have clarified the various responsibilities of HCPs and of the DVLA in ensuring the safety of drivers and all road users. I hope that any HCP who has a concern regarding their patient's driving will be encouraged to contact one of the doctors here at DVLA to discuss those concerns confidentially, using either the secure email (medadviser@dvla.gov.uk) or on our "doctor-to-doctor" telephone line (01792-782337 - line is open 10.30am – 1pm Monday-Friday). Our priority is to ensure that your patient is safe to drive - we would like to assist you in ensuring that your patient is able to continue in their driving career for as long as they are safe to do so.

This blog was first published by the Society of Occupational Medicine and has been reproduced with permission.

Blue Badge Parking

For drivers or passengers with severe mobility problems, the Blue Badge scheme offers a range of parking benefits throughout the UK.

The scheme applies to on-road parking only, and allows you to park without charge at metered or 'pay and display' parking bays. It is also possible for Blue Badge holders to park on yellow lines for up to three hours (except where there are other stopping restrictions in force), and there is generally an exemption from the parking time limits imposed on other vehicles.

There are certain parking spaces reserved exclusively for Blue Badge holders, and it is an offence to park a vehicle without a Blue Badge there.

Off-road parking facilities – for example, supermarket car parks – are not covered by the Blue Badge scheme, and although they will have designated disabled parking bays, there is no legal power to prevent non-disabled motorists from using them.

Do you qualify for a Blue Badge?

You may do if:

- you receive the higher rate of the Mobility Component of the Disability Living Allowance (DLA) or the enhanced Mobility Component of Personal Independence Payment (PIP)
- you are a registered blind person
- you receive a War Pensioner's Mobility Supplement
- you use a motor vehicle supplied by a government health department
- you are a regular driver with severe disability in both arms, making it impossible to turn a steering wheel by hand, even if it has a turning knob
- you have a permanent and substantial disability which makes it impossible or extremely difficult for you to walk

There are also conditions under which people with hidden disabilities can apply:

- you cannot undertake a journey without the risk of serious harm to your health or safety or that of any other person (such as young children with autism)
- you cannot undertake a journey without it causing very considerable psychological distress
- you have very considerable difficulty when walking (both the physical act and experience of walking)

Source: https://www.independentliving.co.uk/il-editorials/blue-badge-parking/#qualify

How to Apply for a Blue Badge

You can now apply online, via a link on the DirectGov website: **https://www.gov.uk/apply-blue-badge**. You will be asked some questions to establish whether you should be eligible, and when you have completed the application, it will be sent to your local authority for a decision. This is also a convenient way to apply for renewal of your existing Blue Badge permit.

If you feel happier using a paper application form, contact your local authority. Generally, but not always, it is Social Services which is responsible for Blue Badge applications. It might be Highways or Customer & Exchequer Services, but whichever is the relevant department at your Council, just ask for an application pack, and they will post one out to you.

The Baywatch Campaign, which has the support of the RAC, Department of Transport, and the four big supermarket chains, monitors the situation, and campaigns to change attitudes. Their latest annual survey found around one in five disabled parking spaces being used by a non-disabled motorist: there is still clearly some way to go in changing attitudes.

Your Blue Badge can also be used when travelling around some European countries.

If you travel to London, the Blue Badge will exempt you from the Congestion Charge – but you need to apply to Transport for London (TfL), before travelling.

Telephone: 0845 900 1234
Minicom users: 020 7649 9123

Medical conditions, disabilities and driving

Please visit the GOV.UK website for further information
www.gov.uk/guillain-barre-syndrome-and-driving

Guillain-Barré syndrome and driving

You must tell DVLA if you have, or are recovering from, **Guillain-Barré syndrome**

This also applies to **CIDP** and **all associated inflammatory neuropathies**

You can be fined up to £1,000 if you don't tell DVLA about a medical condition that affects your driving. If you're involved in an accident, you may be prosecuted

Car, motorcycle, bus, coach, or lorry licence. Tell the DVLA.

You must tell DVLA if you have a driving licence and;

- you develop a 'notifiable' medical condition or disability
- a condition or disability has got worse since you got your licence

'Notifiable conditions' are anything that could affect your ability to drive safely. They can include;

- epilepsy
- strokes
- other neurological conditions
- mental health conditions
- physical disabilities
- visual impairments

Car or motorcycle licence

Fill in form CN1 and send it to DVLA. The address is on the form.

