

Strategies to Provide Sufficient Anti-Protease Protection at Rest and During Acute Inflammation in ZZ Alpha-1 Antitrypsin Deficiency

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CITATION

Mcelvaney, Oisin (2022): Strategies to Provide Sufficient Anti-Protease Protection at Rest and During Acute Inflammation in ZZ Alpha-1 Antitrypsin Deficiency. Royal College of Surgeons in Ireland. Thesis.
<https://doi.org/10.25419/rcsi.19735954.v1>

DOI

[10.25419/rcsi.19735954.v1](https://doi.org/10.25419/rcsi.19735954.v1)

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https://repository.rcsi.com/articles/thesis/Strategies_to_Provide_Sufficient_Anti-Protease_Protection_at_Rest_and_During_Acute_Inflammation_in_ZZ_Alpha-1_Antitrypsin_Deficiency/19735954/1

Alpha-1 COVID Survey

* Required

1. Please enter your unique anonymised code. *

Pharmacy, GP and hospital details.

2. Do you know what type of alpha-1 you have? *

Mark only one oval.

☐ MZ

☐ SZ

☐ ZZ

☐ I don't know

☐ Other:

3. May we have permission to call your pharmacy about antibiotic and steroid usage? (We will be contacting them to figure out how many times you have needed antibiotics or steroids for chest infections over the past 3 years) *

Mark only one oval.

☐ Yes

☐ No

☐ Other: _____

4. Pharmacy name. *

5. Pharmacy address. *

6. Pharmacy number (if known). *

7. GP name. *

8. GP address. *

9. GP number (if known). *

10. Which hospital would you normally attend for chest infections? *

11. May we have permission to review the X-ray/ CT scan reports from that hospital? (This will help us figure out how many chest infections you have had over the past 3 years) *

Mark only one oval.

☐

Yes

☐

No

☐

Other:

Smoking

Smoking habits.

12. Have you ever smoked? (More than 20 in your lifetime) *

Mark only one oval.

☐ Yes *Skip to question 13*

☐ No *Skip to question 16*

Smoking Habits

Smoking habits

13. When did you start smoking? (Try to remember to the nearest month and year) *

Example: January 7, 2019

14. When did you quit smoking? (Try to remember to the nearest month and year ** Enter current date if still smoking**) *

Example: January 7, 2019

15. On average, how many cigarettes did you smoke PER DAY during this time? ***Be as accurate as you can (You can say 4 or 9 or 53 per day for example)*** *

Vaping

Vaping

16. Have you ever vaped? (More than 5 times in your lifetime) *

Mark only one oval.

- ☐ Yes *Skip to question 17*
- ☐ No *Skip to question 22*

Vaping habits

Vaping Habits

17. When did you start vaping? *

Example: January 7, 2019

18. When did you stop vaping? *

Example: January 7, 2019

19. What concentration of nicotine did / do you normally use? *

Mark only one oval.

- ☐ 0mg
- ☐ 3mg
- ☐ 6mg
- ☐ 12mg
- ☐ 18mg
- ☐ Other: _____

20. How much fluid (millilitres) was / is in each refill bottle? *

21. How many days did / does each refill bottle last? *

Cigars

Cigars

22. Have you ever smoked cigars? (More than 5 in your lifetime) *

Mark only one oval.

☐ Yes *Skip to question 23*

☐ No *Skip to question 26*

Cigar Habits

Cigar habits

23. When did you start cigars? *

Example: January 7, 2019

24. When did you stop smoking cigars? *

Example: January 7, 2019

25. On average, how many cigars would you smoke PER WEEK during this time? *

Rollies

26. Have you ever smoked rollies / roll-up / roll-your-own cigarettes? (More than 1 pouch in your lifetime) *

Mark only one oval.

- ☐ Yes *Skip to question 27*
- ☐ No *Skip to question 31*

Rollies (cont'd)

27. When did you start smoking rollies? *

Example: January 7, 2019

28. When did you stop smoking rollies? *

Example: January 7, 2019

29. What size pouch would you normally buy (in grams)? *

Mark only one oval.

☐

25

☐

30

☐

Other: _____

30. On average, how many days would a pouch last you? *

Alcohol

31. Do you drink alcohol? (More than 3 times per year) *

Mark only one oval.

