



Reaching out while you stay in

GAIN / coronavirus COVID-19 newsletter issue 6 01/05/2020

Welcome to issue 6 of GAIN's Weekly Lockdown Lowdown. Six weeks in, and we now have a clearer understanding of the real death toll from COVID-19. Testing is up, numbers both of new cases and deaths each day appear to be down, and we are reported as being 'past the peak'. Next week, we can expect to hear the first details of what life might look like when the Government starts to lift the lockdown.

For the time being though, the message remains the same.

Stay at home. Protect the NHS. Save lives.



DATA



KNOWLEDGE



ACTION

Mixed mask messages

Since the start of the pandemic, we have been told that the official guidance is 'led by the science'.

Because science is evidence-based, it constantly evolves, so as we learn more, we can expect the guidance to change. However, you would be forgiven for feeling a little confused by the advice surrounding whether or not to cover your face.

As we mentioned in last week's newsletter, there is evidence that **covering your nose and mouth reduces the chance of you passing on infection to other people** through coughs and sneezes, and this is now widely accepted as either mandatory or recommended practice in many countries around the world. It offers little protection from others who may be infected, but little is better than none if you need to go into a public place where social distancing is difficult, such as a shop or on public transport. The mantra is simple.

I wear mine to protect you. You wear yours to protect me.

The UK Government has now accepted that there are good reasons for people to cover their faces in certain situations.

"What I think Sage is saying, and what I certainly agree with is that as part of coming out of the lockdown I do think face coverings will be useful, both for epidemiological reasons, but also giving people confidence they can go back to work," PM Boris Johnson said during Thursday's Downing Street press briefing.

Make your own washable mask from a cotton hankie and a couple of hair bobbles;
<https://blog.japanesecreations.com/no-sew-face-mask-with-handkerchief-and-hair-tie>

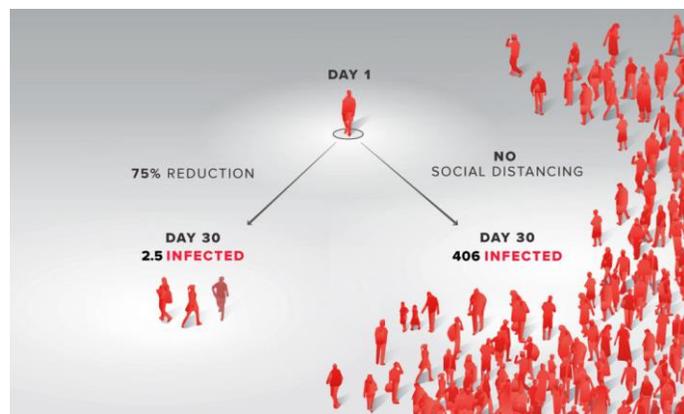


R is for...

Every week at the moment, it seems we adopt a new word or phrase into our language that few of us had call to use a couple of months ago. Everyday conversation of the 'new normal' has become littered with 'coronavirus', 'COVID-19', 'pandemic', 'self-isolating', 'social distancing', 'flatten the curve', 'lockdown' and 'reaching the peak'. Before COVID-19 arrived, how many of us would ever have considered signing off an email with the words 'stay safe'?

The 'new' word this week isn't so much a word as a letter. So what is 'R' and why is it important?

R is the abbreviation used for the **reproductive** value of a virus and illustrates why social distancing has helped to slow down the spread of the coronavirus. It is the number of people that one infected person will pass the virus on to. Back in March, before lockdown, R was around three, so every infected person would pass the coronavirus on to three other people, and those three people would in turn infect three others.



Since lockdown, the R value has been reduced from three to under one (most likely between 0.3 and 0.9). This means that every infected person is now infecting fewer than one other person, so the viral spread is on the decline, and gradually coming under control. One of five UK Government tests for lockdown to be relaxed, is to ensure R stays well below one.

As many of you will be aware, GAIN has partnered with McClure Solicitors to provide a free Will-writing service. This service is free both to you and to GAIN and carries no obligation to donate. McClure would like you to know that it is (almost) business as usual.

“McClure are continuing to make appointments. In fact, our appointments for March 2020 were up 5% on 2019. As we are currently unable to conduct appointments face to face, all our appointments are taking place as video (by Skype, WhatsApp or Zoom) or telephone. Making sure that estate planning remains an important issue for your supporters, perhaps now more so than ever. We are here, ready to service your supporters, service users, staff and volunteers should they decide to go ahead with getting their Will instructed, or their Power of Attorney or Trust.”

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



Fake stories wrongly claim Elisa Granato, one of the UK's first COVID19 vaccine trial participants, has died.

False news reports have been circulating online claiming that Dr Elisa Granato, one of the first participants in the UK's human trials of a possible vaccine for the SARS-CoV-2 coronavirus, has died shortly after being injected with the vaccine. Dr Granato is not dead, and the reports are fake.

Malicious and mischievous false news stories are spread on social media every day, and all too often they are passed on, with the best of intentions, to friends and family. At the best of times, this can leave you feeling a bit silly for being caught out, but in the times we're currently living through, spreading false and misleading information can do a great deal of harm.

Fortunately, you can easily check the validity of information you read or hear. **Fullfact** is the UK's independent fact-checking charity, providing free tools, information and advice so that anyone can check the claims we hear from politicians and the media.

<https://fullfact.org/>

Exercising sitting down

We know that some of you are not able to keep as fit and active as you would like, due to ongoing recovery from Guillain-Barré syndrome, or living with long-term residual effects or a chronic condition such as CIDP. Gentle sitting exercises will help improve your mobility and prevent falls and can be done at home.