Bus, coach or lorry licence

Fill in form CN1V and send it to DVLA. The address is on the form.

Contact DVLA if you're not sure what to do

You could be fined up to £1,000 if you don't tell DVLA about a condition that might affect your ability to drive safely. You could also be prosecuted if you have an accident.

How to tell DVLA

By phone
DVLA Drivers' Medical Enquiries
Telephone: 0300 790 6806
Monday to Friday, 8am to 7pm
Saturday, 8am to 2pm

By email
You can email DVLA to tell them about your driving and medical issues by typing this into your browser;
https://live.email-dvla.service.gov.uk/w2c/en_gb/decisions/drivers%20medical

By post
Drivers' Medical Enquiries
DVLA
Swansea
SA99 1TU

If you're in **Northern Ireland** you must contact the Driver and Vehicle Agency (DVA)
www.nidirect.gov.uk/articles/how-tell-dva-about-medical-condition

If you're in the **Republic of Ireland** contact the National Driver License Service (NDLS)
www.rsa.ie/RSA/Licensed-Drivers/Safe-driving/Medical-Issues/

Keeping the Hope Alive

My name is Karen Pennington - I'm 60 years young. I am a partner, mother, grandmother, sister, aunt, great aunt, cousin, friend and occasionally a pain in the bum!

And oh yes, I'm recovering from having had Guillain-Barré syndrome.

Once upon a time not so long ago I lived in a world where my body had free movement until the great, the bad and complete utter basket named GB came into my world and took it all away - I was frozen in time. But the big bad GB had made a big, big mistake - he left me with free will and the battle commenced.

Apologies for the fairy story analogy but for me it all happened so quickly that there was a sense of unreality to it all. I finished work on the Friday not feeling too sparkly, in fact my last conversation with my friend Carolyn was she would bring me some tonic in! During the weekend I had terrible pains in my hands and feet and in the early hours of Tuesday 14.02.17 I was taken into hospital and have not been back home since. Happy Valentine's.

I was saved by the wonderful nurses, doctors, physios and staff on ICU at Royal Preston Hospital. My whole body was frozen from the top of my head to the bottom of my feet. I couldn't talk, breathe or open my eyes, I was totally locked in and ventilated. I was found to be able to communicate when my eyelids were lifted, and I moved my eyeballs up and down for yes and side to side for no.

The staff were brilliant and communicated with me all the time, they took what could have been a terrifying experience and made me feel very safe, and I would give them ten out of ten for entertainment value. I loved them so much I stayed for six months!

I was so lucky to have been introduced to Rachael Moses (physio consultant) at the hospital by Danielle and Sarah two physios on ICU. Rachael fought very hard for me to come off the ventilator and did so with great success. Rachael did make me promise not to die - being such a people pleaser, I didn't!

continued overleaf

My life now is nothing like how I imagined it, but I can honestly say I have a wonderful life

When I was in ICU my very proactive sisters and niece had very early on found and contacted the Guillain-Barré charity, GAIN, and when my eyelids were opened to see the paperwork all I could think was what are all these tortoises! I wonder no more. The symbol couldn't be more appropriate for such a slow recovery.

I am recovering really well, just very slowly, I have had to make time irrelevant. From being totally locked in I can breathe independently, I can eat and drink, I can feed myself and the best thing ever, I can talk. I now have some movement in all my limbs and currently with the physios, I'm learning to walk.

My life now is nothing like how I imagined it, but through the incredible people in my life and the amazing people I have met I can honestly say I have a wonderful life. I have seen our boys meet and marry and bring into our lives much loved daughters-in-law, I have seen our beautiful grandchildren growing up, new grandchildren born, and great-nephews. I have shared my family and friends' highs and lows. I am still the person I was before; I just have wheels!

I would like to say a fantastical huge thank you to everyone for all their unconditional support and to all the family, friends and colleagues who have worked hard to raise money for GAIN.

By the way, my very happy ending to this particular adventure is, I shall be returning to my own home in the New Year. Yippeeee!

Left: Karen surrounded by loved ones at a family wedding. Above: some of the many people in Karen's life who helped her keep the hope alive

HMP Wymott's year of

~~Living Dangerously~~

Giving Generously

Inspired by Karen Pennington's determination to recover from Guillain-Barré syndrome, her colleagues at HMP Wymott decided to run a year-long fundraising campaign to help raise funds and awareness for the charity and conditions.

