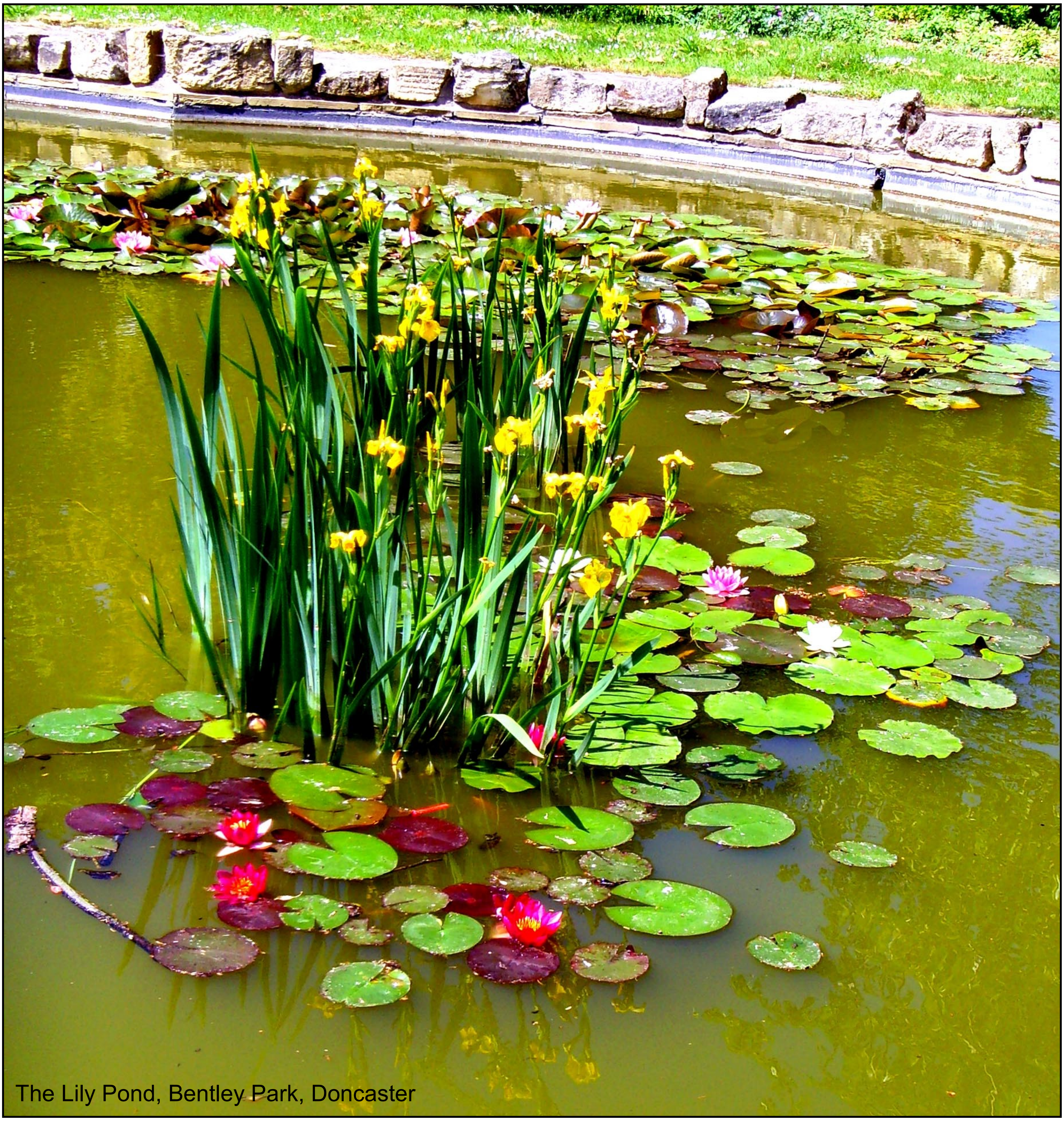
Price £ 4.00 (Free to members)

Pathways

The newsletter of Leger ME/CFS Supporting Myalgic Encephalopathy or Encephalomyelitis (ME), Chronic Fatigue Syndrome (CFS), Post Viral Fatigue Syndrome (PVFS), Fibromyalgia Syndrome (FMS), Patients & Carers.

Welcome to Pathways No. 68. Summer 2021.

An Update on the Delta Variant of Covid 19.



The Lily Pond, Bentley Park, Doncaster

You Write In. *Members own thoughts and opinions.*

Here are your experiences with Covid Vaccinations

Julie Writes: I have had my second vaccination of the Astra Zeneca. I had a sore arm for a couple of days and felt slightly more fatigued for about 5 days but no other symptoms.

Bill Writes: I was unwell, fatigued felt very strange for two days with first dose of Covid vaccine. I have been fine with the second one

Kay Writes: I was extremely ill for 4 days with first dose of the AstraZeneca vaccine, but I was fine with the second. Not even a sore arm!

Carol Writes: I had Astra Zeneca jab and had no problems at all with my first jab, and only a slight ache in my arm muscle when I had the second jab. I guess I was very lucky, as I have heard that it made some others very poorly.

Gari Writes: Loving your weekly updates. So informative. I had my 2nd vaccine at the start of May and apart from an aching upper arm suffered no significant aftereffects !

Sharon Writes: I work in retail (coffee shop) at a local hospital and from feedback from staff, customers sentiment is that the first dose seems 'mild' compared to the second. I had raised temperature with the 2nd dose. Dave, my husband also had one with the 2nd dose too. Dave's brother was quite ill and it knocked him off his feet with the 2nd one. I agree I would 'put off' the easing off of lock down and carry on as we are doing. This country has done amazing with the vaccine program. Take care!

Liz Writes: Thank you for the weekly updates. They make Interesting reading.

Maria Writes: I had my 2nd AstraZeneca vaccine on 5th June. My only symptoms have been mild headache and feeling drowsy. They went after 7 days. The 1st vaccine made me feel very rough with bad headache, arm pain, all over aches, nausea and feeling extreme fatigue for 7 days. So the 2nd vaccine has been a lot better

Anthony Writes: Regarding Covid-19. We have to start thinking now about what is going to happen next. It has always seemed to me just too much of a coincidence that COVID-19 originated in the only city in China which has a bio-safety level 4 laboratory and which is an active research centre for the study of coronaviruses. I don’t think for a moment that the virus was released deliberately, but there is a very strong possibility that it was released into the community accidentally through poor biosecurity; and also that it was in part the product of chimeric research into gain of function.

The clinching argument seems to be the complete absence of any zoonotic (animal replated) evidence for the jumping of the species barrier by the SARS-COV-2 virus, in stark contrast to both SARS-COV-1 and MERS, where such evidence is manifest. I also suspect that we are going to hear a great deal more about something called the furin cleavage site in the spike protein of SARS-CoV-2 which was previously unseen in other SARS-like CoVs.

So, if it does turn out that China, through carelessness and subsequent obfuscation has been responsible for the release of this virus into the global community, what next? Anybody who has recently tried to establish the origin of almost any manufactured product will realise that an enormous production of the West’s manufacturing has been contracted out to China. We must recognise the likelihood that this simply will not be acceptable in a post-COVID world. We need to rebuild our manufacturing capacity, which will be expensive and inflationary. And we need to recognise that if we do succeed in putting the China under significant economic pressure, their first reaction is likely to be try and take Taiwan.

Strong stuff! China is a tightly run country which can keep things to itself. Although the United Nations sent a delegation to Wuhan in China to investigate the Origin of the Covid 19 virus, they did not find anything definitive or conclusive. Somewhere the truth is out there !

Sandra Writes: A friend of my daughters, who teaches in Doncaster has had both Covid injections, and is very ill with Covid. I did not want to scare people, but I think they should take note that a vaccination is not a 100 per cent effective. There is no guarantee that you will not get Covid. I know you have been trying to remind people to carry on taking care, but this shows people how important it is to stick to the rules. There is always an exception to every rule so people should continue hands face space so that they do not contract Covid.

If you read into the data on Covid vaccinations, after two doses they are reported as being over 90% effective. There will always be some cases of people who have been vaccinated fully who do catch it. The fact that she had the two vaccinations means that the chances of being hospitalised, or going into intensive care or dying are very massively reduced. So vaccination is worthwhile. It is well known that some people do not respond to vaccinations due to some underlying health problem that they are not aware of.

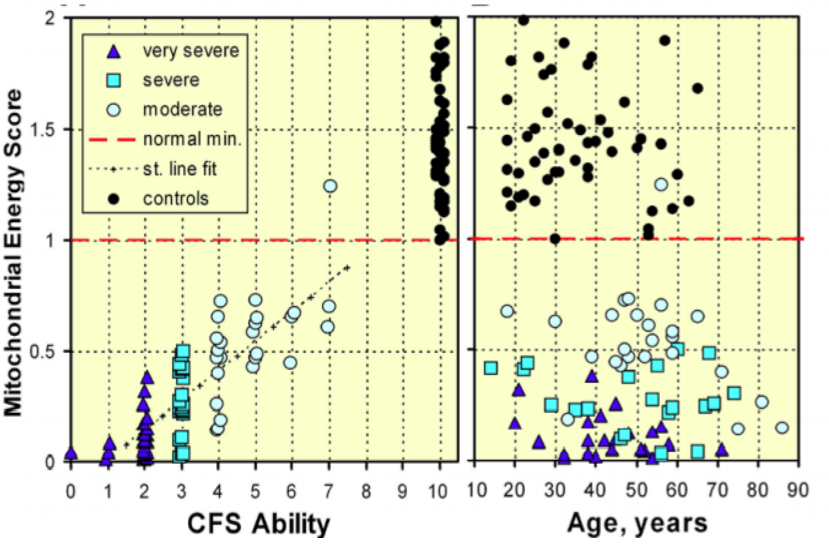
The main problem now is the Covid delta variant which predominates current cases is not as sensitive to vaccination as the original variant and is 5-8 times more contagious. The government is considering a top-up vaccination targeted at the new variants in the Autumn. There are also trials of specific antiviral monoclonal antibodies targeted to Covid which is hoped could be given to someone who tests positive in a similar way to antibiotics.

I have tried to cover all the angles in this Pathways, but the situation is changing so fast that the features I've produced are out of date before printing is due. A present hands, face, space, and fresh air essential and will work with whatever variant covid comes our way.

Bill Writes: I have just read a feature about Motor Neurone Disease (MND), where regular and strenuous exercise increases the risk of motor neurone disease in people who are genetically vulnerable. say scientists. Studies in Italian footballers have suggested rates up to six times higher than normal. Athletes including Rob Burrow (rugby league), Stephen Darby (football) and Doddie Weir (rugby union) have all spoken openly about the disease.

We are aware that if we have ME/CFS, where regular exercise can make us worse, and we have adaptive pacing as a strategy. Is there any link?

I would say so. ME/CFS is a neurological disease, like MND, and multiple sclerosis (MS). They are possibly caused by some immune system abnormality which damages specific components of the immune system. All seem to have people who are genetically prone. With MND it has been suggested that intense exercise damages the lower motor neurone which is affected in MND. The mechanism thought to be due to low levels of oxygen in the body during strenuous exercise could be leading to a process called oxidative stress in the motor neurones - some of the biggest and most oxygen-demanding cells in the body.



This is the summary of the results from Dr. Myhills first research paper showing the relationship between mitochondrial damage and ME/CFS ability. Sadly, the research project has now been suspended due to the Covid pandemic.

We know through the work a Dr Myhill and others that in many cases of ME/CFS there are mitochondrial abnormalities in our body cells. These are the power houses of the cell, and there is a direct relationship between the intensity if ME/CFS and the mitochondrial damage. It is believed that the mechanism may involve similar factors.

With ME/CFS, MND and MS, although there are strategies available to mitigate the disease, there is no sign of anything which can control the conditions within the long term or cure the condition.

Welfare Rights Matters

with thanks from Benefits and Work.

Benefits and Work
Guides you can trust

Leger ME members have access to B&W Guide. Please contact the office for further details.

Face to Face assessments to Restart

A DWP minister has indicated that face-to-face assessments will once again become the norm for both PIP and the WCA, though there will continue to be some telephone and video and assessments. Justin Tomlinson, minister for disability, health and work told the commons work and pensions committee earlier this month that the pandemic had a severe effect on assessments, beginning with the closure of assessment centres.

“*First of all, we had to close down all our assessment centres. We then had to scale up telephone and video assessments, which we have never done before and, but for Covid, would have only been looking to discuss them in the Green Paper, let alone do a pilot. We then had to roll this out nationwide, literally in days. Again, we were using our stakeholders to let us know whether it was working. So far there has been very positive feedback.*

A large number of assessors then moved on to COVID related jobs.

We also lost our health professionals. They all have at least two years’ health professional background so were at the front of the queue for the NHS’s rallying of secondment for Test and Trace, the vaccination roll-out and the immediate support in hospitals when there were the high levels of Covid infections in hospitals. That impacted massively on our capacity.”

However, Tomlinson says that the system is now returning to normality, with WCA assessments resuming and face to face assessments returning for both the WCA and PIP.

