

Inherited Metabolic Disease and Coronavirus (COVID-19)

Facilitator:
Dr William Evans
Chair, NPUK



Coronavirus (COVID-19)

- You can submit questions through the online Q&A facility and we will try to provide answers to these questions after the webinar
- We will not be able to address questions relating to specific patients or conditions
- Please contact your patient organisation for practical, social care or financial support

Expert Panel:

Dr. Robin Lachmann

PhD, FRCP Consultant in Metabolic Medicine, Charles Dent Metabolic Unit, National Hospital for Neurology and Neurosurgery

Dr Roshni Vara

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Dr Elaine Murphy

Consultant Adult Inherited Metabolic Disease, Charles Dent Metabolic Unit, National Hospital for Neurology and Neurosurgery

Dr Simon Jones

Consultant in Paediatric Inherited Metabolic Diseases, Willink Unit, St Mary's Hospital, Manchester

Lynne Aitkenhead

Clinical Psychologist, Charles Dent Metabolic Unit, National Hospital for Neurology and Neurosurgery



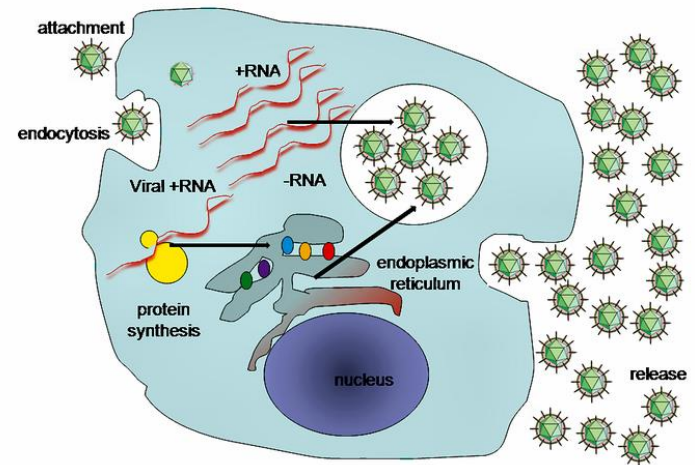
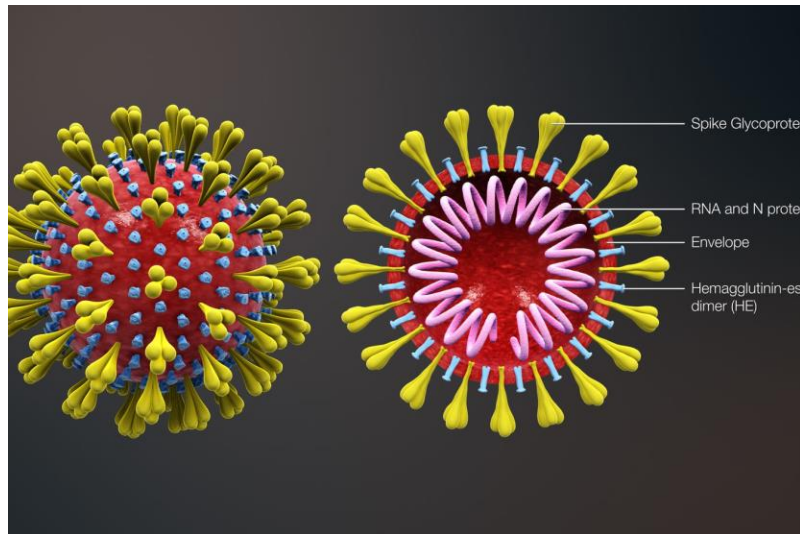
What is Coronavirus