Wymott staff raising money for GAIN

Words from Governor Graham Beck

I am really delighted that we were able to come together to support the work of GAIN through our activities at Wymott this year. We had a local connection with the work as one of our colleagues has suffered with Guillain-Barre disease, and she had taught us about its effects and impact.

We were grateful to GAIN for coming to our staff meeting and explaining the impact of the condition with personal stories and helping us to understand the excellent work that GAIN deliver.

Over the course of the year, we were able to engage with all our people to raise money, including a memorable Christmas Fair for our staff, which was a lovely occasion. One member of staff rowed a million metres to raise awareness and gain the support of staff, which was an amazing effort!

Many of us may never have known about GAIN without this experience, and I know that we have benefitted from the time that GAIN's staff and volunteers have been able to dedicate to helping us learn more and supporting our beloved colleague through her recovery.

I hope that our efforts are able to contribute to the ongoing work of this fantastic charity and to continue to raise awareness of the condition, to learn more about its treatment and to provide support to sufferers.

Rowing challenge

John Ashton, an officer at HMP Wymott completed a challenge to row one million metres (600 miles) within the charity year. The challenge was verified via the Concept 2 web site and certificated. John started in March 2019 and completed the event in August 2019 well ahead of schedule and raised in excess of **£700** for the charity.

Easter lunch

During April 2019, the Education Staff organised a very special Easter lunch which was a sell-out event. The lunch was attended by our very own Karen who was the inspiration for the Prison to support this wonderful charity. An amazing three course lunch was prepared and enjoyed by all that attended.

Above; Karen sits down to enjoy an Easter lunch fundraiser organised by friends and colleagues

Sports Day

One of the other main events we held was a staff and prisoners' sports day. Prison Staff and partner agencies from all over the prison took part in the event with around 200 prisoners paying an entry fee to be involved or just making a donation for the charity. Karen and Ann attended for most of the day and took part in the lunch time quiz, they both really enjoyed it even though they were freezing when they left!

Mountain Walk

In June 2019 staff from the Programmes Department raised money for the charity through a sponsored walk up Snowden. Well done to everyone involved for completing this achievement. The team managed to raise just over **£2800** from this, which was amazing!

Christmas Fayre

The Programmes Team held a Christmas Fayre in December 2019 to continue the fundraising. The event was attended by prison staff and even Eddie the therapy dog helped out. This included a number of different stalls with items made within the establishment as well as donations from staff for gift stalls. There were a number of games stalls and an auction after many local business in the area kindly donated prizes to help us raise as much money as possible. This one event raised around **£2600**.

A massive THANK YOU! to all the staff and prisoners at HMP Wymott who helped organise and contribute to such a successful and inspirational Year of Giving Generously!

Remembering Candice, Ten Years On

Extract courtesy of the Warrington Guardian (published 19th August 2020)

'I thought love would save her' - family thank supporters on 10th anniversary of daughter's death

TEN years after losing their 'quirky and spirited' youngest daughter, a family is paying thanks to those who have supported them and helped raise more than £50,000 for charity.

Candice Marie Roberts, from Appleton, died on August 23, 2010 from Guillain-Barré syndrome (GBS). It was her 26th birthday. Candice's parents, Karen and Stephen Roberts, have spent the past decade fundraising for GAIN, a charity raising awareness about the very rare, but devastating syndrome.

For Candice's parents, fundraising has helped them feel close to their daughter. "We had lost everything that was, it's indescribable," Karen said. "She took us with her and all we can do is do things to feel close to her. She's with us all the time, it never stops and her being with us never stops."

Now, to celebrate Candice's 36th birthday, the family commissioned a special yellow rose called 'I Candi' from Dickinson Roses which has been gifted to bloom for the occasion.

Published 14 December 2020 in Brain, Journal of Neurology
Epidemiological and cohort study finds no association between COVID-19 and Guillain-Barré syndrome

Neuroscientists at University College London have found **no significant association** between COVID-19 and the potentially paralysing and sometimes fatal neurological condition Guillain-Barré syndrome.

