

Coronavirus (COVID-19) and Multiple Endocrine Neoplasia

MEN and Coronavirus

This survey is currently open only for those with multiple endocrine neoplasia disorders (MEN1, 2A and 2B). If you, a family member, or a patient with MEN has had Coronavirus (living or sadly died), your/their experience could help others. Thank you for your help.

Other rare endocrine disease surveys are coming soon. Please do not complete this survey unless you have MEN.

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Permission

1. By completing this survey, you are confirming that you are happy for AMEND and its medical advisors to use the anonymous data gathered in research that will be shared publicly for the benefit of others. Are you happy for your data to be shared?

- Yes
- No

Coronavirus (COVID-19) and Multiple Endocrine Neoplasia

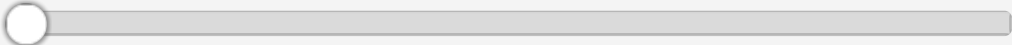
The Patient

2. Who are you completing this survey for? [if 'my child', 'a patient' or 'someone who has died from COVID-19, 'you' and 'your' refers to the patient throughout]

- Myself
- My child
- A patient (hospital staff only)
- Other, including someone who has died from COVID-19 (please specify, including your relationship to the patient)

* 3. Age

0 50 100



* 4. Gender

- Female
- Male
- Prefer not to say

* 5. In what country do you live?

* 6. Multiple Endocrine Neoplasia disorder type

- MEN1
- MEN2A
- MEN2B

Coronavirus (COVID-19) and Multiple Endocrine Neoplasia

MEN1

Because you selected MEN1, please let us know how this has affected you and what medicines you currently take

* 7. Please tell us what surgery you have had so far, if any [select all that apply]

- Partial parathyroidectomy (3 or fewer glands removed)
- Total parathyroidectomy (all glands removed)
- Transsphenoidal resection (removal of the pituitary gland)
- Pancreatic enucleation (removal of tumour only, leaving pancreas in place)
- Distal pancreatectomy (removal of the body and tail of pancreas)
- Total Pancreatectomy (complete removal of the entire pancreas as well as part of the duodenum causing diabetes mellitus)
- Partial Pancreatectomy / Whipple's Procedure (removal of the head of the pancreas, a portion of the bile duct, the gallbladder and part of the bowel and sometimes a part of the gut)
- Other (please specify)

	Same dose	Higher dose (including emergency injections)	Lower dose	Temporarily stopped	Don't know	N/A
Desmopressin (for diabetes insipidus)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Levothyroxine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Corticosteroids (e.g. hydrocortisone, prednisolone and fludrocortisone)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Somatostatin analogues (e.g. octreotide or lanreotide).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Proton pump inhibitors (PPIs) (e.g. lansoprazole, omeprazole)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
H2 blockers (e.g. cimetidine or ranitidine)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Diazoxide	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pancreatic enzymes (taken with food to aid its digestion)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Insulin injections (to replace the insulin normally secreted by the pancreas if diabetes mellitus occurs)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other (please specify)

Coronavirus (COVID-19) and Multiple Endocrine Neoplasia

MEN2A

Because you selected MEN2A, please let us know how this has affected you and what medicines you currently take

* 10. Please tell us what surgery you have had so far, if any [select all that apply]

- Total thyroidectomy
- Partial parathyroidectomy (3 or fewer glands removed)
- Total parathyroidectomy (either alone or as part of total thyroidectomy)
- Single side adrenalectomy (one adrenal gland only)
- Bilateral adrenalectomy (both adrenal glands)
- Other (please specify)

* 11. What medicines are you currently on for MEN2A? [select all that apply]

- Calcium carbonate (e.g. Calcichew, Adcal)
- Vitamin-D (e.g. ergocalciferol)
- Vitamin-D Analogue (e.g. calcitriol, alphacalcidol)
- Magnesium supplement
- Calcimimetics (Cinacalcet)
- Parathyroid Hormone Replacement Therapy (PTH-RT)
- Levothyroxine
- Corticosteroids (e.g. hydrocortisone, prednisolone and fludrocortisone)
- Proton pump inhibitors (PPIs) (e.g. lansoprazole, omeprazole)
- Alpha-blockers (e.g. phenoxybenzamine, doxazosin, prazosin)
- Beta-blockers (e.g. propranolol)
- Other (please specify)

* 12. How were your medicines changed during your treatment for Coronavirus?