How is it spread

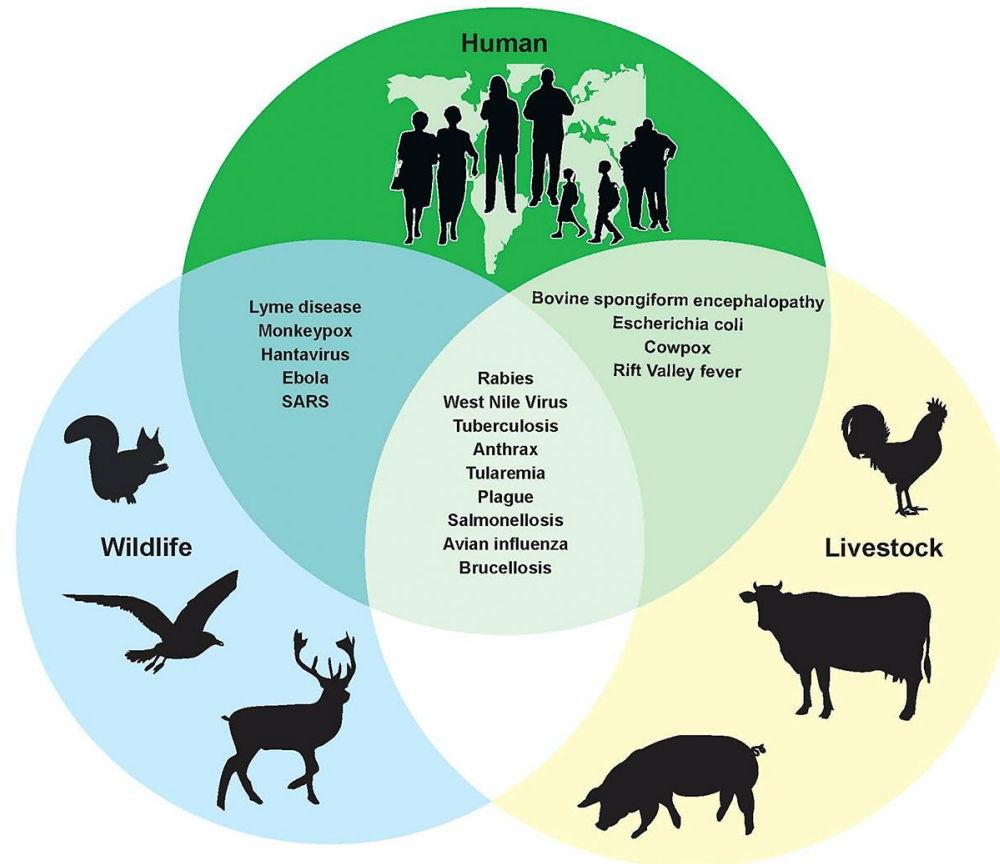
Who is at high risk

Dr Robin Lachmann

SARS-CoV-2: Severe Acute Respiratory Syndrome Coronavirus 2



Zoonoses



COVID-19

SYMPTOMS OF CORONAVIRUS DISEASE 2019

Patients with COVID-19 have experienced mild to severe respiratory illness.

Symptoms* can include

FEVER

COUGH

*Symptoms may appear 2-14 days after exposure.

Seek medical advice if you develop symptoms, and have been in close contact with a person known to have COVID-19 or if you live in or have recently been in an area with ongoing spread of COVID-19.

SHORTNESS OF BREATH



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For more information: www.cdc.gov/COVID19-symptoms



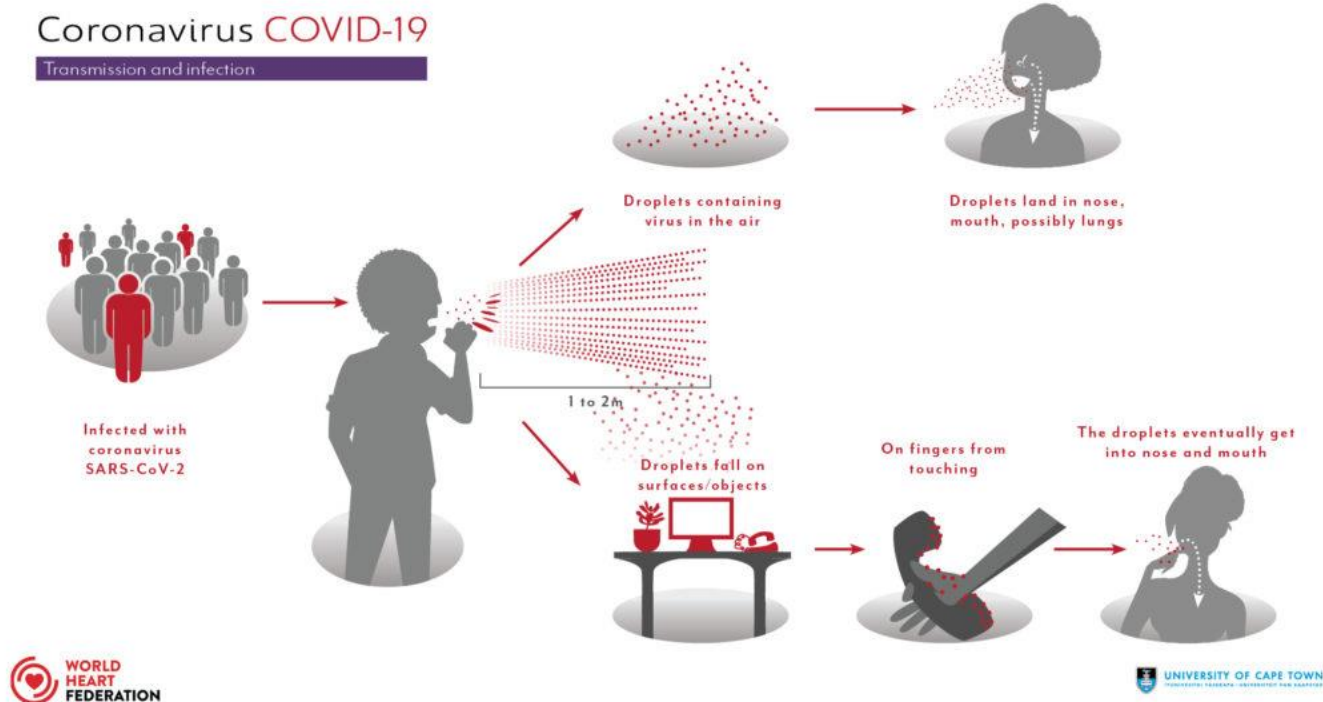
British Inherited Metabolic Disease Group

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Our common fight.



Transmission



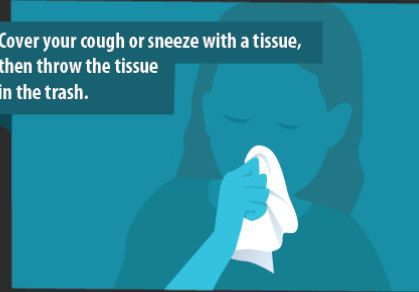
STOP THE SPREAD OF GERMS

Help prevent the spread of respiratory diseases like COVID-19.