Within the study, and the Special Commentary published alongside, Lunn et al write, “Within a population of 1 billion people, about 17,000 cases of GBS will occur sporadically per annum, of which 1962 would occur in any 6-week period. When considering a more optimistic 4-billion-person immunization programme conducted over 1 year, 68,000 cases of GBS would be expected to occur naturally within this time period, irrespective of any vaccination programme. Of these GBS cases, 13,076 would occur in the 10-week window following double-dose vaccination with injections separated by 4 weeks. It is therefore inevitable that many thousands of sporadic cases of GBS caused by other factors will appear temporally associated with COVID-19 vaccination. But, as any statistician can confirm, this cannot be considered causal."

“Responsible citizens understand the value and risk of any vaccine. The individual risk for GBS and other rare complications is likely to be very small indeed, and the benefit of protection against COVID-19 both for individuals and society is far greater. It should be implicit for regulators, pharmaceutical companies, mass media and the general public to understand that rare diseases will inevitably occur by chance during the vaccination window, and that the temporal association between vaccination and GBS onset even in large numbers of individuals within a huge population of billions is not adequate evidence of causation. In those conditions like GBS where minds are pre-programmed to leap to causative assumptions through cognitive bias, this is a particularly vital message to convey.”

Read the full study; https://academic.oup.com/brain/advance-article/doi/10.1093/brain/awaa433/6031905?searchresult=1
and the commentary; https://academic.oup.com/brain/advance-article/doi/10.1093/brain/awaa444/6031904?searchresult=1

Here at GAIN, we do our best to provide the information and support you need, even if that means signposting you elsewhere

These are a few suggestions for other organisations who may be able to help

www.carersuk.org

Helpline
0808 808 7777
10am–4pm Mon & Tue

Carers UK

www.carers.org

carerstrust
action · help · advice

money & benefits, support for young carers, health & wellbeing, working & learning, out & about, getting a break, legal & rights

OPEN 7 DAYS PER WEEK NHS

Carers Direct
Information, advice and support for carers

You can call the Carers Direct helpline on **0300 123 1053** if you need help with your caring role and want to talk to someone

Family Carers Ireland
Fairness for Carers

www.familycarers.ie

citizens advice

Benefits
Work
Money
Consumer
Family
Housing
Legal
Immigration
Health

www.citizensadvice.org.uk

Citizens Information Phone Service
Mon-Fri 9am-8pm
0761 07 4000

Citizens Information

www.citizensinformation.ie

contact *For families with disabled children*

WE ARE CONTACT, THE CHARITY FOR FAMILIES WITH DISABLED CHILDREN

We support families with the best possible guidance and information. We bring families together to support each other. And we help families to campaign, volunteer and fundraise to improve life for themselves and others.

www.contact.org.uk

FacialPalsy UK
INFORM • SUPPORT • RESEARCH

Inform
Support
Research

www.facialpalsy.org.uk

Disability Rights UK

Advice / Information / Jobs / Volunteering
Projects / Programmes / Training

www.disabilityrightsuk.org

Cruse Bereavement Care
Somewhere to turn when someone dies

Helpline 0808 808 1677

www.cruse.org.uk

THE BRITISH PAIN SOCIETY
EXPERTISE WHERE IT MATTERS

Links and information for people with pain

www.britishpainsociety.org/people-with-pain/

Chronic Pain Ireland

Information & support for people living with chronic pain

Self-management / Events & meetings
Support phone line / Online library

www.chronicpain.ie

If you know of any useful organisations not listed here, please let us know about them

McClure
SOLICITORS

GAIN has partnered with McClure Solicitors to provide a free Will-writing service for our members, friends, volunteers and staff who want to write, update or review their Will. This service is FREE both to you and to GAIN and carries no obligation.

Why do you need a Will?

You already know that every adult should have a Will. Without a Will the law decides who inherits, but with a Will, you decide.

Why should you do it now?

No-one knows what is around the corner. If you leave it until you need it, it will be too late.

There is no obligation to make a donation or leave a legacy to GAIN, but we would be very grateful if you consider it. A gift in a Will, no matter how small, would help us to provide the practical, emotional and financial help that people affected by GBS, CIDP and the associated inflammatory neuropathies rely on.

McClure has offices throughout the UK, but if there isn't one in your area, they can come to you, or even have a COVID-secure chat via video link. It really couldn't be easier, so why not arrange a free consultation today!

Tel 0800 852 1999

https://www.mcclure-solicitors.co.uk/wills