	Same dose	Higher dose (including emergency injections)	Lower dose	Temporarily stopped	Don't know	N/A
Calcium carbonate (e.g. Calcichew, Adcal)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Vitamin-D (e.g. ergocalciferol)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Vitamin-D Analogue (e.g. calcitriol, alphacalcidol)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Magnesium supplement	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Calcimimetics (Cinacalcet)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Parathyroid Hormone Replacement Therapy (PTH-RT)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Levothyroxine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Corticosteroids (e.g. hydrocortisone, prednisolone and fludrocortisone)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Proton pump inhibitors (PPIs) (e.g. lansoprazole, omeprazole)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Alpha-blockers (e.g. phenoxybenzamine, doxazosin, prazosin)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Beta-blockers (e.g. propranolol)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other (please specify)

Coronavirus (COVID-19) and Multiple Endocrine Neoplasia

MEN2B

Because you selected MEN2B, please let us know how this has affected you and what medicines you currently take.

* 13. Please tell us what surgery you have had so far, if any [please select all that apply]

- Total thyroidectomy
- Partial or total parathyroidectomy
- Unilateral adrenalectomy (removal of one adrenal gland)
- Bilateral adrenalectomy (removal of both adrenal glands)
- Bowel surgery
- Other (please specify)

* 14. What medicines are you currently on for MEN2B? [select all that apply]

- Calcium carbonate (e.g. Calcichew, Adcal)
- Vitamin-D (e.g. ergocalciferol)
- Vitamin-D Analogue (e.g. calcitriol, alphacalcidol)
- Magnesium supplement
- Calcimimetics (Cinacalcet)
- Parathyroid Hormone Replacement Therapy (PTH-RT)
- Levothyroxine
- Corticosteroids (e.g. hydrocortisone, prednisolone and fludrocortisone)
- Proton pump inhibitors (PPIs) (e.g. lansoprazole, omeprazole)
- Alpha-blockers (e.g. phenoxybenzamine, doxazosin, prazosin)
- Beta-blockers (e.g. propranolol)
- Other (please specify)

* 15. How were your medicines changed during your treatment for Coronavirus?

	Same dose	Higher dose (including emergency injections)	Lower dose	Temporarily stopped	Don't know	N/A
Calcium carbonate (e.g. Calcichew, Adcal)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Vitamin-D (e.g. ergocalciferol)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Vitamin-D Analogue (e.g. calcitriol, alphacalcidol)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Magnesium supplement	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Calcimimetics (Cinacalcet)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Parathyroid Hormone Replacement Therapy (PTH-RT)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Levothyroxine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Corticosteroids (e.g. hydrocortisone, prednisolone and fludrocortisone)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Proton pump inhibitors (PPIs) (e.g. lansoprazole, omeprazole)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Alpha-blockers (e.g. phenoxybenzamine, doxazosin, prazosin)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Beta-blockers (e.g. propranolol)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other (please specify)

Coronavirus (COVID-19) and Multiple Endocrine Neoplasia

* 16. Do you fall into any the the official high-risk underlying medical condition categories?

	Yes	No
aged 70 or older	<input type="radio"/>	<input type="radio"/>
chronic (long-term) respiratory diseases, such as asthma, chronic obstructive pulmonary disease (COPD), emphysema or bronchitis	<input type="radio"/>	<input type="radio"/>
chronic heart disease, such as heart failure	<input type="radio"/>	<input type="radio"/>
chronic kidney disease	<input type="radio"/>	<input type="radio"/>
chronic liver disease, such as hepatitis	<input type="radio"/>	<input type="radio"/>
chronic neurological conditions, such as Parkinson's disease, motor neurone disease, multiple sclerosis (MS), a learning disability or cerebral palsy	<input type="radio"/>	<input type="radio"/>
diabetes	<input type="radio"/>	<input type="radio"/>
problems with your spleen – for example, sickle cell disease or if you have had your spleen removed	<input type="radio"/>	<input type="radio"/>
a weakened immune system as the result of conditions such as HIV and AIDS, or medicines such as steroid tablets or chemotherapy	<input type="radio"/>	<input type="radio"/>
being seriously overweight (a body mass index (BMI) of 40 or above)	<input type="radio"/>	<input type="radio"/>
those who are pregnant	<input type="radio"/>	<input type="radio"/>

* 17. Did you have the flu vaccination in preparation for this winter?