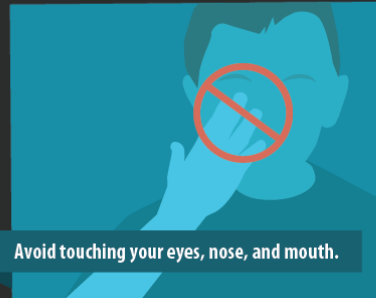
Avoid close contact with people who are sick.



Cover your cough or sneeze with a tissue, then throw the tissue in the trash.



Avoid touching your eyes, nose, and mouth.



Clean and disinfect frequently touched objects and surfaces.



Stay home when you are sick, except to get medical care.



Wash your hands often with soap and water for at least 20 seconds.



cdc.gov/COVID19

314915-A March 16, 2020 1:02 PM



British Inherited Metabolic Disease Group

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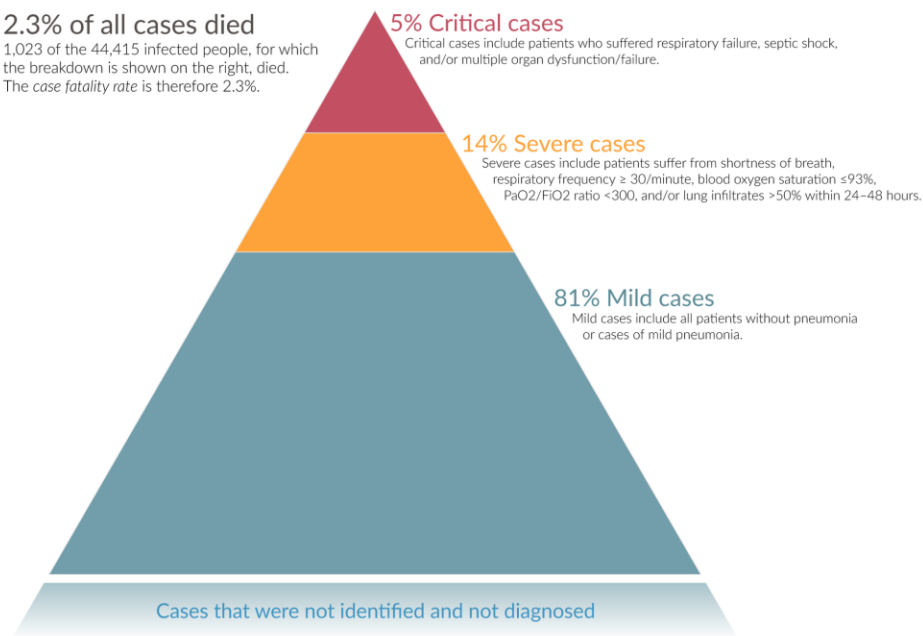
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COVID-19

2.3% of all cases died

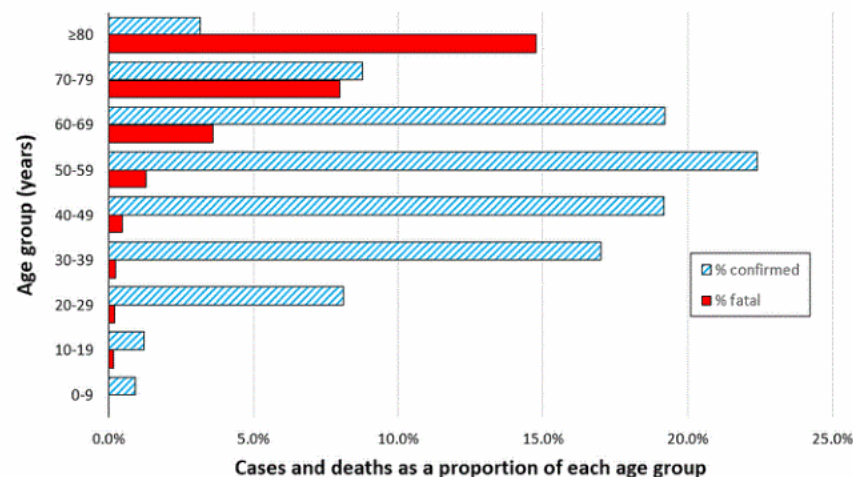
1,023 of the 44,415 infected people, for which the breakdown is shown on the right, died. The case fatality rate is therefore 2.3%.



Infected but not tested

COVID-19 cases and deaths by age (%)

From among 44,672 confirmed cases, Mainland China as of February 11, 2020



Data from Novel Coronavirus Pneumonia Emergency Response Epidemiology Team
The Epidemiological Characteristics of an Outbreak of 2019 Novel Coronavirus Diseases (COVID-19) — China, 2020