Chest stretch

This is good for posture



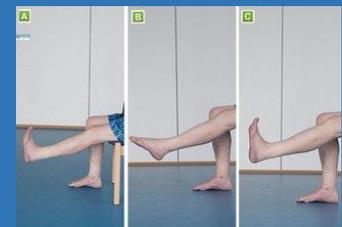
Upper-body twist

This stretch will develop and maintain flexibility in the upper back



Hip marching

This exercise will strengthen hips and thighs, and improve flexibility



Ankle stretch

This stretch will improve ankle flexibility and lower the risk of developing a blood clot



Arm Raises

This exercise builds shoulder strength



Neck rotation

This stretch is good for improving neck mobility and flexibility



Neck stretch

This stretch is good for loosening tight neck muscles

Full instructions available on the NHS website
<https://www.nhs.uk/live-well/exercise/sitting-exercises/>

#DeclutterAndDonate

5 May 2020



How does it work?

1. Gather together all your unwanted books, CDs, DVDs and console games.
2. Download the Ziffit app to your smartphone or tablet. Using the app, scan the barcodes for an instant price.
3. If you're using a PC or laptop, manually enter the numerical digits above or under the barcode. On CDs, DVDs and games, this is the EAN and on books it's the ISBN.
4. During check-out, choose the option to 'Donate' and type **Guillain** into the search bar to pick up our charity details.
5. Complete the trade, pack your items and either take your parcel to your local Collect+ store, or await the free courier collection service if your package is over 5kg (Ziffit will work this out for you).
6. Sit back and feel smug. You've got rid of unwanted stuff and helped your favourite charity!



There's never a good time to ask for money, but fortunately a new type of giving is in town! @VMGiving have partnered with trade-in site Ziffit to help you support us by donating your old books, console games, CDs and DVDs.

Join the nation for #DeclutterAndDonate on 5th May #GivingTuesdayNow

Since launching our Emergency Appeal at the start of April, we have received more than £5,600 in donations via Just Giving, Facebook / Paypal Giving and Virgin Money Giving.

The 2.6 Challenge £3,471

To everyone who has already contributed, through donations or fundraising efforts, **THANK YOU.**

Emergency Appeal £215

#GAINmomentum £484

Every pound goes towards covering the expected shortfall in income this year of between £50,000 and £100,000 so we can still be here to help those who need us when all this is over.

General donations £1,460

Although the 2.6 Challenge has come to an end, our #GAINmomentum campaign has only just started! It runs throughout May (GBS/CIDP awareness month) and is all about being more active. If you are one of the many people getting fatter rather than fitter during lockdown, this is the perfect opportunity to take control and make some good new habits!

If you would like to join in, you can register online and receive a pack including information about the campaign, a special edition T-shirt and either a waterproof mobile phone holder or kitbag, plus a medal when you tell us you have completed your challenge. Or if you don't want the T-shirt and medal, why not join in for fun anyway? Set yourself a personal goal and see what you can achieve in a month.

To register for #GAINmomentum, visit

<https://gaincharity.org.uk/gainmomentum/>

THANK YOU

To make a donation to our emergency appeal, visit

<https://gaincharity.org.uk/donate>

Join the conversation

Video calling is as easy as having an actual face-to-face conversation and is almost like being in the same room. WhatsApp, Facetime, Skype and Zoom may be familiar names, but we'd like to introduce you to Starleaf, the app GAIN uses for our **weekly chat**. Wherever you are and whatever device you are on, the StarLeaf app lets you chat to anyone, anywhere. Download Starleaf from your app store, or online via www.starleaf.com/products/portfolio/the-starleaf-app/

No smartphone or computer? Don't worry! You can't video chat using a landline, but you can still join the conversation using your ordinary phone. Call us to find out how.

Join the weekly chat every Tuesday at 2pm and connect with other people who understand what it means to be affected by GBS, CIDP and the variants

Visit our website for details of how to join in www.gaincharity.org.uk



Coronavirus: Guard of honour for 'miracle' radiographer

A hospital radiographer who suffered a rare complication of Covid-19 that caused complete paralysis has walked out of hospital to a guard of honour. Paul Skegg spent 11 days as a patient in intensive care at Darent Valley Hospital. Mr Skegg, 42, was admitted on 3 April and later developed Guillain-Barré syndrome, a very rare complication of Covid-19. Dr Kwan, divisional medical director for the hospital in Kent, said: "His rapid recovery is just short of a miracle." The hospital's neurologists had used a "groundbreaking" therapy to treat Mr Skegg, he added. "Today, we lined the corridor for one of our own and clapped this front-line NHS staff home, following a 16-day stay at Darent Valley Hospital."

This is an extract from a story appearing on BBC Kent regional news on 19th April, and shared on social media platforms. It was brought to our attention by a few of our members, who were wondering what this new treatment could be. Unfortunately, the treatment wasn't ground-breaking or new, just regular IVIG (intravenous immunoglobulin), which is the standard and most common form of treatment for GBS, the alternative being plasma exchange. It was first found to be effective in helping to halt the progress of GBS in the early 1990s and has been widely used for at least the last couple of decades. To see a patient go from completely paralysed to walking out of hospital within a matter of days would seem quite miraculous, and to be fair, it isn't often we hear of such a rapid recovery, but the reality is that Mr Skegg was just very fortunate, and there is no ground-breaking miracle cure out there.

Keep in touch

Post is being picked up from the office regularly, and emails and social media are monitored during office hours

 office@gaincharity.org.uk

 www.facebook.com/groups/727400487277814/

 @gaincharity

 gaincharity

If you need to phone any of us, please use the mobile numbers below (Mon-Fri 9am-3pm)

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And if you want to drop us a line, you can write to us at the usual address;

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