“As issues like this came up, we were able to respond, and we are returning to normality on capacity issues. The WCA assessments will begin shortly and start to be scaled back up, as in face to face, and PIP will follow a few weeks later. However, we will keep video and telephone assessments. Through the health and disability Green Paper, we will explore to what extent and where they are best to be used. It is not clear what proportion of assessments will continue to be by telephone and how many will be face to face, though we have yet to hear from anyone who has had a video assessment, so it is likely that these are likely to form a very small proportion of assessments at this stage.”

PIP Mobility awards on Mental health grounds.

Benefits and Work has been looking further into the statistics for PIP mobility awards on mental health grounds, and our research continues to provide grounds for serious concern. On the face of it, there appears to be a high degree of manipulation of award results. Earlier this month we looked at awards for anxiety and depression, before and after the decisions in MH and RJ. We found that, as expected, award rates increased after the two cases were implemented in June 2018, but we also discovered that within a year they had fallen back almost to their previous levels. This is not something that should have happened. Award rates should have remained significantly higher. We have now looked at the award rates for all the conditions the DWP considered would be affected by MH, as a group.

And the result is the same. According to the DWP’s estimates, as a result of the MH case alone, 6% of the entire PIP caseload should have moved from no award of the mobility component to enhanced and a further 6% from no award to standard. In addition, 2% should have moved from standard mobility to enhanced.

Around three quarters of all PIP awards include the mobility component. Yet, as the graph below shows after an initial surge when MH was implemented, the standard rate in particular drops down to the same level it was before June 2018, before beginning to rise again. The enhanced rate falls though not quite so low as it had been, before beginning to rise again.

Social Security appeal Statistics.

Social security appeal numbers and success rates for claimants have all fallen according to the latest statistics released by Her Majesty's Courts and Tribunals Service (HMCTS). The number of social security appeals being lodged has fallen by 37% overall compared to the same quarter last year, to 22,000 appeals.

Employment Support Allowance (ESA) appeals are down 74%, Universal Credit (UC) 66% and Personal Independence Payments (PIP) down 22%. PIP continues to make up the highest proportion of appeals at 67%, with UC on 12% and ESA on 3%. 66% of completed cases were cleared at hearing, rather than for example being settled before they reached a hearing. This is down from 70% in the same quarter last year. The overall success rate for claimants was 66%, down from 71% last year. The success rate varies by benefit.

- The PIP success rate was 72%, down 4%
- The ESA success rate was 67%, down 9%.
- The DLA success rate was 67%, down 3%.
- The UC success rate was 54%, down 11%

Changes to PIP Assessment Forms: Removal of Tick boxes.

Personal Independence Payment is a non-taxable, non-contributory benefit for people with chronic health conditions. It is not an easy benefit to get, but the vast majority of Leger ME members qualify.
Part of the application process involved filling out a complex form known as a PIP1003.

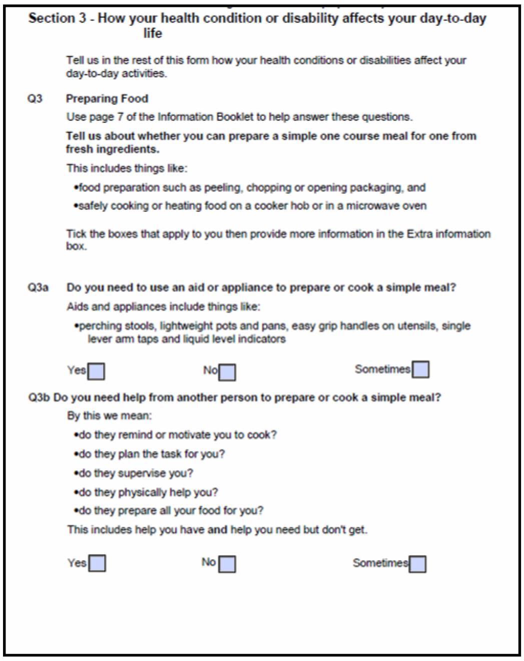
There are forty plus pages to this form, and many people have difficulties in completing it correctly. In fact, many people are refused the first time for reasons outside their control.

Recent changes to the latest editions of the form have had the tick boxes removed and all that shows is a blank page. This means there are really no guidelines to help at all.

However, as a group Leger ME can help its members with these forms. We strongly advise you to contact us for guidance before putting pen to paper.

Further the details can be obtained by telephoning the Leger ME office or attending a 1 to 1 session..

Old style



Section 3 - How your health condition or disability affects your day-to-day life

Tell us in the rest of this form how your health conditions or disabilities affect your day-to-day activities.

Q3 Preparing Food

Use page 7 of the Information Booklet to help answer these questions.

Tell us about whether you can prepare a simple one course meal for one from fresh ingredients.

This includes things like:

- food preparation such as peeling, chopping or opening packaging, and
- safely cooking or heating food on a cooker hob or in a microwave oven

Tick the boxes that apply to you then provide more information in the Extra information box.

Q3a Do you need to use an aid or appliance to prepare or cook a simple meal?

Aids and appliances include things like:

- perching stools, lightweight pots and pans, easy grip handles on utensils, single lever arm taps and liquid level indicators

Yes ☐ No ☐ Sometimes ☐

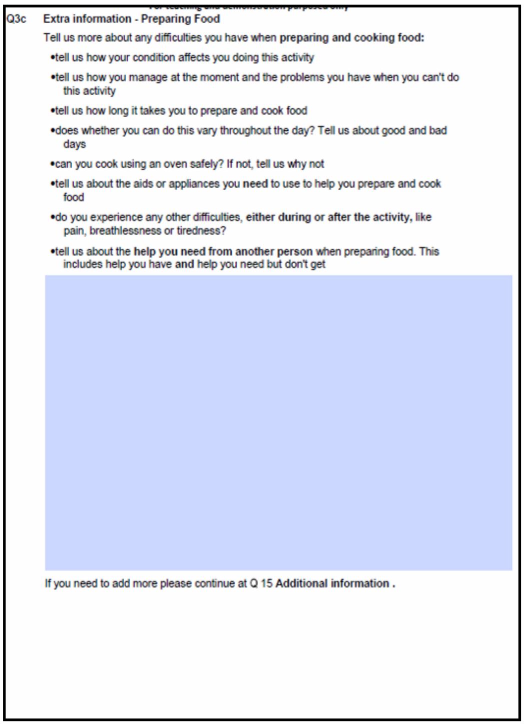
Q3b Do you need help from another person to prepare or cook a simple meal?

By this we mean:

- do they remind or motivate you to cook?
- do they plan the task for you?
- do they supervise you?
- do they physically help you?
- do they prepare all your food for you?

This includes help you have and help you need but don't get.

Yes ☐ No ☐ Sometimes ☐



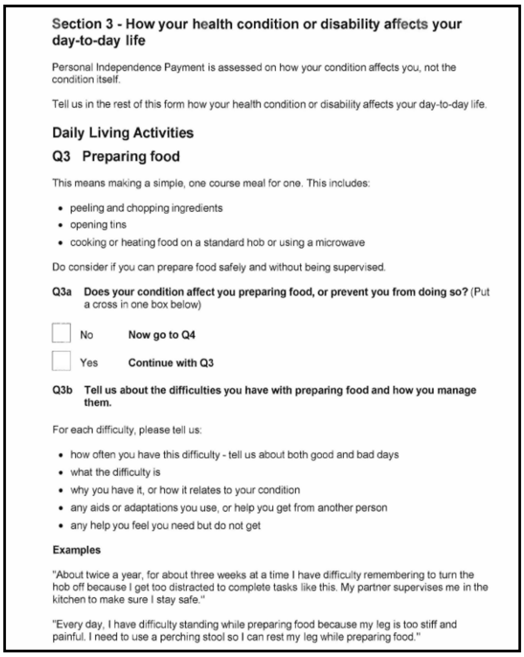
Q3c Extra information - Preparing Food

Tell us more about any difficulties you have when **preparing and cooking food:**

- tell us how your condition affects you doing this activity
- tell us how you manage at the moment and the problems you have when you can't do this activity
- tell us how long it takes you to prepare and cook food
- does whether you can do this vary throughout the day? Tell us about good and bad days
- can you cook using an oven safely? If not, tell us why not
- tell us about the aids or appliances you **need** to use to help you prepare and cook food
- do you experience any other difficulties, **either during or after the activity,** like pain, breathlessness or tiredness?
- tell us about the **help you need from another person** when preparing food. This includes help you have **and** help you need but don't get

If you need to add more please continue at Q 15 **Additional information .**

New style



Section 3 - How your health condition or disability affects your day-to-day life

Personal Independence Payment is assessed on how your condition affects you, not the condition itself.

Tell us in the rest of this form how your health condition or disability affects your day-to-day life.

Daily Living Activities

Q3 Preparing food

This means making a simple, one course meal for one. This includes:

- peeling and chopping ingredients
- opening tins
- cooking or heating food on a standard hob or using a microwave

Do consider if you can prepare food safely and without being supervised.

Q3a Does your condition affect you preparing food, or prevent you from doing so? (Put a cross in one box below)

☐ No **Now go to Q4**
☐ Yes **Continue with Q3**

Q3b Tell us about the difficulties you have with preparing food and how you manage them.

For each difficulty, please tell us:

- how often you have this difficulty - tell us about both good and bad days
- what the difficulty is
- why you have it, or how it relates to your condition
- any aids or adaptations you use, or help you get from another person
- any help you feel you need but do not get

Examples

"About twice a year, for about three weeks at a time I have difficulty remembering to turn the hob off because I get too distracted to complete tasks like this. My partner supervises me in the kitchen to make sure I stay safe."

"Every day, I have difficulty standing while preparing food because my leg is too stiff and painful. I need to use a perching stool so I can rest my leg while preparing food."

Q3 Preparing food continued

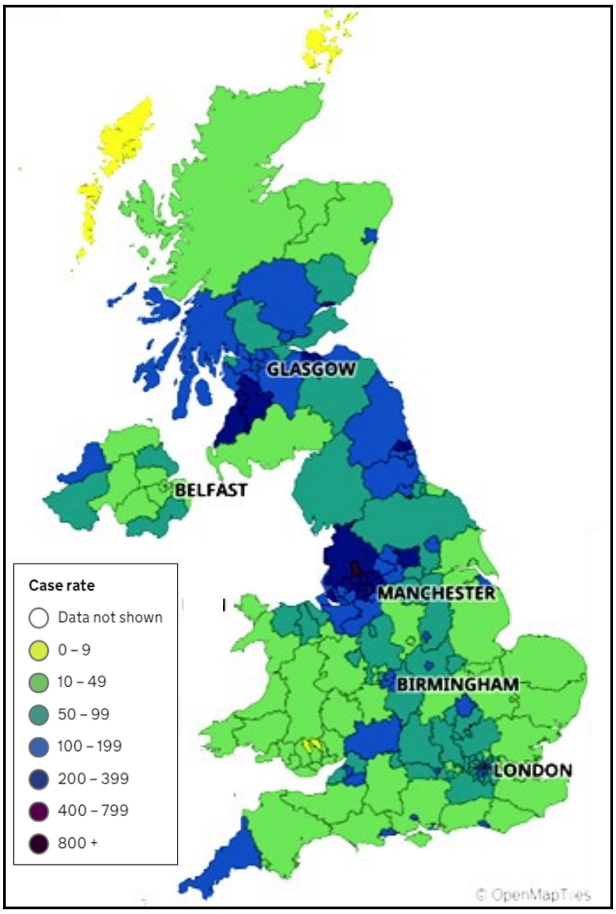
From PIP 1003 part 2 Page no: 10

The Covid Situation as of 22nd June 2021.

Currently in all areas there are increased covid case counts, the highest being in the Greater Manchester area. The dominant variant is the Delta or Indian variant. The variant is many more times more transmissible and the earlier variants, and because of the level of vaccinations is mainly affecting young adults.

At the time the Prime Ministers roadmap out of lockdown was conceived, the Delta Variant was only a ‘Variant of Interest’. Over the last month of so this variant has no become a ‘Variant of Concern’. The current wave started in Bolton Great Manchester and in succeeding weeks has spread out to neighbouring areas and form other hotspots around the country. It was clear several weeks before the stage four lifting of the roadmap on the 21st of June that there was a problem, although it took the politicians about a week to admit there was a problem, like a Christmas.