China CDC Weekly Vol.2

Prepared by Ian M Mackay, virologydownunder.com

Data up to: 11FEB2020

Last update: 25FEB2020 AEST



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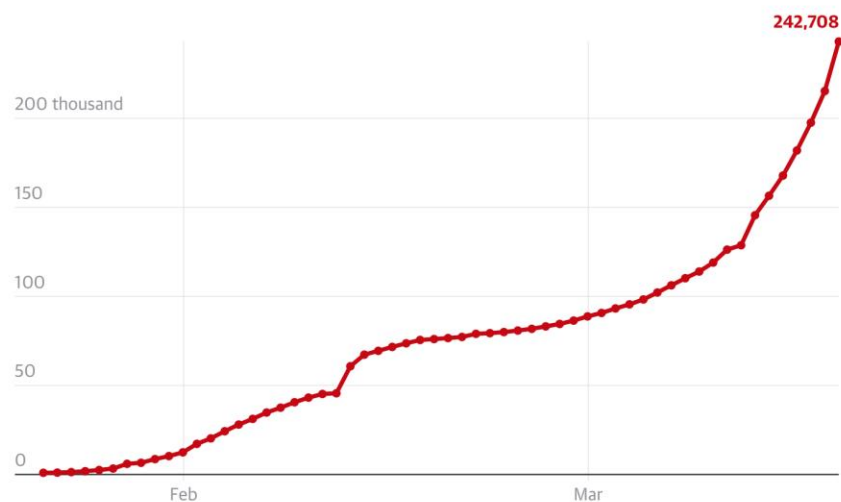
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Pandemic

Confirmed cases of Covid-19

Data correct at 23.59 UTC 19 March



Source: Johns Hopkins CSSE Note: The CSSE states that its numbers rely upon publicly available data from multiple sources, which do not always agree

18 March

Daily cases 17,768 | Total cases 214,910

New cases in Kyrgyzstan, Mauritius, Zambia and Djibouti



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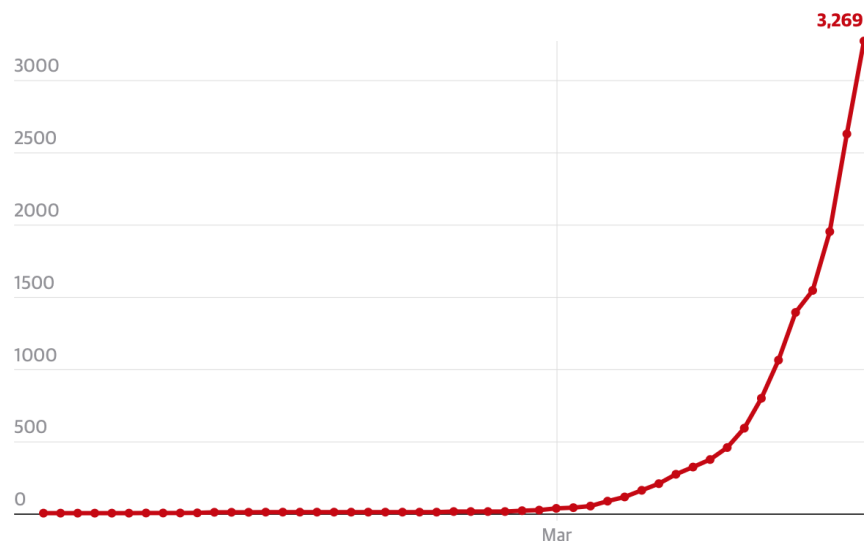
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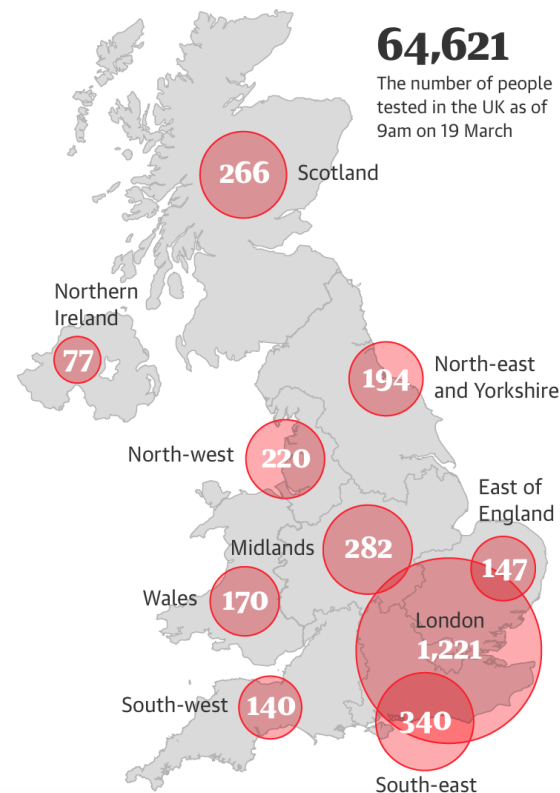
COVID-19 UK Epidemic

Data from Public Health England at 12:55 GMT 20 Mar 2020

Cumulative confirmed UK cases



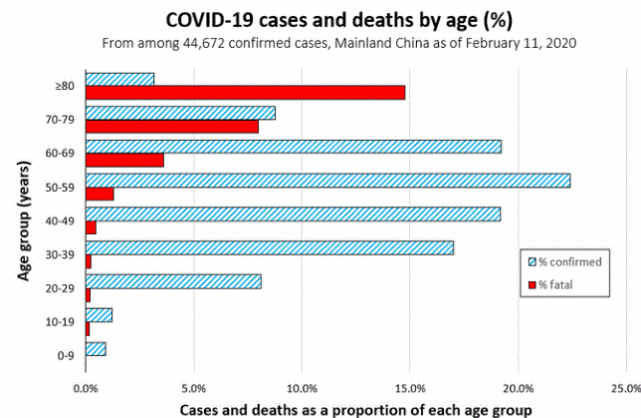
The UK has more than 3,000 cases of Covid-19



Guardian graphic. Source: Public Health England - data correct at 9am on 19 March

Public Health Response

- Protect the most vulnerable



- Protect the NHS

Profile of the epidemic under different approaches

Illustrative impact of social and behavioural interventions
lasting several months on a Reasonable Worst Case epidemic



Current Advice

How to avoid catching and spreading coronavirus (social distancing)

Everyone should do what they can to stop coronavirus spreading.