- Yes
- No

* 18. How were you diagnosed with COVID-19

- Via the telephone/online NHS Direct 111 service (without a blood test or swab)
- Via the telephone/online NHS Direct 111 service (with a blood test or swab)
- Via my GP/family doctor (without blood test or swab)
- Via my GP/family doctor (with blood test or swab)
- At a hospital A&E (with blood test or swab)
- As a hospital inpatient (with blood test or swab)

Coronavirus (COVID-19) and Multiple Endocrine Neoplasia

Blood test

* 19. You selected 'with blood test or swab' – how long did it take to get the result? [please answer in 'days']

20. What type of test did you have?

- To detect the virus during illness
- To detect the antibodies after illness
- I don't know / can't remember

Coronavirus (COVID-19) and Multiple Endocrine Neoplasia

About your COVID-19 experience

* 21. What was the date that you first noticed symptom(s)

Date

Date

DD/MM/YYYY

* 22. What were the first symptom(s) of the virus that you noticed? [select all that apply]

- Fever
- Stomach pains
- Sore throat
- Diarrhoea
- Nausea (with or without vomiting)
- Vomiting (without nausea)
- High temperature
- Cough
- Muscle aches
- Loss of sense of smell
- Tiredness / Sleepiness
- Headache
- Other (please specify)

* 23. Please tell us more about how severe the symptoms during your illness were (at their worst point)

	Slight	Moderate	Severe	N/A
Stomach pains	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sore throat	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Diarrhoea	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Nausea (with or without vomiting)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Vomiting (without nausea)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
High temperature / fever	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cough	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Blocked nose	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Runny nose	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Muscle aches	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Loss of sense of smell	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Tiredness / Sleepiness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Headache	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other (please specify)

* 24. What over-the-counter medicines did you take to help with these symptoms and did they work?

	Did not work at all	Worked a little bit	Worked quite well	Definitely worked	N/A
Cough medicine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Paracetamol (pain killer)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ibuprofen (pain killer)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Aspirin (pain killer)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Codeine (pain killer)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Throat lozenges	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other (please specify)

Coronavirus (COVID-19) and Multiple Endocrine Neoplasia

25. Did you need to go to hospital due to Coronavirus?

Yes

No

Coronavirus (COVID-19) and Multiple Endocrine Neoplasia

26. Why did you need to go to hospital [select any that apply]

- Severe breathing problems
- Complication related to my endocrine condition (e.g. adrenal crisis)
- Other (please specify)

27. Did you need to be cared for in the Intensive Care Unit (ITU)?

- Yes
- No

28. What intervention(s) did you need in hospital? [select all that apply]

- Oxygen only (mask or nostril tubes/prongs)
- Ventilation machine (e.g. CPAP)
- Tracheostomy (hole through the throat)
- Other (please specify)

29. How long did you have to stay in hospital for coronavirus? (days)

Coronavirus (COVID-19) and Multiple Endocrine Neoplasia

30. If you have any other comments or symptoms you'd like to tell us about, please use this box to tell us more.

Coronavirus (COVID-19) and Multiple Endocrine Neoplasia

31. May we contact you for further details or updates in the future?

Yes

No

Coronavirus (COVID-19) and Multiple Endocrine Neoplasia

32. Contact Details

Name	<input type="text"/>
City/Town	<input type="text"/>
Country	<input type="text"/>
Email Address	<input type="text"/>
Phone Number	<input type="text"/>

33. Name of Endocrine/Neuroendocrine Consultant