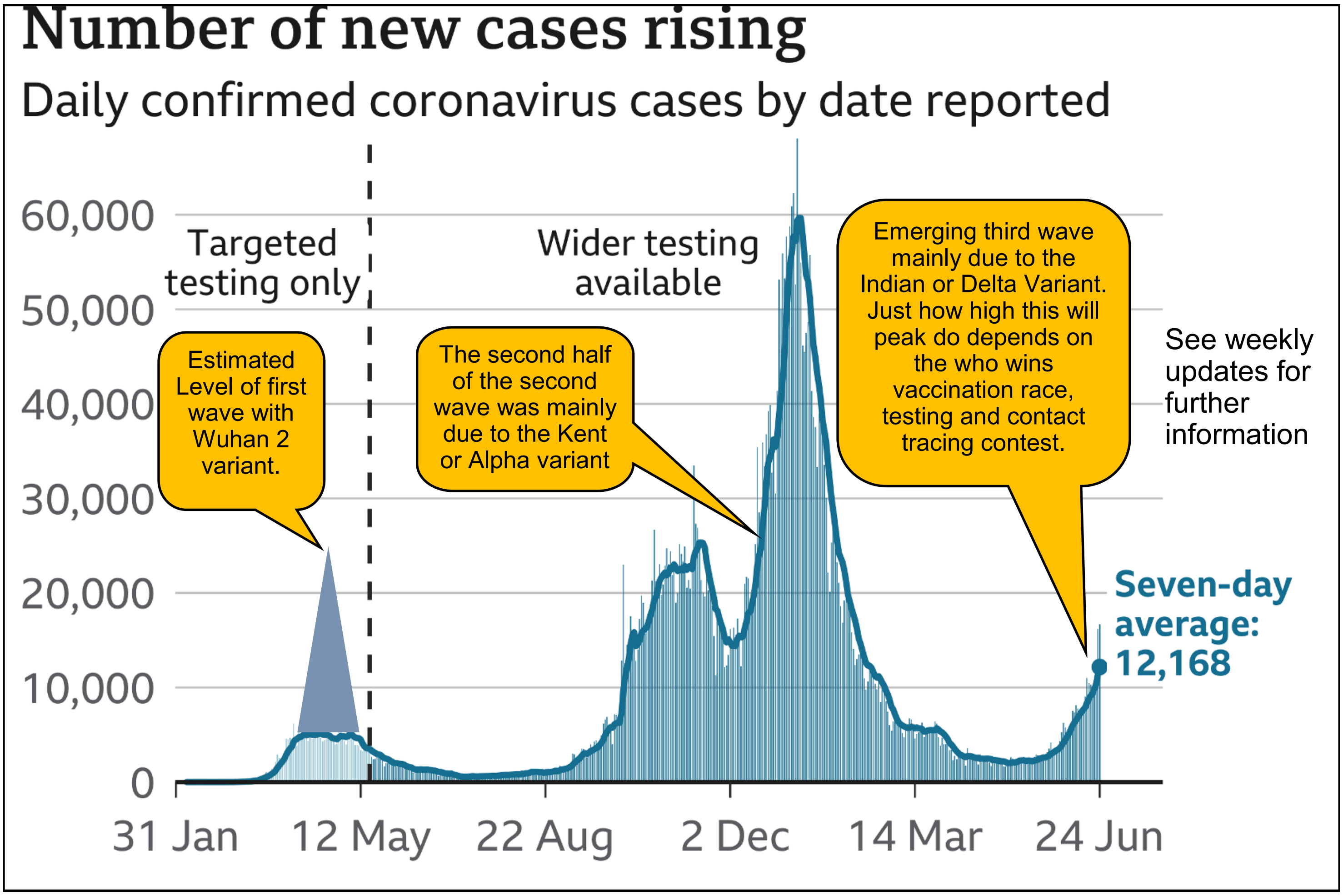
Although a provisional date for lifting of all Coronavirus restrictions of the 19th of July has been set, it is by no means guaranteed. Anyone wo is making arrangement in the next few months needs to take this into account. I think that the probability of this happening is only about one in three.



With thanks to
www.coronavirus.data.gov.uk

National History of case counts.

You will have seen earlier versions of the graph - here it is updated. Please see the following pages for further background information.


Number of new cases rising

Daily confirmed coronavirus cases by date reported

Estimated Level of first wave with Wuhan 2 variant.

The second half of the second wave was mainly due to the Kent or Alpha variant

Emerging third wave mainly due to the Indian or Delta Variant. Just how high this will peak do depends on the who wins vaccination race, testing and contact tracing contest.

See weekly updates for further information

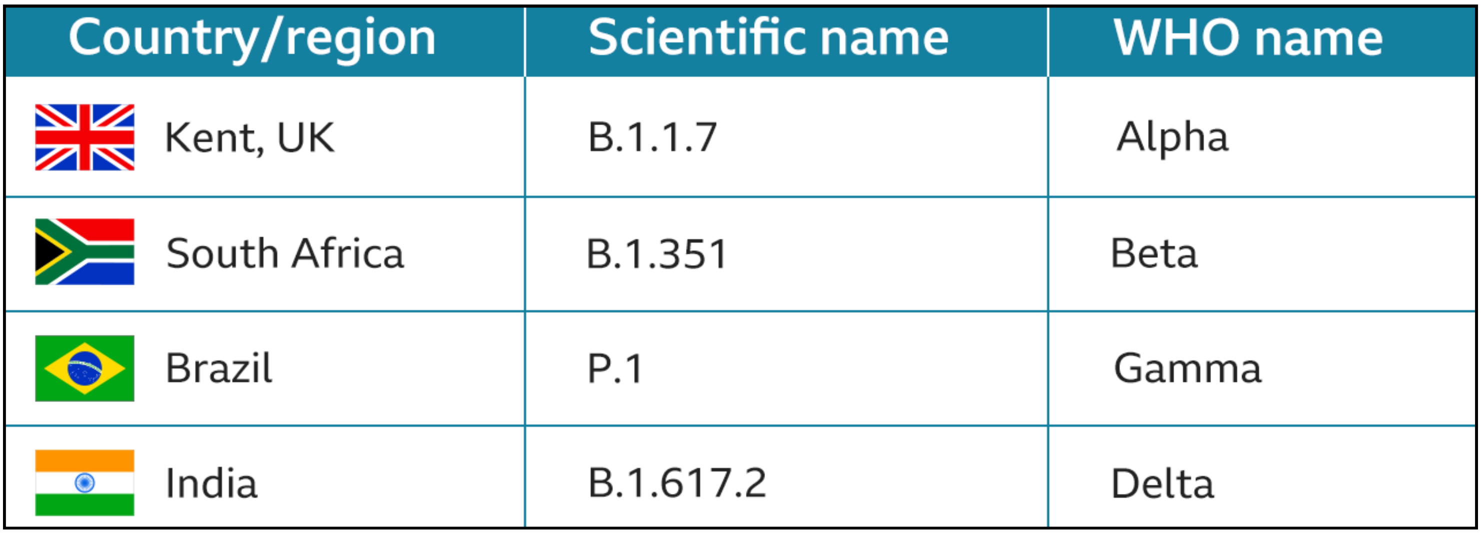
A new way of describing Covid 19 Variants

With Thanks to the World health organisation.

Variants of Concern

A SARS-CoV-2 variant that meets the definition of a VOI (see below) and, through a comparative assessment, has been demonstrated to be associated with one or more of the following changes at a degree of global public health significance:

- Increase in transmissibility or detrimental change in COVID-19 epidemiology; or
- Increase in virulence or change in clinical disease presentation; or
- Decrease in effectiveness of public health and social measures or available diagnostics, vaccines, therapeutics.



Country/region	Scientific name	WHO name
Kent, UK	B.1.1.7	Alpha
South Africa	B.1.351	Beta
Brazil	P.1	Gamma
India	B.1.617.2	Delta

Variants of Interest

A SARS-CoV-2 isolate is a Variant of Interest (VOI) if, compared to a reference isolate, its genome has mutations with established or suspected phenotypic implications, and either:

- has been identified to cause community transmission/multiple COVID-19 cases/clusters, or has been detected in multiple countries, OR
- is otherwise assessed to be a VOI by WHO in consultation with the WHO SARS-CoV-2 Virus Evolution Working Group.

WHO label	Pango lineage	Earliest documented	Date of designation
Epsilon	B.1.427/B.1.429	United States of America, Mar-2020	5-Mar-2021
Zeta	P.2	Brazil, Apr-2020	17-Mar-2021
Eta	B.1.525	Multiple countries, Dec-2020	17-Mar-2021
Theta	P.3	Philippines, Jan-2021	24-Mar-2021
Iota	B.1.526	United States of America, Nov-2020	24-Mar-2021
Kappa	B.1.617.1	India, Oct-2020	4-Apr-2021

The Covid Delta Variant. *with thanks to the BBC*

A coronavirus variant, first identified in India, is causing a spike in cases in some parts of the UK and experts are worried. Experts say this variant, Delta by the World Health Organization, is more transmissible than even the "Kent" or Alpha variant and is now dominant in the UK. It could delay the final stage of easing of England's Covid restrictions on 21st June, although hospitalisations remain flat.

What is happening with the India variant in the UK?
There are a few "India" variants, but one called B.1.617.2 appears to be spreading more quickly in the UK. Surge testing is being deployed in some areas, including Bolton and Blackburn, to identify infections - but it may not be stopping the spread. Second jabs for all over-50s (and the clinically vulnerable) in England are now being brought forward to protect more people, faster. Second doses will come eight weeks after the first, rather than 11-12 weeks. Latest research suggests the Pfizer and AstraZeneca coronavirus vaccines are effective the variant after two doses, but protection from one dose appears to be reduced.

What do we know about the different variants?
There are thousands of different variants of Covid circulating across the world. Viruses mutate all the time, and most changes are inconsequential. Some even harm the virus. But others can make the disease more infectious or threatening - and these mutations tend to dominate. Those with the most potentially concerning changes are called "variants of concern" and under the closest watch health officials, and include:

- The Delta variant(B.1.617.2) of which more than 12,000 cases have been seen in across the UK
- The Kent or Alpha variant (also known as B.1.1.7) is prevalent in Britain - with more than 200,000 cases identified - and has spread to more than 50 countries and appears to be again
- The Africa or Beta variant(B.1.351) has been identified in at least 20 other countries, including the UK
- Theor Gamma variant(P.1) has spread to more than 10 other countries, including the UK

Are they more dangerous?
There is no evidence that any of them cause much more serious illness for the vast majority of people. As with the original version, the risk remains highest for people who are elderly or have significant underlying health conditions. But a virus being more infectious and equally dangerous will in itself lead to more deaths in an unvaccinated population. The advice to avoid infection remains the same for all strains: wash your hands, keep your distance, wear a face covering and be vigilant about ventilation.

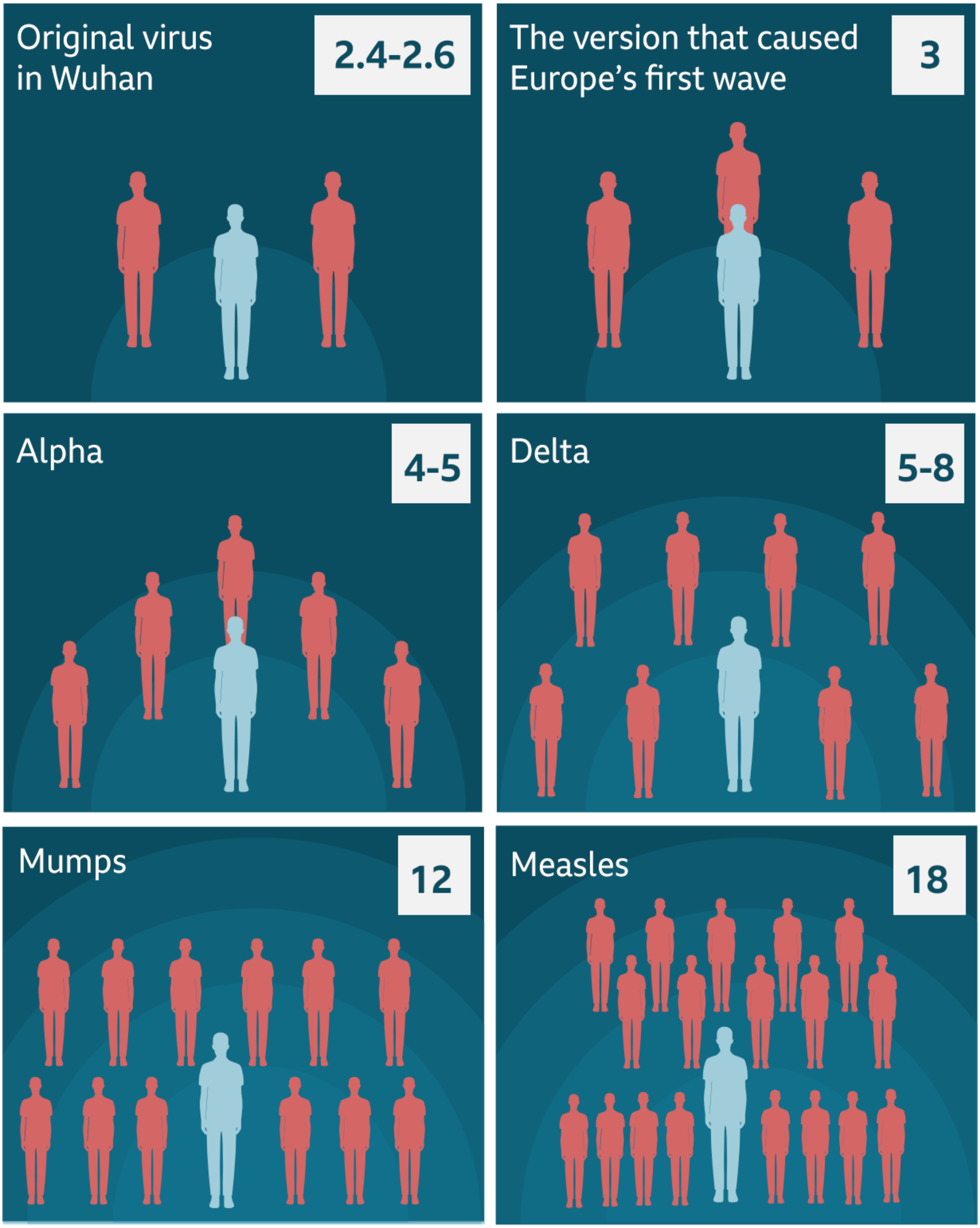
How are the mutants behaving?
The variants experts concerned about have all undergone changes to their spike protein - the part of the virus which attaches to human cells. The Delta variant has some potentially important ones (such as L452R) that might make it spread more easily. There is no evidence to indicate it causes more severe disease or might make current vaccines less effective, say UK officials. The World Health Organization, meanwhile, has classified another, similar variant that is also circulating in India - called B.1.617 - as a variant of concern. One mutation, called N501Y, shared by the Alpha, Gamma and Beta variant seems to make the virus better at infecting cells and spreading. The Beta and Gamma variants also have a key mutation, called E484K, that help the virus evade antibodies, key parts of the immune system which help bodies fight off infection. Experts recently found small number of cases of the Alpha variant that have this change too.