It is particularly important for people who:

- are 70 or over
- have a long-term condition
- are pregnant
- have a weakened immune system



Public Health
England

Guidance

Guidance on shielding and protecting people defined on medical grounds as extremely vulnerable from COVID-19

Published 21 March 2020



British Inherited Metabolic Disease Group



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Our common fight.



What do we mean by extremely vulnerable?

People falling into this extremely vulnerable group include:

1. Solid organ transplant recipients
2. People with specific cancers:
 - people with cancer who are undergoing active chemotherapy or radical radiotherapy for lung cancer
 - people with cancers of the blood or bone marrow such as leukaemia, lymphoma or myeloma who are at any stage of treatment
 - people having immunotherapy or other continuing antibody treatments for cancer
 - people having other targeted cancer treatments which can affect the immune system, such as protein kinase inhibitors or PARP inhibitors
 - people who have had bone marrow or stem cell transplants in the last 6 months, or who are still taking immunosuppression drugs
3. People with severe respiratory conditions including all cystic fibrosis, severe asthma and severe COPD.
4. People with rare diseases and inborn errors of metabolism that significantly increase the risk of infections (such as SCID, homozygous sickle cell).
5. People on immunosuppression therapies sufficient to significantly increase risk of infection.
6. Women who are pregnant with significant heart disease, congenital or acquired.

Inherited Metabolic Disease: Who is at High Risk?

High risk of serious coronavirus infection

- Underlying respiratory problems (Pompe, MPS, NP-B, GSD III)
- Immunosuppressed patients (Bone marrow or organ transplants)

Risk of metabolic decompensation

- UCDs
- FAODs
- MSUD
- Organic acidaemias (MMA, PA, IVA, GA1)

Age-group (years)	% symptomatic cases requiring hospitalisation	% hospitalised cases requiring critical care	Infection Fatality Ratio
0 to 9	0.1%	5.0%	0.002%
10 to 19	0.3%	5.0%	0.006%
20 to 29	1.2%	5.0%	0.03%
30 to 39	3.2%	5.0%	0.08%
40 to 49	4.9%	6.3%	0.15%
50 to 59	10.2%	12.2%	0.60%
60 to 69	16.6%	27.4%	2.2%
70 to 79	24.3%	43.2%	5.1%
80+	27.3%	70.9%	9.3%

Most people, and most people with IMDs, will have a mild infection and make a full recovery

Helping to stop the spread of Coronavirus Information on Medications and Treatment

Dr Elaine Murphy

How **everyone** can help stop coronavirus (social distancing)

Social distancing measures are steps you can take to reduce social interaction between people. This will help reduce the transmission of coronavirus (COVID-19).

They are to:

1. Avoid contact with someone who is displaying symptoms of coronavirus (COVID-19).
2. Avoid non-essential use of public transport when possible
3. Work from home, where possible. Your employer should support you to do this.
4. Avoid large and small gatherings in public spaces, noting that pubs, restaurants, leisure centres and similar venues are currently shut as infections spread easily in closed spaces where people gather together.
5. Avoid gatherings with friends and family. Keep in touch using remote technology such as phone, internet, and social media
6. Use telephone or online services to contact your GP or other essential services

Everyone should be trying to follow these measures as much as is practicable.

Social distancing is really important if.....

You are...

- aged 70 or older
- under 70 with an underlying health condition
 - chronic (long-term) respiratory diseases, such as asthma, chronic obstructive pulmonary disease (COPD), emphysema or bronchitis
 - chronic heart disease, such as heart failure
 - chronic kidney disease
 - chronic liver disease, such as hepatitis
 - chronic neurological conditions, such as Parkinson's disease, motor neurone disease, multiple sclerosis (MS), a learning disability or cerebral palsy
 - diabetes
 - problems with your spleen – for example, sickle cell disease or if you have had your spleen removed
 - a weakened immune system as the result of conditions such as HIV and AIDS, or medicines such as steroid tablets or chemotherapy
 - seriously overweight
- pregnant

Stay at home advice for extremely vulnerable individuals

From this week, the government will be asking people at even higher risk of severe illness from COVID-19 to follow **even more stringent measures**. **These people will receive a letter or text from the NHS.**

This is to try and **prevent these people from being exposed to and catching the virus at all**

- **Solid organ transplant recipients**
- People with specific cancers:
 - people with cancer who are undergoing active chemotherapy or radical radiotherapy for lung cancer
 - people with cancers of the blood or bone marrow such as leukaemia, lymphoma or myeloma who are at any stage of treatment
 - people having immunotherapy or other continuing antibody treatments for cancer
 - people having other targeted cancer treatments which can affect the immune system, such as protein kinase inhibitors or PARP inhibitors
 - people who have had bone marrow or stem cell transplants in the last 6 months, or who are still taking immunosuppression drugs
- People with **severe respiratory conditions** including all cystic fibrosis, severe asthma and severe COPD.
- People with **rare diseases and inborn errors of metabolism** that significantly increase the risk of infections (such as SCID, homozygous sickle cell).
- People on immunosuppression therapies sufficient to significantly increase risk of infection.
- Women who are pregnant with significant heart disease, congenital or acquired.