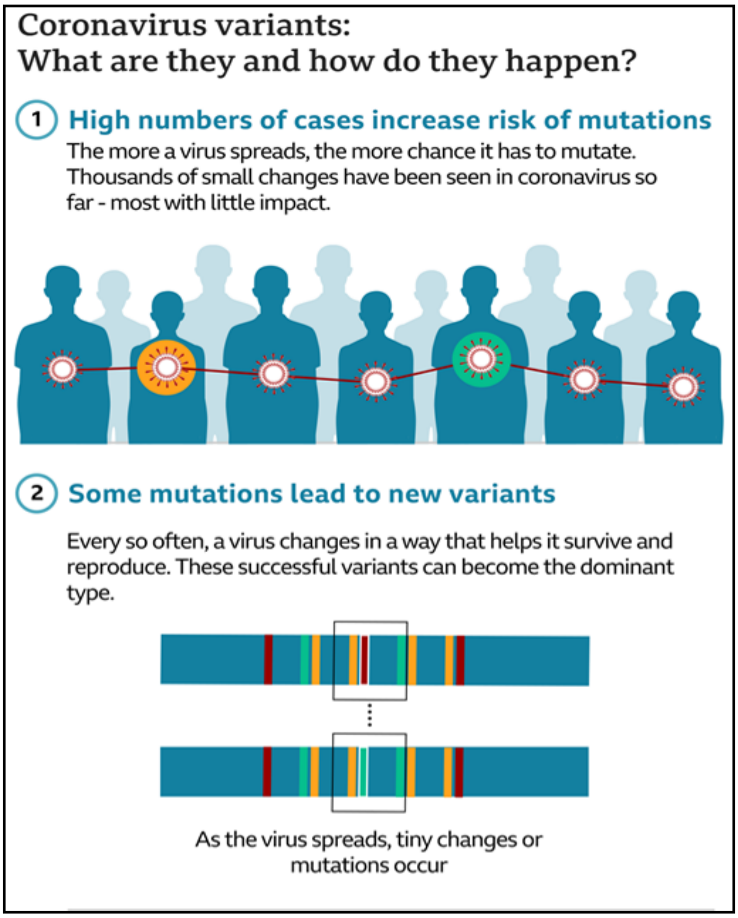
Will vaccines still work against variants?
Current vaccines were designed for earlier versions of coronavirus, but scientists believe they should work, albeit potentially less well. Lab research suggests that can fight the infection - triggered by vaccination or past infection - may be somewhat less effective against Delta. Two doses of either the Pfizer or AstraZeneca vaccine still people from getting extremely ill, however. Real life data the Pfizer vaccine can protect the new variants, although slightly less effectively. Data from the Oxford-AstraZeneca vaccine team, it protects just as well against the Alpha variant. It offers less protection against the Beta variant - but should protect against severe illness. One recent study the Gamma variant may resist antibodies in people who have recovered from Covid before. Some early results the Moderna vaccine is effective against the Beta variant, although the immune response triggered may be weaker and shorter-lived.

Do variants mean booster jabs are more likely?
Yes, experts are confident existing vaccines can be redesigned to better tackle emerging mutations. The UK government has deal with biopharmaceutical company Cure Vac to develop vaccines against future variants and has pre-ordered 50 million doses. Depending on how variants continue to develop, these could potentially be used to offer a booster vaccine to older or clinically vulnerable people later in the year.

How the R0 numbers of Covid-19 variants and other diseases compare

The more contagious, the higher the R0 number





Coronavirus variants: What are they and how do they happen?

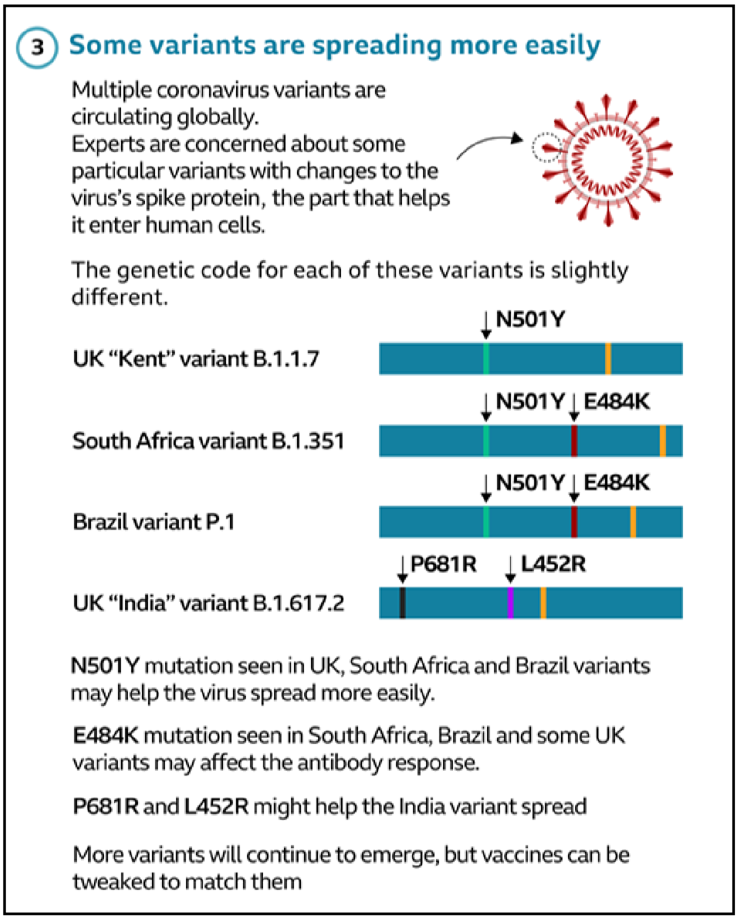
① **High numbers of cases increase risk of mutations**

The more a virus spreads, the more chance it has to mutate. Thousands of small changes have been seen in coronavirus so far - most with little impact.

② **Some mutations lead to new variants**

Every so often, a virus changes in a way that helps it survive and reproduce. These successful variants can become the dominant type.

As the virus spreads, tiny changes or mutations occur



③ **Some variants are spreading more easily**

Multiple coronavirus variants are circulating globally. Experts are concerned about some particular variants with changes to the virus's spike protein, the part that helps it enter human cells.

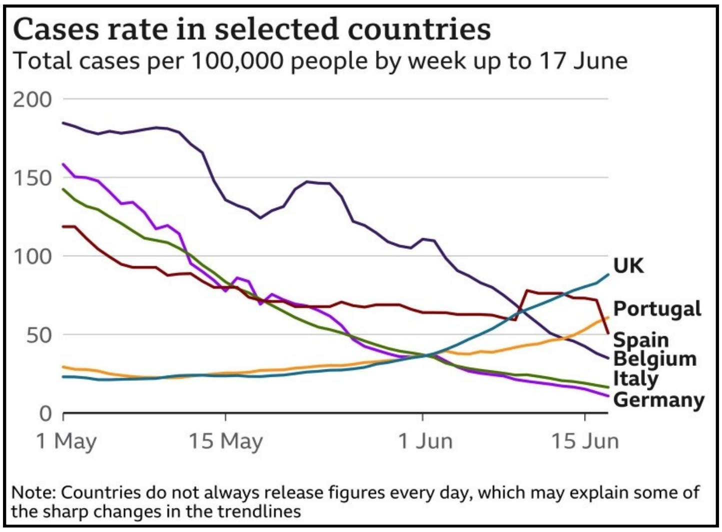
The genetic code for each of these variants is slightly different.

N501Y mutation seen in UK, South Africa and Brazil variants may help the virus spread more easily.

E484K mutation seen in South Africa, Brazil and some UK variants may affect the antibody response.

P681R and L452R might help the India variant spread

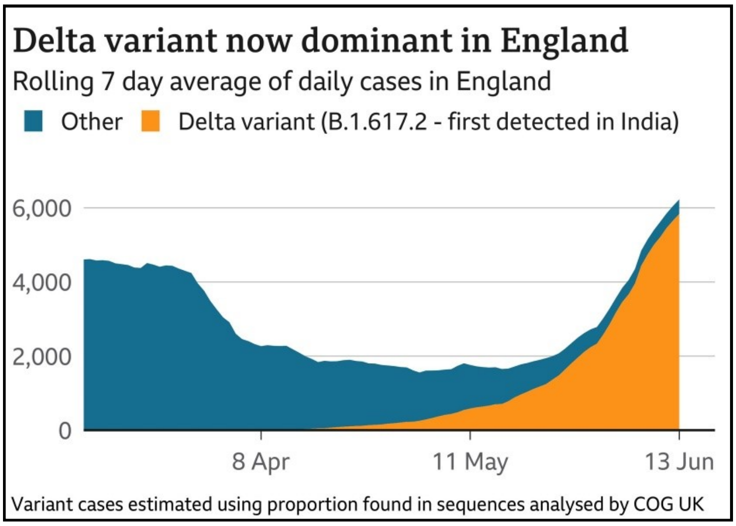
More variants will continue to emerge, but vaccines can be tweaked to match them



Cases rate in selected countries

Total cases per 100,000 people by week up to 17 June

Note: Countries do not always release figures every day, which may explain some of the sharp changes in the trendlines



Delta variant now dominant in England

Rolling 7 day average of daily cases in England

Variant cases estimated using proportion found in sequences analysed by COG UK

Poets Corner *with thanks to Polly B from Interaction*

M.E.

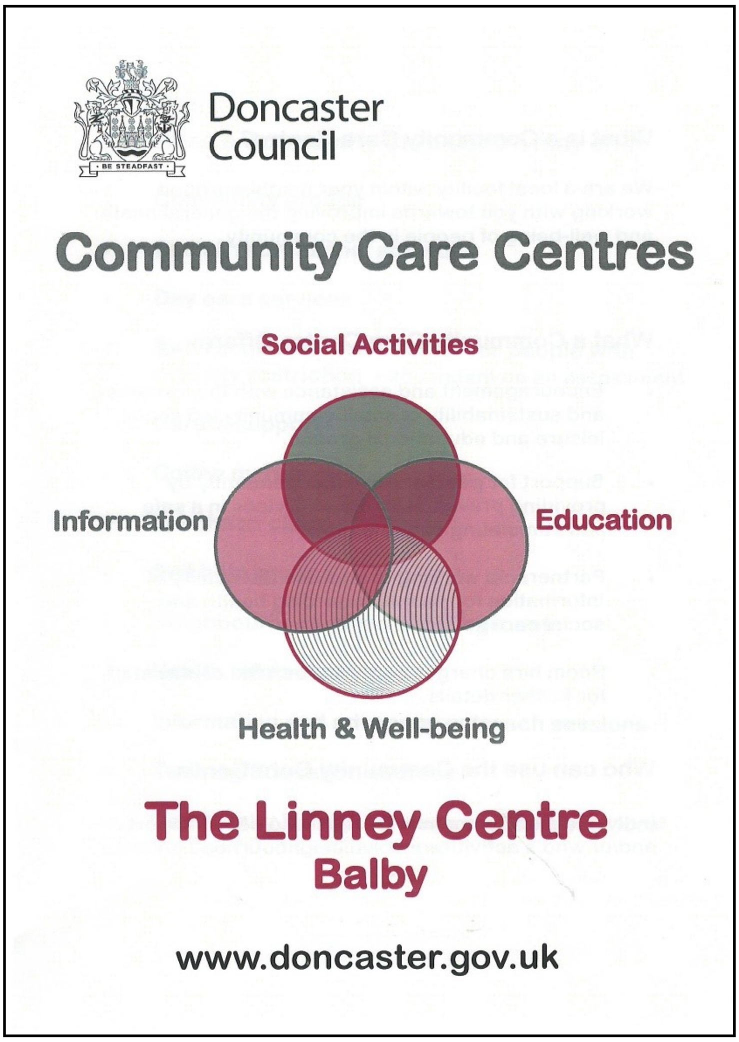
Must **E**xplain **M**yalgic **E**ncephalomyelitis;
Many **E**xperience
Maladies **E**xtraordinary, **M**edical **E**xcuses and **M**odern **E**vils -
Many **E**ntrenched, **M**inus **E**nergy **M**iss **E**vents,
Miserable **E**nduring **M**any **E**motions.
More **E**xperiments **M**ay **E**nsure **M**edical **E**xperts **M**ust **E**mbrace
More **E**vidence **M**ore **E**ffectively;
Meaning **E**vermore ?

The move to the Linney Centre.

The Linney Centre

Since the Covid pandemic started, we have not been able to hold Face to Face meetings. In May, this year it became apparent that we would not be able to resume meetings are the Redmond Centre, Carcroft unchanged. This and a number of similar local community centres have been allocated the SMILE group. During discussion with the SMILE coordinator, it has become apparent that although they are willing to allow us to use the small meeting room, we could not the big room. I can see the Redmond Centre being used for 1 to 1 appointments, in the future, subject to how much we will be charged.

However, I was surprised to receive a telephone from Jane, now the former Redmond Centre manager asking me to go down to inspect the Linney Centre in Balby. Apparently, herself and Carole have moved jobs to the Linney Centre. I spent and afternoon there on the 17th of May. The Linney Centre is an exact copy of the Redmond Centre, except it is in Balby, and has a different plaque on the wall. I have agreed with Jane that we will used the Linney Centre on the same terms and have a regular monthly meeting there on the third Thursday of the month, plus 1 to 1's as required once the lockdown ends.
Please refer to my weekly emails and the Leger ME Facebook page for any further



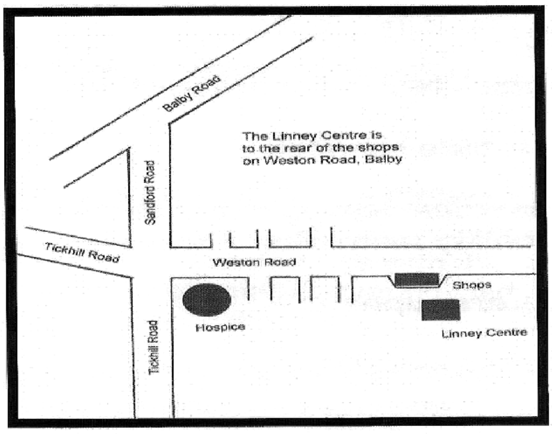
Doncaster Council

Community Care Centres

The Linney Centre
Balby

www.doncaster.gov.uk

WHERE TO FIND US



The Linney Centre
Off Weston Road
Balby
Doncaster
DN4 8NF

Centre Co-ordinator - Jayne Briggs
Centre Support Worker - Carole Clarke

Tel: (01302) 570608
Linney.Centre@doncaster.gov.uk

Information can be made available in other formats such as Braille or Audio Tape on request. If you know someone who may need this service, please contact a member of staff for more information or if you need any other help or advice.

www.doncaster.gov.uk

The Two Main UK Organisations Supporting ME/CFS. And Magazine Reviews -

THE ME ASSOCIATION

ISSUE 157 ■ SPRING 2021

me ME Essential

Extract from the new NICE clinical guideline draft:

"Do not offer people with ME/CFS any therapy based on physical activity or exercise as a treatment or cure for ME/CFS - by Russell Fleming"

THE NEW NICE DRAFT GUIDELINE
The new NICE guideline is welcomed with cautious optimism. Russell Fleming reports.

COVID VACCINES
Priorities, safety and making a decision - all in the enclosed leaflet written by Dr Charles Shepherd.

ME AWARENESS WEEK
The most important week in the ME calendar takes place from 10th to 16th May.

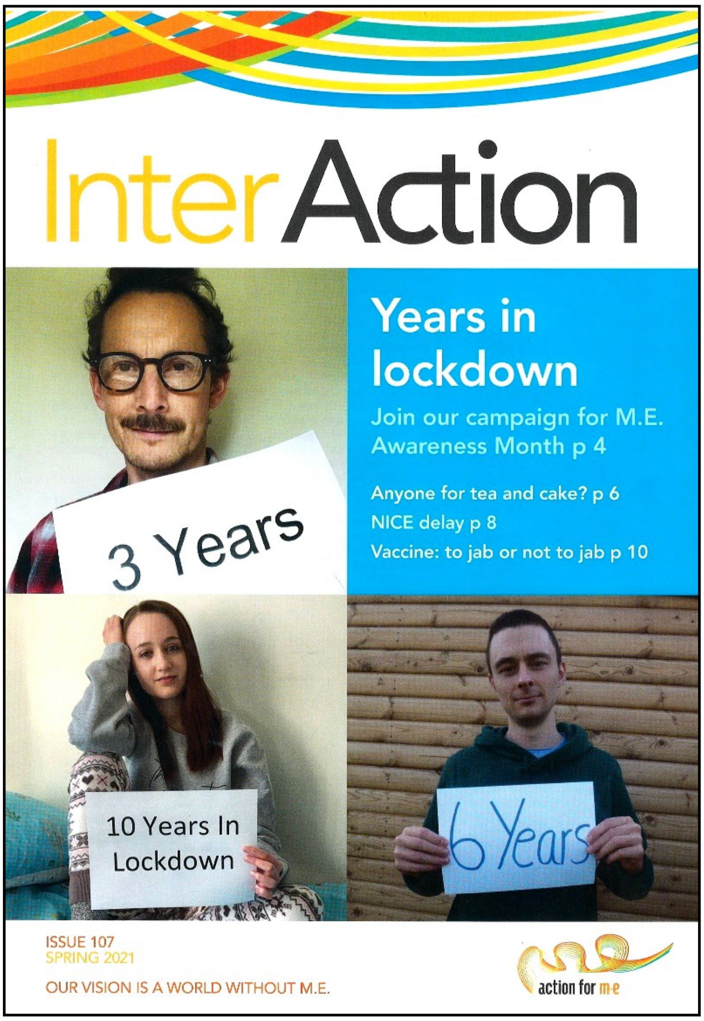
OUR CHRISTMAS APPEAL
Your support helped us to raise over £25,000!

INTIMACY AND M.E.
A sensitive discussion regarding the difficulties in coping with intimacy when you have ME/CFS.

ME Essential is the magazine of the ME Association. In this edition we see a tribute to Dr. Charles Shepherd, at 70. Charles is the Medical Director of the ME Associations, and represent our interests with many organisations. He is also well known for several books, the most well-known being "Living with ME". The ME Association is the major charity for ME/CFS and has many resources available to members on both printed and electronic form on their website. ME Essential covers many topics of interest and many of the problems related to life with ME/CFS.

When I first got ME, it took a lot of searching as at that time the internet was not available. What I did find useful in the early days was their information service. This answered many of my questions and at least I found an organisation that could help. It those early days there was no local NHS ME/CFS clinic. If was not until around 2004 the first patients were being seen by the Sheffield Clinic.

The ME Association can be contacted in the following ways.
By post: ME association, 7 Apollo Office Court
Radclive Road, Buckingham MK18 4DF
By Telephone: 01280 818963
By Website: https://meassociation.org.uk/



InterAction

Years in lockdown

Join our campaign for M.E. Awareness Month p 4

Anyone for tea and cake? p 6
NICE delay p 8
Vaccine: to jab or not to jab p 10

ISSUE 107
SPRING 2021
OUR VISION IS A WORLD WITHOUT M.E.

action for me

InterAction is the Magazine of Action for ME. In this edition, Topics around long covid syndrome, the lockdowns, and related topics around living with ME/CFS. Several feature in this issue compare life with ME/CFs to living life in lockdown.

Interaction like Action for ME takes is lead from the People rather than the experts. Originally, I joined Action for ME because of their information handouts. They have a range of information booklets covering all aspects of living with ME/CFS .

The most useful resource from Action is ME for anyone new to the condition is their booklet on Pacing - which is a must if you have just been diagnosed. This publication is used as a major resource used by the Sheffield ME/CFS clinic in the session management. They have a website which covers all aspects on ME/CFS with plenty of downloads.

Action for ME can be contacted in the following ways:
By post: Action for ME3Rd Floor, Canningford House,
38 Victoria St, Bristol BS1 6BY
By Telephone: tel:08451232380
By Website: https://www.actionforme.org.uk /

ME/CFS and Covid Vaccinations: The experience of members.

Because of the pandemic, and there being no vaccinations available in early 2020, researchers and manufactures start desperately looking for vaccine recipes. In previous years there had been two epidemics MERS and SARS1 which were due to members of the coronavirus family, and a successful vaccine had been made for these. So, they tried adapting the vaccine for MERS and SARS1 to SARS2 (the early name for Covid 19) with genome information supplied by the Chinese government from the original Wuhan outbreak. They all try in some way to get the immune system to recognise the Covid virus spike protein as an invader (surface antigen). Following express clinical trials, there have been two main manufacturers vaccines used locally earlier this year. The first vaccine to be used is the Pfizer type. This is made from RNA (Ribose Nucleic acid) coding for the spike protein, which is wrapped in a soap like substance to form a micelle (bubble). The AstraZeneca vaccine is made from RNA. However, the RNA is wrapped up in a coronavirus coat derived from a chimp virus. The idea behind both vaccinations is that somehow the RNA finds its way into a body cell, which then makes the cell produce the spike protein. The assumption is that the immune system recognizes the spike protein as an invader, that it creates antibodies, T cells (a type of white blood cell) and other immune components which attack anything looking like the spike protein.

It is well known that ME/CFS is associated with immune system abnormalities which in many cases is overactive . For some people with ME/CFS, the identified trigger is a vaccination, the most notorious being Hepatis B. I suspected that some members may abnormally adversely react to a Covid vaccination. Leger ME has a membership of about 70 active members, and through social media and emails I have kept in contact and asked them to report their experiences with the Covid vaccination. About 40 people responded and divided into two groups.

Group 1 consists of the people which reported sides effects of a minor nature. These consisted of the known side effects .e.g. sore arm, headache, fatigue, and what lasted less than a week.

Group 2 consists of people who reported major sides effects outside the known range. These were mainly a rebound of the ME/CFS malaise that lasted more than a week. Eight cases that come forward that were serious enough to report to the MHRA yellow card scheme. However only six supplied enough information to register. Here is a summary.

Case number	Gender	Manufacturer	Date of first Dose-2021	Reaction and Outcome after 12 weeks.	Second Dose
1	Female	Astra Zeneca	6th March	Rebound to Grade 3 ME/CFS 50% better as three months	Declined on GP advice. Had been ME/CFS free for 9 years. .
2	Female	Pfizer	24th March	Rebound lasted 7 weeks	18/5 Reported that there were no excess side effects.
3	Female	Astra Zeneca	13th February	Rebound 50% better at three months	22/4 Reported that there were no excess side effects
4	Female	Astra Zeneca	6th March	Rebound - no change at three months	Declined. ME/CFS was caused by hepatitis B vaccination
5	Female	Astra Zeneca	27th-February	Rebound - lasted 4 weeks.	25/4 Reported no excess side effects
6	Male.	Astra Zeneca	15th March	Rebound - appears to be ongoing.	Not responding to follow up enquiries

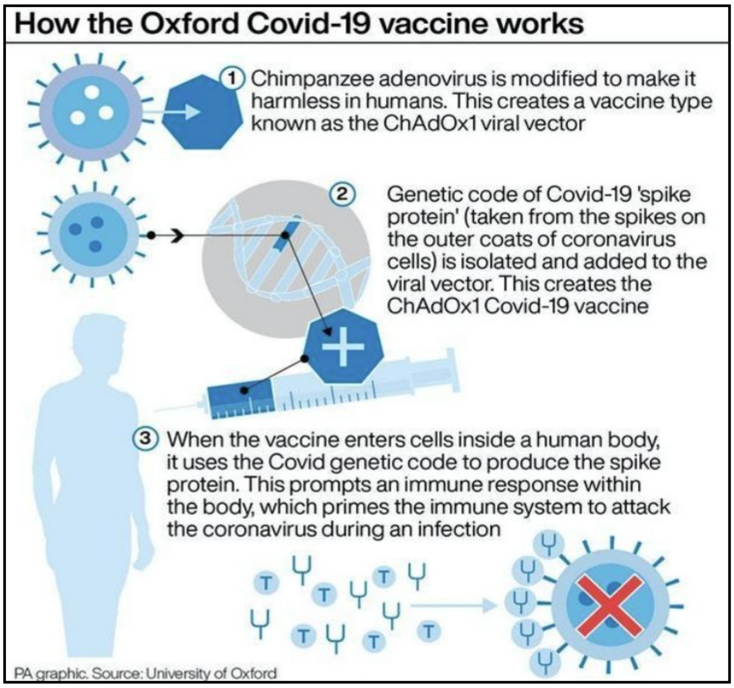
Comments

1) Although the table only contains six cases, all record a rebound occurring almost immediately after the vaccination. Curiously enough those which had the second vaccination report a very small or minor response. This seems to be the case as well with those in the first group who only reported the known minor side effects.

2) None of the cases reported symptoms of blood clots

3) Three reported fading of the rebound after many weeks, with one being no better.

4) Of the eight serious cases, seven were from the AstraZeneca vaccine, with only one from the Pfizer version. About 62% of the Covid vaccinations given in Doncaster are the AstraZeneca type, so based on that information, it tells me that we would have more problems with the AstraZeneca vaccine. It is difficult to know why, but I think it could be that AstraZenica vaccine viral shell is the problem for people with ME/CFS. So where possible, I have advised people to go for the Pfizer vaccine if they have a choice. Also, independently of ME/CFS there have been enough reports regarding the AstraZenica vaccine association with blood clots for the government to instruction that the AZ vaccine should not be given to those under 40.