You will be contacted this week if it is felt that you fall into one of these groups

Stay at home advice for extremely vulnerable individuals

If you are considered vulnerable to complications from COVID19 or have a vulnerable person living with you...

Minimise as much as possible the time any vulnerable family members spend in shared spaces such as kitchens, bathrooms and sitting areas, and keep shared spaces well ventilated.

Aim to keep 2 metres (3 steps) away from vulnerable people you live with and encourage them to sleep in a different bed where possible. If they can, they should use a separate bathroom from the rest of the household. Make sure they use separate towels from the other people in your house, both for drying themselves after bathing or showering and for hand-hygiene purposes.

If you do share a toilet and bathroom with a vulnerable person, it is important that you clean them every time you use them (for example, wiping surfaces you have come into contact with). Another tip is to consider drawing up a rota for bathing, with the vulnerable person using the facilities first.

Stay at home advice for extremely vulnerable individuals

If you are considered high risk or have a vulnerable person living with you...

If you share a kitchen with a vulnerable person, avoid using it while they are present. If they can, they should take their meals back to their room to eat. If you have one, use a dishwasher to clean and dry the family's used crockery and cutlery. If this is not possible, wash them using your usual washing up liquid and warm water and dry them thoroughly. If the vulnerable person is using their own utensils, remember to use a separate tea towel for drying these.

We understand that it will be difficult for some people to separate themselves from others at home.

You can only do your best to follow this guidance and everyone in your household should regularly wash their hands, avoid touching their face, and regularly clean frequently touched surfaces.

There may be some vulnerable people, perhaps those towards the end of their life, who will choose not to stay at home – this is a voluntary choice.

Getting support for extremely vulnerable individuals

The screenshot shows a web browser window with the URL <https://www.gov.uk/coronavirus-extremely-vulnerable>. The browser's address bar and tabs are visible at the top. The GOV.UK logo is in the top left, and a search bar is in the top right. The main heading is "Get coronavirus support as an extremely vulnerable person". Below this, a paragraph states: "If you have a health condition that makes you especially vulnerable to coronavirus, the government is advising you to stay at home and take special steps to protect yourself." A section titled "Register to get coronavirus support - registrations open soon" follows, with text explaining that users can register for a new service if they or someone they care for is extremely vulnerable to coronavirus and needs support. It also mentions that the service will be ready over the week beginning 23 March 2020. A "Related content" section on the right lists a link: "Coronavirus (COVID-19): what you need to do". At the bottom, there is a feedback bar asking "Is this page useful?" with "Yes" and "No" options, and "Is there anything wrong with this page?". The Windows taskbar is visible at the very bottom.

<https://www.gov.uk/coronavirus-extremely-vulnerable>

GOV.UK

Home

Get coronavirus support as an extremely vulnerable person

If you have a health condition that makes you especially vulnerable to coronavirus, the government is advising you to stay at home and take special steps to protect yourself.

Register to get coronavirus support - registrations open soon

You'll be able to register for a new service if you or someone you care for is extremely vulnerable to coronavirus and needs support. For example, with getting essential supplies.

The service will be ready over the week beginning 23 March 2020. You'll be able to register from this page.

Related content

[Coronavirus \(COVID-19\): what you need to do](#)

Is this page useful? [Yes](#) [No](#) [Is there anything wrong with this page?](#)

<https://www.gov.uk/contact/govuk>

Medications

Is the NHS able to ensure that there will be no medication shortages?

The BIMDG pharmacists group have a UK network.

They are communicating regularly.

As of now, there are no shortages of critical specialist medications (including medications for urea cycle defects (sodium benzoate, sodium phenylbutyrate, glycerol phenylbutyrate), betaine, biotin and carnitine)

Similarly there are no shortages of essential dietary products such as glucose polymer

Several pharmaceutical companies have already communicated directly to us that they do not anticipate shortages.

Medications

Should I order a larger stock of medication just in case?

NO. We have seen what has happened when individuals have tried to stockpile food (a few people have more pasta than they can ever eat; many others have little or none currently).

We must not let this occur with medications.

The metabolic pharmacists will know when they have last dispensed medications for an individual and they will control demand and supply.

The pharmacists network means that they know where medication is and it can easily be moved around the country from one pharmacy to another as needed.

As with all services, pharmacists may be shorted staffed – so don't please leave your requests for medication until the last minute.

Medications

How will medication get to me if I am self-isolating?

Medication that is normally dispensed to you from the hospital pharmacy may now be delivered to you by post (many hospital pharmacies are now asking people not to turn up in person)

If you normally collect your medication from a local pharmacy or GP surgery – then start thinking now about who would collect this for you if you were isolating at home

Ask family, friends and neighbours to support you and use online services. If this is not possible, then the public sector, business, charities, and the general public are gearing up to help those advised to stay at home (particularly if you live alone).

Enzyme replacement therapy

What will happen with homecare delivered enzyme replacement therapy (ERT)?

We are making arrangements to continue with homecare delivered ERT (both for children and adults)

We recognise that for some patients there may be interruptions to treatment

- If there is a shortage of homecare nurses

- If the patient or a member of the patient's household is self-isolating

For some conditions we feel that the risk from missing a few ERT infusions will be low

- MPS

- Pompe disease (adult)

- Gaucher disease type 1

- Fabry disease

- LAL deficiency (adult)

Enzyme replacement therapy

Are there any conditions for which enzyme replacement therapy (ERT) will be prioritised?