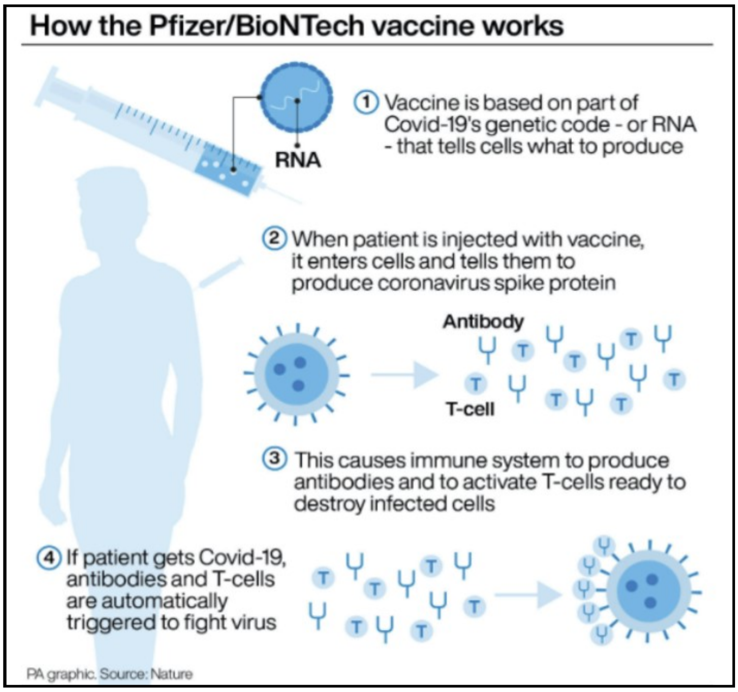


① Chimpanzee adenovirus is modified to make it harmless in humans. This creates a vaccine type known as the ChAdOx1 viral vector

② Genetic code of Covid-19 'spike protein' (taken from the spikes on the outer coats of coronavirus cells) is isolated and added to the viral vector. This creates the ChAdOx1 Covid-19 vaccine

③ When the vaccine enters cells inside a human body, it uses the Covid genetic code to produce the spike protein. This prompts an immune response within the body, which primes the immune system to attack the coronavirus during an infection

PA graphic. Source: University of Oxford



① Vaccine is based on part of Covid-19's genetic code - or RNA - that tells cells what to produce

② When patient is injected with vaccine, it enters cells and tells them to produce coronavirus spike protein

③ This causes immune system to produce antibodies and to activate T-cells ready to destroy infected cells

④ If patient gets Covid-19, antibodies and T-cells are automatically triggered to fight virus

PA graphic. Source: Nature

Email received from Dr Charles Shepherd, Medical Director, ME Association

Hi Mike,
Hope all is well with you in Doncaster - I have not paid a visit to God's Own County for well over a year! And thanks for providing this feedback.

If you are following MEA social media, you will have seen that we have been collecting a large amount of feedback on how people with ME/CFS are reacting to the covid vaccines - this includes a small but significant number who are reporting a more severe and/or persistent reaction. There should be a further MEA website update on vaccine feedback later this week

I am afraid I do not think there is any quick or easy solution here - because trying to open up any sort of meaningful discussion with the JCVI on issues of vaccine concern and ME/CFS is a real uphill task. What I am asking people to do, and I suspect that you have already done the same, is to make sure that these reactions are reported on the Yellow Card reporting system

I have also provided some guidance regarding second doses, where people with ME/CFS have had a bad reaction to the first dose in our latest COVID-19 and ME/CFS update:

https://meassociation.org.uk/2021/05/covid-19-me-cfs-infection-vaccines-long-covid-by-dr-charles-shepherd/

Wiped out. Energy and the Mitochondria in ME/CFS

With thanks to Dr Eleanor Roberts from M E Research UK

As anyone with ME/CFS can testify, the reason why people with the illness cannot do many everyday activities with the same ease with which they used to is that their muscles seem drained of energy. But what, in biological terms, is this energy that is so depleted? Understanding the process by which energy is stored and released in the body, and the ways in which this may be disrupted, could help explain two of the core features of ME/CFS: fatigue and post-exertional malaise.

ATP and the mitochondria

Two of the most important components of energy storage and production in the body are the molecule ATP (adenosine triphosphate), and structures called mitochondria which are found in most cells. Energy from the food we eat is stored as ATP by a process known as cellular respiration. ATP is often referred to as our energy currency because it can travel around the body and release that energy wherever it is needed.

Found in large numbers in most cells in the body, mitochondria are small structures whose main role is to produce the energy stored within ATP, which is why they are often referred to as the ‘power plants’ of the body. This whole process of energy storage and production is fairly complicated and involves a variety of other molecules and different biological pathways, so there are lots of ways in which it can go wrong.

One of the challenges in trying to investigate how the mitochondria might be dysfunctional in ME/CFS is narrowing down exactly where any abnormalities might occur.

This whole process of energy storage and production is fairly complicated and involves a variety of other molecules and different biological pathways, so there are lots of ways in which it can go wrong. One of the challenges in trying to investigate how the mitochondria might be dysfunctional in ME/CFS is narrowing down exactly where any abnormalities might occur.

Mitochondrial research in ME/CFS

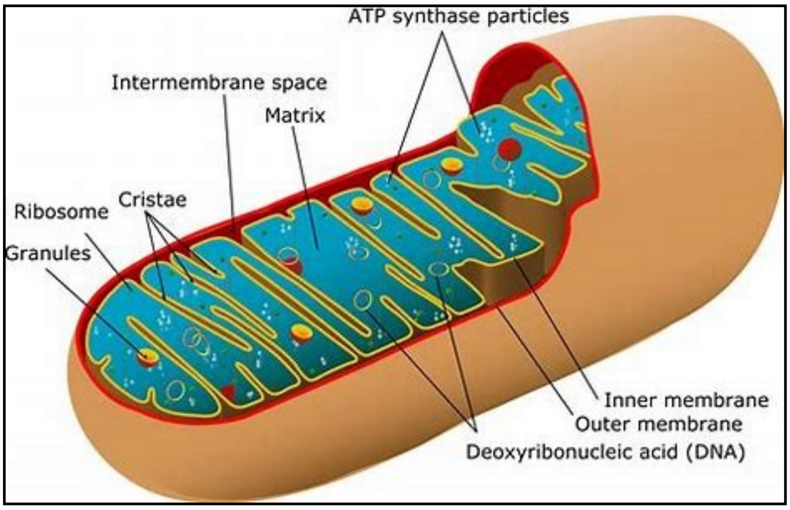
There has been much ME/CFS research in this area but arriving at a definitive answer is challenging because different studies have used a range of methods to examine the mitochondria in differing cell types, using samples from ME/CFS patients with a variety of levels of function and years of illness, and diagnosed using different criteria. These factors may have a huge impact on study results, highlighting the unmet need for large, multi-centre investigations using the same protocol and participant criteria to examine one of the basic underlying theories of what causes the disabling symptoms of ME/CFS.
In a bid to rationalise research in this area, Dr Sean Holden and colleagues conducted a systematic review of studies published in English that investigated the mitochondria in adults diagnosed with ME/CFS. In all of these studies, analyses were carried out using validated methods, and the results were compared with those from healthy control subjects. It should be noted that most of these studies looked at immune cells from the blood, which are easy to access and to work with. But it is not clear whether changes in one cell type will necessarily be reflected in other cell types.

Genetic defects

Although there are currently no signs that people with ME/CFS have any abnormality in the amount of mitochondrial DNA they have, some studies have found differences in mitochondrial DNA. These are subgroups of DNA which indicate a common ancestor.

One study reported that people with specific haplogroups were more likely to have experienced particular ME/CFS symptoms, including joint pain, bloating and a “dead/heavy feeling after exercise”. This suggests that, while haplogroups do not predispose a person to develop ME/CFS, they may play a role in determining which symptoms they experience.

Furthermore, while the DNA itself may be intact, there could be differences in how it is expressed (i.e., what proteins are being made from particular DNA sections). For example, one study of white blood cells found increased expression of genes involved in oxidative stress (which can cause cell damage) and decreased expression of genes involved in metabolism.



Mitochondrial structure

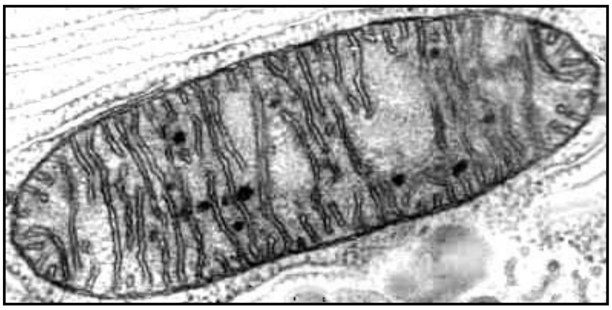
The number and structure of mitochondria in a cell can change according to the needs of the body. One obvious question is whether people with ME/CFS simply fewer mitochondria have available to release energy – but there does not seem to be any evidence of this.
One study has found differences in the structure of mitochondria in ME/CFS patients, namely irregular joining and branching of the. These are folds in the inner membrane of the mitochondria and are where most of the energy production takes place. So, changes in these cristae could conceivably affect energy release. However, other studies have not reported any changes in mitochondrial structure.

Energy production

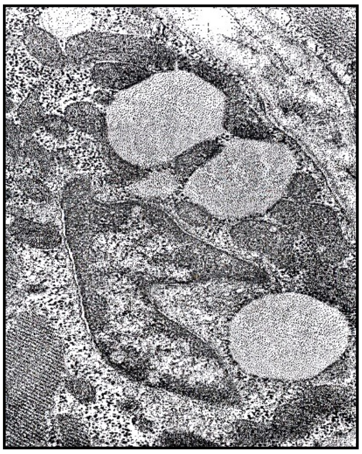
While the number and structure of mitochondria may not be drastically altered in ME/CFS, there are still lots of ways in which their function and effectiveness can be reduced. Findings that point to problems in mitochondrial function in ME/CFS include reduced cellular respiration (i.e., the conversion of carbohydrates into ATP) in some cell types, as well as various biochemical abnormalities that may also affect the production of energy as ATP. These abnormalities involve relatively complex processes, and a more in-depth discussion is beyond the scope of this article (see the links below for more detailed articles). There is also the possibility that the mitochondria are working fine but the problem lies in a biochemical pathway somewhere else within the cell, and there is a knock-on effect on mitochondrial function.

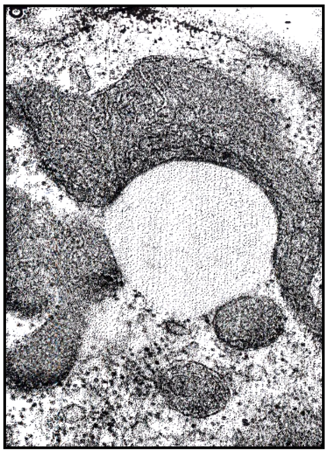
Summing up

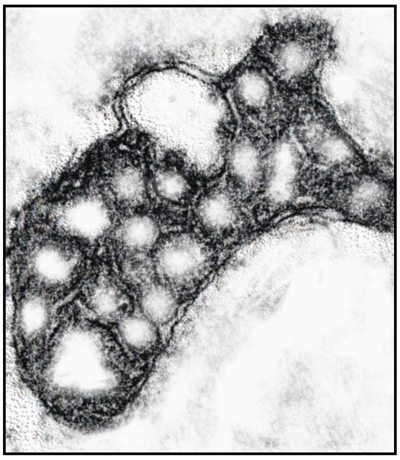
As the energy-producing centres of most cells in the body, the mitochondria seem like the obvious place to look for a cause of the profound fatigue and loss of energy experienced by people with ME/CFS. There does not yet seem to be a clear picture of what is going on, but research findings to date do strongly suggest some disruption to the mitochondria in ME/CFS. And this may be due more to problems in the actual process of energy production rather than any large genetic or structural faults in the mitochondria. As this picture becomes clearer, we hope to get closer to understanding what causes the fatigue and post-exertional malaise experienced by people with ME/CFS.



The theory of Mitochondrial damage being the cause of ME/CFS has been around for at least 30 years.
The electron micrograph to the left is the normal structure. The four micrographs below are mitochondria from ME/CFS patients show definite anatomical abnormalities. Disappointingly we are no further forward with treatment or exactly what these abnormalities mean.







Recipe Corner *with thanks to Carolyn*

GRILLED CHICKEN SALAD WITH AVOCADO DRESSING

*Serves 2/ Prep 20 mins/Cook 8 mins

Method:-
Put the chicken breasts between two sheets of cling film and beat with a rolling pin until 1cm thick. Stir together the yogurt, lemon and thyme and season with pepper.

Put the chicken and marinade into a bowl and leave for 15 mins.

Meanwhile, put the radish, cucumber, onions, bean sprouts and cress on a large salad bowl and toss.
Add the avocado, vinegar, oil, coriander and yogurt to a blender and blitz until smooth.
Cook the chicken under the grill for approximately 8 mins, turning once.