We will be trying to maintain regular ERT in particular for these conditions

- Pompe disease (child)

- LAL deficiency / Wolman disease (child)

- Type III Gaucher disease (child)

- Some patients with MPS being prepared for stem cell transplant

- Niemann-Pick disease type B

- Intrathecal (spinal) ERT

Bottom line: We will be balancing risks and benefits at all times

Enzyme replacement therapy

What will happen with homecare delivered enzyme replacement therapy (ERT)?

Patients who are not self-isolating

Patients who are not self-isolating and do not have another person in their household who is required to self-isolate, can receive their infusions as normal.

You will be contacted by your homecare provider, to answer some questions and may be given specific instructions before a nurse is able to visit.

Enzyme replacement therapy

What will happen with homecare delivered enzyme replacement therapy (ERT)?

Patients who are self-isolating

If a patient is self-isolating, (this includes isolating due to another member of the household presenting with symptoms), then nurse visits for ERT infusions are paused for the duration of self-isolation.

You should inform your treatment centre if you are self-isolating and also let them know when you are ready to resume infusions.

Bottom line: If any member of a household is self-isolating or unwell – then please let the homecare teams know so that they do not visit your home.

Enzyme replacement therapy

Will homecare nurses be wearing full personal protective equipment (PPE)?

Homecare nurses will be following the latest NHS guidance (at present this does not include full facemasks)

They have a duty of care not to attend your home if they have symptoms

We are aware that some patients are choosing to interrupt their ERT (a 'drug holiday'), so as not to have any outside visitors or nurses come to their home

If you choose to do this, you will be supported by your team – it is best to discuss this decision with your metabolic team first so that the risks / benefits are clear (particularly if you are making this decision on behalf of a child)

Enzyme replacement therapy

I am completely independent with my ERT at home and don't require a homecare nurse to support me – will my ERT continue?

Yes – the aim will be that you continue your ERT as normal

There may be an option to train some people who are currently requiring homecare support to become semi- or completely independent (staff resources permitting). Ask your team for more information if you are interested in this.

Homecare resources are however unlikely to be able to arrange large-scale training rapidly if a large number of patients request this

ERT for extremely vulnerable individuals

Extremely vulnerable individuals, who are advised to stay at home to protect themselves from COVID-19

Will be offered

- a drug (ERT) holiday, or
- a switch to oral therapy if appropriate, or
- the possibility of continuing ERT if they are completely independent with this

Enzyme replacement therapy

I have a port-a-cath (central venous access device) inserted – what will happen to this if there is an interruption to my ERT?

Your device will need to be flushed

This will be done at the longest interval possible in line with the specific guidance for your device

Your team will be in touch to discuss this

Enzyme replacement therapy - other groups

Patients enrolled on an MAA (managed access agreement) eg. Vimizim for MPS IVa

We are expecting guidance from NICE and NHSE in the next few days
Your team will be in touch to discuss this

Patients waiting to start ERT

These decisions will be reviewed individually by your team
Some patients may start, others may have treatment delayed
Your team will be in touch to discuss this

Acute metabolic care during the pandemic
Advice for patients who already have a (dietary) emergency regimen

Dr Roshni Vara

Emergency regimens (ERs)

I have a dietary emergency regimen (ER) – do I need to do anything now?

Some individuals have specific guidance on what to do if they are unwell generally (eg. those with urea cycle defects, fatty acid oxidation disorders, some (not all) glycogen storage disorders, maple syrup urine disease, methylmalonic academia (MMA), glutaric aciduria type 1 (GA1) or propionic acidemia (PA)

- Read through your guidance if you haven't needed to use your ER for a long time
- Check that any medications or supplements that you keep at home are in date
- Keep a copy of your written emergency guidelines handy to show to other healthcare professionals if needed. Ask your team now if you can't find your guidance.
- Keep the contact details of your metabolic team handy eg. on your mobile phone
- If you use an oral emergency regimen (eg. oral glucose polymer) make sure you have enough supply at home to last at least 5 days

THE EMERGENCY GUIDELINES ARE ALL HELD HERE: WWW.BIMDG.ORG.UK

Emergency regimens

Will the metabolic emergency regimens continue to be followed by hospitals if a patient presents with a metabolic decompensation?

YES. Hospitals will continue to provide emergency care. If you or your child is unwell with a metabolic emergency please call 999 or present to A&E as you usually would.

The reason for cancelling the majority of routine work is to free up the hospital beds and staff to treat **ALL** emergencies – both COVID and non-COVID related.

You can help make things run more smoothly by:

- 1) Having your emergency guidance ready to show to the emergency staff
- 2) Bringing your usual medications / dietary supplements with you to hospital
- 3) Having the contact details of your metabolic team ready

Acute care during crisis: a child with IMD

- If your child with IMD is unwell at home – please commence your oral ER as advised / usual
- Contact your metabolic team as per normal guidance
- If the oral emergency is not tolerated at home and your child has no respiratory symptoms – then follow your usual open access process
- If your child has respiratory symptoms and needs medical assessment / not tolerating ER at home – the metabolic team will liaise with your local hospital and advice accordingly (i.e. where and when to attend)
- End of life care issues – please contact your local PPC or metabolic team

Remember – you can still call 999 in an emergency.