Drizzle the dressing over the salad, scatter over the sesame seeds, add the sliced chicken on top and serve.
Per Serving 402g, Carbs 8.1g, Cals 349

Ingredients

2 Chicken breasts (180g each)
2 tbsp Greek yogurt
2 tbsp lemon juice
1 tbsp fresh thyme
100g radish, thinly sliced
10cm cucumber, deseeded and sliced
4 spring onions, very thinly sliced
75g bean sprouts
1 punnet cress
½ an Avocado
1 tbsp rice wine vinegar
1 tsp sesame oil
1 tbsp chopped coriander
1 tbsp natural yogurt
1 tbsp toasted sesame seeds

RUNCHY VEGETABLE `SLAW` SLIDERS

*Serves 2/ Prep: 20 mins

Method:-
Very finely slice the fennel, Chinese leaf, radishes, spring onions and white onion and put into a bowl. Coarsely grate the apple and stir into the vegetables.

Put the dressing ingredients in a jam jar, close the lid and shake well. Drizzle over the slaw just before serving and toss well.

Divide between the six lettuce leaves and arrange on a serving platter. Sprinkle with the zaatar and nuts and serve.
Per Serving 329g:-Carbs – 21g ,Cals – 300.

Ingredients
Mains

¼ bulb Fennel
150g Chinese leaf cabbage
2 large radishes
3 spring onions
¼ white onion
50g carrots
1 large red apple
6 large little gem lettuce leaves
2tsp zaatar (or sesame seed/herb mix)
50g roasted mixed nuts, roughly chopped

Dressing :-

3 tbsp Greek no-fat yogurt
1 tbsp lemon juice
½ clove garlic, crushed
¼ tsp sugar
1 tsp canola oil

Out and About in Doncaster - Bentley Park

I have lived in Doncaster for many years, but it is only in the lockdown search for places to visit that I have visited Bentley Park. I have driven past it many times, but not really taken a good hard look. Like many of the parks around Doncaster, Bentley Park started off as a resource for the local miners and their families. With the mines closing, Bentley Park was transferred to Doncaster MBC and has in recent years received National Lottery funding. Please be aware that there are no public toilets in the park.

Accessibility There are several entrances all on the level. There are free car parks on Askern Road, Bentley, opposite the Bentley Baptist Church, with car parking also available at Cooke Street. If you are travelling by bus, several bus routes from Doncaster Frenchgate Interchange pass close by the park.

Bentley Pavilion. This historic building has long being a popular visitor attraction. You can also hire for celebrations, gatherings, meetings and activities; visit the Pit Stop Cafe; and take part in a number of community events.

Places to play: The park has toddler and junior play areas, with great facilities including the only water play area in the borough (please note this is closed during the winter months), a zip-wire and trampoline. There are also a playing fields.

Community Gardens. The park is home to a wonderful community garden, with lots of delicious food growing including strawberries, potatoes and herb mixes. Better yet, it's free to use as you please!. The Lily pond featured on the front page is part of the community garden.

Photos with thanks to DMBC.

BDA The Association of UK Dietitians

Food Fact Sheet

Chronic Fatigue Syndrome

Chronic fatigue syndrome (CFS) is also called ME, which stands for myalgic encephalomyelitis, (or encephalopathy). CFS/ME affects both adults and children, and can be serious, causing long-term illness and disability.

What are the symptoms?

Symptoms include some, or all, of the following:

- constant, overwhelming mental and physical tiredness (exhaustion)
- sleep disturbance, un-refreshing sleep
- post-exertion malaise (feeling worse after exercise)
- muscle pain and/or weakness or joint pain
- headaches, poor concentration or poor memory recurring sore throats or 'flu-like' symptoms
- feeling sick, (nausea)
- symptoms of IBS (Irritable Bowel Syndrome), such as wind/bloating, stomach pain, diarrhoea and constipation
- intolerance, or sensitivity, to alcohol, caffeine, some foods or medications

CFS/ME is poorly understood, with no specific diagnostic test. Diagnosis is made by excluding other causes of the symptoms.

Can what I eat help CFS/ME?

Eating a variety of healthy foods is very important for your health and wellbeing. Although diet alone isn't the cause, or cure, of CFS/ME, a poorly-balanced diet can compromise your health. Use the Eatwell guide to ensure your diet contains the best balance of foods from each group.

- **Potatoes, bread, rice, pasta and other cereals**, especially wholegrain provide fibre and energy. Try to include low GI (Glycaemic Index) foods, such as oats and wholegrains, which slowly release energy, helping to keep your energy levels stable. Eat a portion at every meal. If you are less active, because of your ME/CFS symptoms, you will use fewer calories, so choose healthier types over those high in added sugars and fats.
- **Fruit and vegetables.** Aim to eat more- 5+ portions a day.

- **Beans, pulses, fish, meat, and eggs.** These provide protein. Eat two portions a day. Eat more pulses and beans, and fish, and less processed meat, such as ham, sausages and burgers. Nuts also provide a nutritious snack, or addition to a salad or cereal.
- **Dairy and alternatives.** An important source of calcium for good bone health. This includes milk, cheese, yoghurts and calcium-enriched milk alternatives, such as soya based products. Note: not all milk alternatives, particularly organic ones, are calcium-enriched.
- **Fluid.** It is important to have a good fluid intake, 6-8 mugs / glasses per day is a good goal. Having too little fluid can lead to headaches, constipation and reduced alertness. Any type of fluid such as squash, juice, water, tea and coffee all count towards this.

Eating a little and often may help your symptoms. For example, have three smaller meals daily, with the addition of three snacks in between.

Unwanted weight changes?

People with CFS/ME may put on weight because they are less physically active. They may also eat more, because of low mood, boredom, comfort eating, or wanting to boost energy levels. Some report feeling more hungry than usual, (polyphagia). To combat weight gain keep higher calorie, fat and sugar foods, such as biscuits, chocolate, cake, crisps and sugary drinks to a minimum. Instead try vegetables and fruit or other healthy snacks.

Weight loss can occur because you are eating less. This may be because of a poor appetite, feeling sick, having altered taste and smell, or if exhaustion makes it difficult to buy, prepare or chew food. It will help to eat regularly, having small, softer texture, meals, quick and easy to prepare, and nourishing snacks and drinks.

If you are feeling sick, try snacking on dry, starchy foods, (such as toast/plain biscuits), eat little and often, and sip drinks throughout the day. Having something at breakfast may help.

Gut symptoms.

IBS-type symptoms, such as wind/bloating, abdominal pain, diarrhoea and constipation are common in CFS/ME. For managing IBS-type symptoms refer to the BDA Food facts on IBS.

If you need further help, ask your doctor to refer you to a dietitian. They may suggest you trial a complex and challenging diet, which reduces short-chain fermentable carbohydrates, (also known as a low FODMAP diet). It is strongly recommended that this is done with the support of a dietitian.

What about gut bacteria (microbiome) and CFS?

There is a lot of research into the role of the gut microbiome and the gut lining, or membrane "leaky gut" in CFS. So far, the results are inconclusive, and it is too early to recommend a specific diet such as gluten-free. There is evidence that some probiotics can be useful for IBS.

Myths about CFS/ME and food

There is a lot of conflicting advice and information on the internet. Many people with CFS do report an improvement in symptoms after changing what they eat. Yet there is no scientific evidence to support the claims that such as the Anti-Candida (low sugar/yeast) diet, or other restrictive diets, like the Paleo/Stone-Age or Blood Type diets, or eating chocolate help CFS.

These are not recommended and can create much more work and effort for sufferers and their carers. Although it is often thought to be better to avoid certain food types it can limit your choices, cost more and be less healthy. Many gluten-free foods, for example, are higher in fat and sugar. Many non-dairy milks are also lower in protein.

Food allergies and intolerances

CFS may affect or be affected by the immune system, but exactly how is unknown. However, CFS food related problems are more likely to be food intolerances, (not involving the immune system), than food allergies (immune system reaction). A detailed history by an experienced healthcare professional is required to diagnose and manage these. There are many commercially available tests claiming to diagnose food intolerance and allergy. These should be avoided as they have no scientific basis.

Are Supplements helpful?

There are many claims that nutritional supplements help CFS, including multi vitamins, B vitamins, magnesium, essential fatty acids (omega-3s), carnitine, and co-enzyme Q10. Any benefit of supplements in CFS is unproven and there is need for further research in this area. Some are very expensive and contain huge doses of the active ingredient. Large doses, for instance of Vitamin A and B6, can be harmful. If you are concerned about your nutritional intake, a multivitamin and mineral supplement, that provides no more than 100% of the recommended daily amount, (RDA - see the ingredients label), may be recommended. If you are housebound, or don't go outside much, your doctor should check your vitamin D levels, as you are at risk of low Vitamin D status. A Vitamin D supplement of 10 Micrograms daily is recommended all year round for those at risk.

Summary

CFS is a medically unexplained illness, with many unproven claims of diet and supplement treatments. If making changes yourself to your diet, care needs to be taken that your diet remains healthy, nutritionally adequate, and that there is no unwanted weight loss/gain. If you need further help with your diet ask your doctor to refer to a registered dietitian.

Further information:

Food facts sheets on other topics include Healthy Eating, Glycaemic Index (GI), Supplements, Food Allergy and Intolerance, Food Allergy and Intolerance Testing and IBS as well as a copy of the Eatwell Guide can be downloaded from **www.bda.uk.com/foodfacts**

This Food Factsheet is a public service of The British Dietetic Association (BDA) intended for information only. It is not a substitute for proper medical diagnosis or dietary advice given by a dietitian. If you need to see a dietitian, visit your GP for a referral or: www.freelancedietitians.org for a private dietitian.
To check your dietitian is registered check www.hcpc-uk.org
This Food Fact Sheet and others are available to download free of charge at www.bda.uk.com/foodfacts
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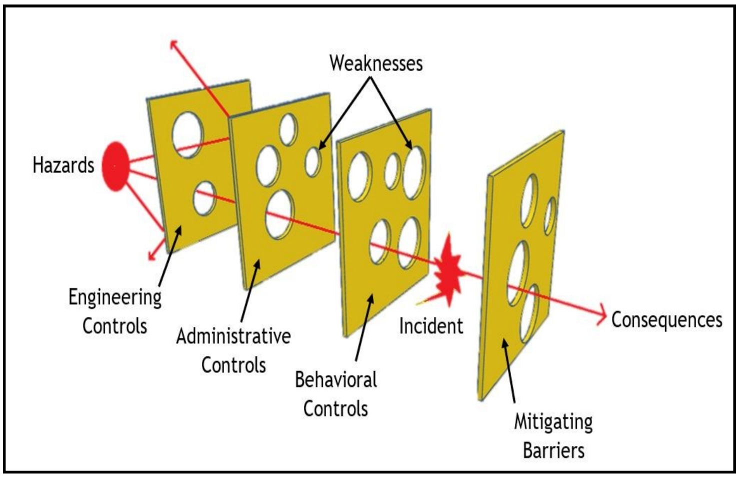
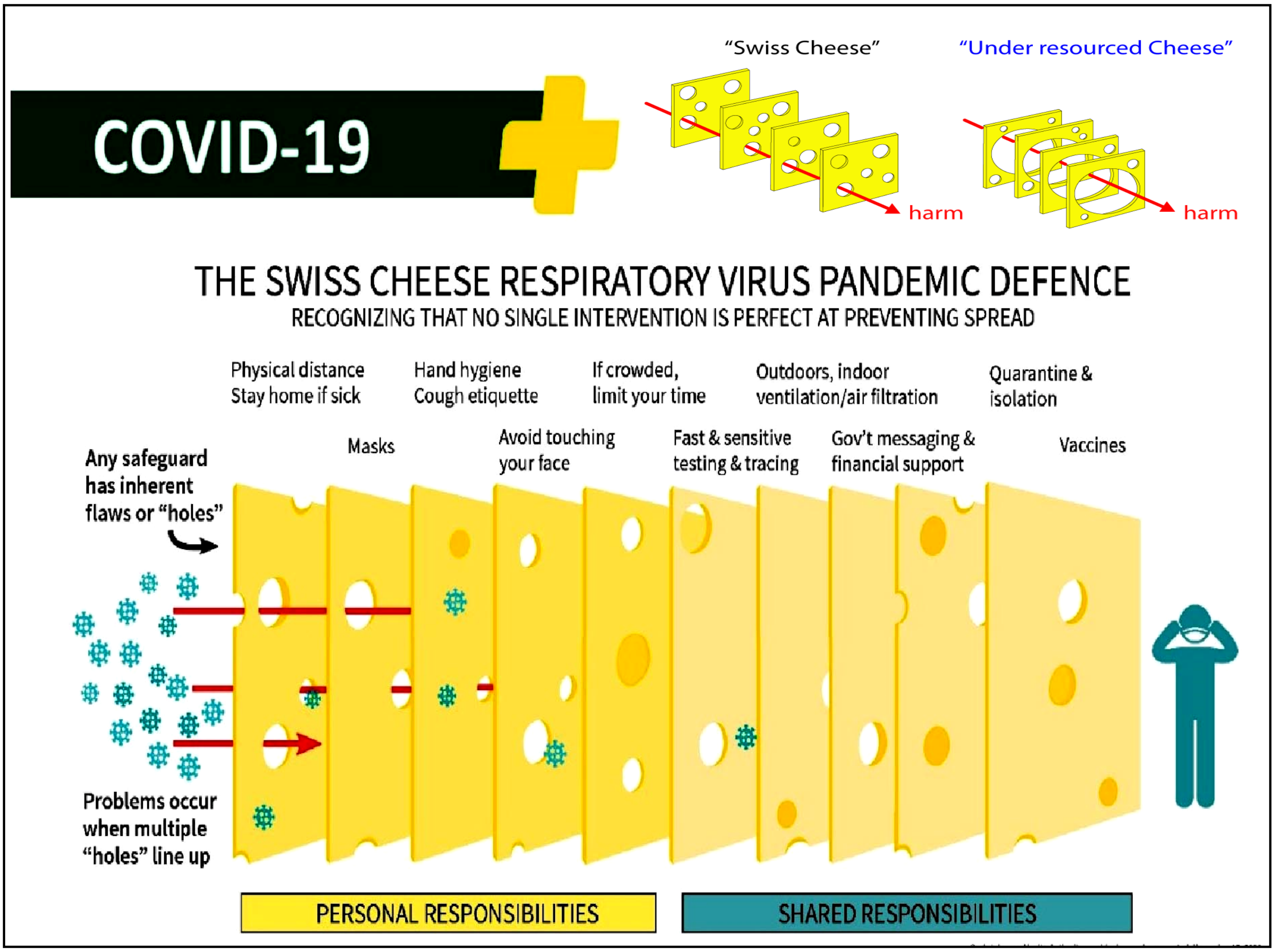
The Swiss Cheese Model.

The Swiss Cheese model is way to model risk analysis and risk management. It is used in accident causation, aviation safety, engineering, healthcare, computer security, emergency services, and by many other organisations. Whatever is being analyzed, it can be broken into layers. Each layer had some weakness or flaw which has been likened to the holes in Swiss cheese.



Suppose that you are thinking about the security of your home. The first priority is a good door lock. But there are problems with locks. They can be easily picked or broken. Adding a second layer may be a second lock, but that has the same weaknesses. Add in TV security system would be a deterrent but could easily be overcome by can of spray paint. A neighbourhood watch scheme would be another layer but there cannot be someone on watch all the time. A big dog would have its strengths and weaknesses, but none would be perfect. It is when holes in the system line up that there are consequences, or it is under resourced that there are consequences.

I have seen several applications Illustrating the Swiss Cheese model for Covid 19 defence. The one featured below is from the Saskatchewan Health authority in Canada and illustrate things very vividly.



Funicular Railways. How They Work

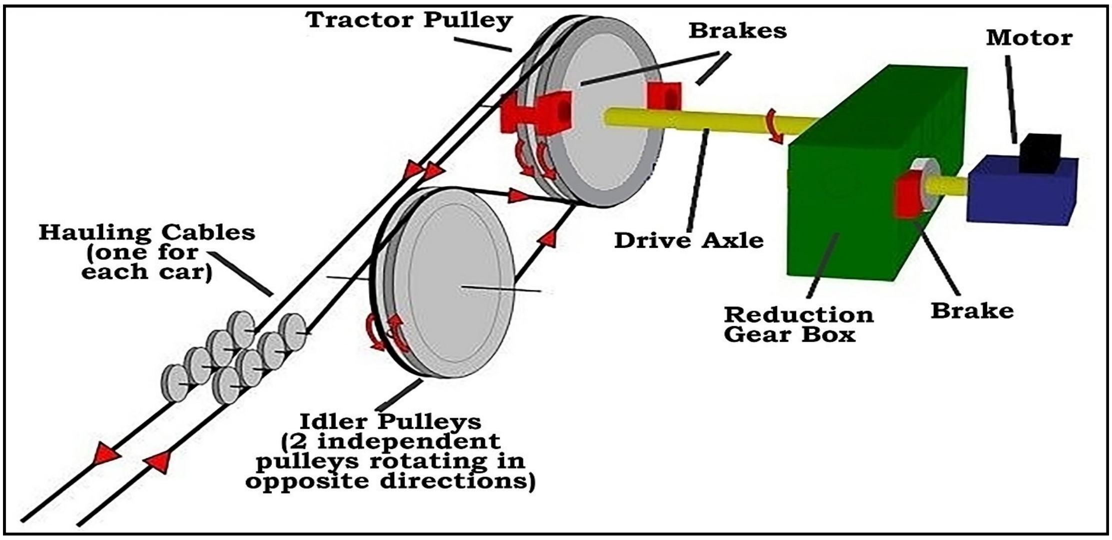
A funicular is form of a cable railway which connects points along a railway laid on a steep slope. Two counterbalanced cars are permanently attached to opposite ends of the haulage cable, which is looped over a pulley at the upper end of a track. The two cars move in opposite directions: as one goes up, the other goes down. This arrangement distinguishes funiculars from inclined elevators which have a single car that is hauled uphill. They are also different from counterbalanced inclines which operate on a similar principle hauling vehicles that are not permanently attached to the cable. The term funicular derives from the Latin word funiculus, the diminutive of funis, meaning 'rope'.

In a funicular both cars (or trains) are permanently connected to the opposite ends of the same cable, known as a haul rope. At the engine room at the upper end of the track, the haul rope runs through a system of pulleys. Sheaves—unpowered pulleys allowing the cable to change direction—guide the cable along the track and to and from the drive pulley. The rope pulls one car upwards while the other car descends the slope at the other end of the rope.

Except for the weight of passengers, the weight of the two cars is counterbalanced, so the engine only has to lift the excess passengers and supply the energy lost to friction.

An example of a funicular cliff railway in Devon. The Lynton and Lynmouth Railway is powered by water. The water is fills the tank underneath the car at the top, weighting the car down, and pulling the other one up. For the bottom car to go up all it has to do is to let the water out of it's tank.

In the past funiculars were powered by steam, the modern ones are usually pulled by an electric motor which is linked via a speed-reducing gearbox to a large pulley – a drive bullwheel. The bullwheel in its turn transfers its torque to the haul rope by friction. The bullwheel has two grooves: after the first half turn around it the cable returns via an auxiliary pulley. This arrangement has the advantage of having twice the contact area between the cable and the groove and returning the downward-moving cable in the same plane as the upward-moving one. Modern installations also use high friction liners to enhance the friction between the bullwheel grooves and the cable. For emergency and service purposes two sets of brakes are used at the engine room: the emergency brake grips directly the bullwheel, the service brake is mounted at the high-speed shaft of the gear. In a case of emergency, the cars are also equipped with spring-applied, hydraulically opened rail brakes. First funicular's caliper brakes which clamp each side of the crown of the rail were invented by the Swiss entrepreneurs Franz Josef Bucher and Josef Durrer and implemented at the Stanserhorn funicular, opened in 1893. The Abt rack and pinion system was also used at some funiculars for speed control or emergency braking.



North of Doncaster. *Personal Thoughts from Trevor Wainwright*

Scarborough’s Cliff Lifts or Funiculars

Well as promised at the end of my last article, here is the story of Scarborough’s Cliff Lifts or Funiculars to give them their proper name.

In the early 1870’s as Scarborough grew in popularity the height difference between the town and its beaches was a geographical hindrance and the need for better transit between the town and its bays was noted so the construction of Scarborough's first funicular commenced in 1873 as a means of better facilitating, and extracting revenue from, such movements, Scarborough would also be home to the first funicular railway in the United Kingdom, it would eventually have a total of five, only two of which are presently operational. What follows is a brief history of all five, and I have had the pleasure of travelling on four of them during family holidays in Scarborough, all of which offered wonderful views of the bays. So, here they are in order of build.


Top entrance


Car at the top ready


Getting in


Going down


Looking back


At the bottom

1) The South Cliff Lift (Operational). Work started in 1873 and it was specifically decided to build this initial cliff railway between the pre-existing Scarborough Spa on South Sands and the South Cliff Esplanade. At a cost of £8,000 it opened on 6th July 1875, two cars, each capable of carrying 14 seated passengers. Each car was attached to a twin-steel cable rope, which was originally operated by a brakeman at the top station, using seawater pumped into the upper car's water tank which was filled until the counterbalance point was reached. The cars then proceeded along their individual tracks, the speed and safety of both being regulated by the brakeman. When the upper car reached the bottom of the incline, both cars were braked, and the seawater released into a pipe set between the two tracks so that it could be reused. Since opening, it has been refurbished several times; the original gas engines replaced by steam pumps. The cars were replaced in 1934–1935. Another refurbishment, involving the replacement of the water system by a 90HP electric motor. During 1993, Scarborough Borough Council purchased the funicular from its owners. In 1997, the control infrastructure of the lift was extensively modified, enabling operations to be handled entirely by its automated systems. It remains the oldest working Funicular in the UK.


There are no known photos of the Queens Parade Cliff Lift, but this could well be where it used to be, the highest point of Queens Parade

2) Queen's Parade Cliff Lift. Observing the South Bay's first cliff railway, opened in 1875, to have been a success, proposals were rapidly actioned for a similar funicular to serve the neighbouring North Bay. So, on 4th March 1878, the Scarborough Queen's Parade Tramway Company Limited was created to build and operate such a lift. The selected route of the lift was 285 feet (87) in length one foot longer than the South Cliff Lift. At a relatively fast pace, it was opened for the first time on 8th August 1878. This first North Bay railway had two cars running. In many respects, its configuration was that of a typical funicular. Its propulsion system involved a pair of counterbalanced water tanks, one underneath each car; these were alternatively filled and emptied while the cars were in either station to change the weight of the cars and thus move the cars via gravity alone. However, the Queens Parade Cliff Lift experienced a series of particularly unfortunate events. The opening day was marred by one of the carriages having broken free and crashed into the lower station, with the resulting damage forcing the immediate closure of the funicular. It was not able to reopen until repairs were complete during the following year. This apparent bad luck continued through a series of accidents, including multiple landslips and equipment failures. The quick succession of misfortune caused the railway's management to conclude that the venture was untenable, resulting in operations being permanently ceased during 1887, barely nine years after opening. The neighbouring pier was also ill-fated, being destroyed by a gale in 1905.


Central Tramway, car waiting

3) Central Tramway (Operational). During the late 1870s, the Tramway was built between Foreshore Road and St Nicholas Gardens the selected route covering a distance of 233 feet. In 1880, work on the Central Tramway was completed head of its official commencement of operations on 1st August 1881. Operated by two cars. It originally used steam power generated by equipment sited roughly 59 feet beneath the top station; this gave the driver no direct view of the cars. To minimise the risk posed by potential equipment failure, each car is equipped with a safety brake system that works in conjunction with a rail located in the centre of each track. Over its operating life, several changes have been made, the original steam plant apparatus retired in favour of an electric drive, the original cars were also replaced, and new motors installed within the top of the station, which provided drivers with a full view of the cars. The lower station has subsequently been replaced by a more modern building, in which there is a mural of Victorian Scarborough. Passenger demand at the Central Tramway was particularly high, especially amongst guests at Scarborough's neighbouring Grand Hotel. The construction of the nearby St Nicholas Cliff Lift was heavily influenced by the level of demand for the Central Tramway. The lift has been continuously operated by the same company throughout its operating life.


Mural at the bottom
Mural at the bottom

St Nicholas Cliff Lift, now a cafe

4) St Nicholas Cliff Lift. Built in 1929 and opened on 5th August of that year. Completed at a cost of £6,000, the Saint Nicholas Cliff Lift is located on the other side of the Hotel the Central Tramway, near the Aquarium. The track is 102 feet long the shortest of the five lifts. During its initial years of operation, there was no bottom station; passengers stepped into the tramcars directly from the pavement. The control equipment was incorporated in the upper station, fares were also paid solely at this station. From the onset, it was powered by electricity. Sold to Scarborough Corporation in 1945. In February 2007, the lift was closed as the borough council could not afford the estimated £445,000 of modifications needed to conform with modern health and safety standards, it had been operating at a loss, allegedly also a factor in its closure. The cost of demolishing the lift was estimated to be around £150,000. After its closure, the two cars were moved to the top of the track and fixed in place, becoming part of the conversion of the top station into the St Nicholas Cafe. The cars offer seating and great panoramic views of the South Bay while enjoying a variety of refreshments a balcony was constructed around them. The lower station was converted into an ice cream parlour called The Seastrand, which has a sundeck seating area on the road reached by stairs on which is written an adaption of Scarborough Fair “Are you going to Scarborough Fair? Parsley, sage, rosemary, and thyme”...Between the salt water and Seastrand there once was a true love of mine”. Sadly, it is closed due to the pandemic.

5) North Bay Cliff Lift. During early 1930, the North Bay Cliff Lift was constructed by the Medway Safety Lift Company Ltd as one element of the wider development of Peasholm Gap giving access to Peasholm and Manor Parks, the corner Cafe complex, and the North Bay itself. Opening for the first time in August of that year, this lift was the only funicular serving the north bay throughout its operating life. Operated by a pair of cars running on parallel tracks, which had a length of 167 feet using an electric drive system. During September 1996, it was decided to close the lift permanently rather than undertake a series of repairs to correct mechanical issues and safety concerns, at an estimated cost of £75,000 to complete. Over the following two years, it was entirely dismantled, with the remaining elements being donated to the Launceston Civic Society in 1998. Much if these assets are presently in storage at the Launceston Steam Railway in Cornwall.