Acute care during crisis: an adult with IMD

- If you are unwell at home – please commence your oral ER as advised / usual
- Contact your metabolic team as per normal guidance
- If the oral emergency is not tolerated at home and you think you need hospital care then please present to your local hospital A&E department as usual. Bring your metabolic team contact details with you so that they can be called for advice.
- Everybody presenting to a hospital A&E department will be asked screening questions regarding COVID-19 on arrival
- Emergency care will be triaged as usual – with the most urgent cases being seen first

Remember – you can still call 999 in an emergency.

Social distancing and Self Isolation

- Children with IMD and families to adhere to current Government advice
- Social distancing where possible and isolate if patient / family or contact with symptoms
- Can only 'self isolate' as much as practically possible
- If a family member (not a main carer) is symptomatic, try to isolate as much as possible from child with IMD, particularly if high risk
- Consider asking neighbours and friends to help
- Higher risk; those at risk of metabolic decompensation (e.g. UCD, OA, GA1, FAOD, MSUD, Cbl disorders, mitochondrial) and those with pre-existing lung or heart disease (NPA/B, MPS with severe lung or airway disease, severe neurological disease)

Remember: the evidence is that COVID-19 is a mild infection for the majority of children – so we hope they will be able to cope as with any other infection

Advice for patients involved in research

Dr Simon Jones

Advice for patients involved in research

There is likely be staff shortages across all teams due to COVID-19

You will be contacted individually by your local metabolic research team

For those involved in registries / natural history studies – routine visits to hospital for tests and assessments may be suspended temporarily

If you are on a clinical trial of a new treatment – we will be aiming to continue that treatment for you as normal (but some hospital visits for assessments may be postponed)

Bottom line: We may need to stop some non-essential research (registries, natural history studies etc) but we aim to continue with trials of therapies of treatments.

How we can work together as an IMD / LSD community

Dr Elaine Murphy

Working together as a community

There is likely be staff shortages across all teams due to COVID-19

In adult care – we expect to be particularly busy...

- The metabolic nurse specialists may be redeployed to the general wards
- The administrative staff may be redeployed to cover essential tasks
- Some doctors have general medical or other qualifications and will be called to support other colleagues in the hospital where needed

We want you to keep contact with us as needed but you can really help by...

- Getting organised now with your medicines, supplements and emergency regimens
- Before you phone or email the metabolic team – check if the answer is available online or from your patient support organisation. Trust yourself – your gut instinct will often be correct
- Accepting that there may need to be some flexibility with days of administration & the frequency of ERT infusions, blood spot reporting, essential hospital appointments etc

Working together as a community

Many, many individuals with IMD have regular prescribed medications or dietary supplements, and are generally well and healthy

This (not exhaustive list) for example includes

- Phenylketonuria (separate advice will be given to women with PKU who are pregnant)

- Homocystinuria

- Galactosaemia

- Trimethylaminuria

- Familial hypercholesterolemia in young individuals without heart disease

- Well treated patients with Gaucher disease type 1

- Hypertyrosinemia types 1, 2 and 3

- Women with Fabry disease without significant heart or kidney involvement

These people should simply continue to take their treatment as prescribed and follow the NHS advice for the general population. We apologise, but some routine metabolic services may be temporarily delayed or disrupted for this group.

Working together as a community

Internet resources

Your patient support organisations – www.metabolicsupportuk.org and others

Government: <https://www.gov.uk/coronavirus>

NHS: <https://www.nhs.uk/conditions/coronavirus-covid-19/>

For mental health support:

<https://www.mind.org.uk/information-support/coronavirus-and-your-wellbeing/>

The LSD collaborative will send out written information this week to their members regarding clinical support and homecare treatments. These have been agreed by the paediatric and adult teams nationally.

Advice regarding coping and mental wellbeing

Dr Lynne Aitkenhead
Charles Dent Metabolic Unit, London

Coping and mental wellbeing

What difficult feelings might I have?

Anxiety and fear: worries about your health, about managing tasks, or the future

Sadness and loss: feelings about changes in your situation or plans

Guilt or shame: comparing yourself to others or thoughts about what you “should” be doing

Feelings related to self-isolation/social distancing: boredom, irritability, frustration, low mood or motivation

These feelings are normal, and there will be good days and bad days.

These feelings may be particularly intense if you or someone you care about become unwell. If these feelings are having a significant impact on your daily life, consider asking for more help.

Coping and mental wellbeing

What can help me to cope?

Set realistic expectations.

Prepare and focus on the practical steps that are in your control.

Talk to other people about how you are feeling. Model positive ways to express your feelings for other people around you.

Be aware that stress, anxiety and a change in routine can make some symptoms and difficulties worse for people with metabolic disorders.

Practice self-care, including following a routine and finding activities you can enjoy.

Coping and mental wellbeing

Where can I get more support?

Your Metabolic Centre may have a psychologist, or if not they will be able to help you to find psychological support elsewhere.

You can make a referral for yourself to your local psychological therapies service. Every borough has one – search online for ‘Can I get free therapy or counselling?’.

Metabolic Support UK, LSD Collaborative and other organizations for people affected by metabolic disorders.

Mind provide support and information for people experiencing mental health problems.

Carers UK have useful practical advice on their website, for example about how to set up a caring contingency plan.

Questions

If you have questions relating to your / your child's clinical care, please contact your metabolic team direct.