☐

Yes

Skip to question 32

☐

No

Skip to question 36

Alcohol (cont'd)

32. What type of alcohol would you normally drink? *

Mark only one oval.

- ☐ Mostly beer
- ☐ Mostly spirits
- ☐ Mostly wine
- ☐ Mostly mixed
- ☐ Other: _____

33. How many units of alcohol would you drink in a TYPICAL WEEK? *

FOR REFERENCE: 1 pint of beer is 2 units. 1 bottle of wine is 10 units. 1 small measure of spirits is 1 unit.

34. How has the pandemic affected your drinking habits, in your opinion? *

Mark only one oval.

- ☐ I drink less now
- ☐ I drink about the same now
- ☐ I drink more now
- ☐ Other: _____

35. What is the main reason for the change in your drinking habits? *

Mark only one oval.

- ☐ Pubs being closed
- ☐ Active decision to change drinking habits
- ☐ Use of alcohol as a coping mechanism
- ☐ Other: _____

Working

36. Are you currently employed? *

Mark only one oval.

- ☐ Yes
- ☐ No
- ☐ Other: _____

37. Are you retired? *

Mark only one oval.

☐

Yes

☐

No

☐

Other:

38. What is/was your main occupation? (The occupation you spent the longest time working in)

Please be as specific as you can.

39. When did you start? (To the nearest month and year if you can)

Example: January 7, 2019

40. When did you finish? (To the nearest month and year if you can)

Insert current date if still employed.

Example: January 7, 2019

Working From Home

41. Did you work from home at any time during the pandemic?

Mark only one oval.

- ☐ Yes *Skip to question 42*
- ☐ No *Skip to question 45*

Working From Home (cont'd)

42. When did you start working from home?

Example: January 7, 2019

43. When did you stop working from home?

Example: January 7, 2019

44. How many months in total did you work from home? (If not continually) *

Sick Leave

45. How many sick days have you had to take in the past ONE YEAR due to alpha-1 / chest infections? *

46. How many sick days have you had to take in the past THREE YEARS due to alpha-1 / chest infections? *

47. Have you had to give up your occupation because of alpha-1 antitrypsin deficiency or conditions related to alpha-1? *

Mark only one oval.

☐

Yes

☐

No

☐

This does not apply to me

☐

Other:

48. If you did have to give up your occupation, what was the MAIN reason in your opinion? *

Mark only one oval.

- ☐ Breathlessness
- ☐ Liver issues
- ☐ Chest infections
- ☐ Too little energy
- ☐ Mental health reasons
- ☐ Deteriorating overall health
- ☐ Concerns over workplace causing illness
- ☐ This does not apply to me
- ☐ Other: _____

49. What age did you stop working?

Cocooning

50. Did you cocoon? *

Mark only one oval.

☐ Yes *Skip to question 51*

☐ No *Skip to question 54*

Cocooning (cont'd)

Cocooning continued

51. What date did you start cocooning? *

Example: January 7, 2019

52. What date did you finish cocooning? *

Example: January 7, 2019

53. How many months in total have you cocooned? (If not continually) *

COVID

54. Did you have confirmed COVID? *

Mark only one oval.

☐ Yes

☐ No

55. Were you hospitalised due to COVID? *

Mark only one oval.

☐ Yes

☐ No

Chest infections over the past ONE YEAR

56. Have you had any chest infections over the past ONE YEAR? *

Mark only one oval.

☐ Yes *Skip to question 57*

☐ No *Skip to question 63*

Chest infections over the past ONE YEAR (cont'd)

57. How many TOTAL chest infections have you had in the past ONE YEAR? *

58. How many of these chest infections went away without treatment? *

59. How many of these chest infections did you need to go to your GP for? *

60. How many of these chest infections did you need to get treated by your GP? *

61. How many of these chest infections did you need to go to your GP more than once for treatment? *

62. How many of these chest infections did you need to be admitted to hospital for? *
-

Chest infections over the past THREE YEARS

63. Have you had any chest infections over the past THREE YEARS? *

Mark only one oval.

- ☐ Yes *Skip to question 64*
- ☐ No

Chest infections over the past THREE YEARS (cont'd)

64. How many TOTAL chest infections have you had in the past THREE YEARS? (Include the chest infections you had in the past one year in this total) *
-

65. How many of these chest infections went away without treatment? *
-

66. How many of these chest infections did you need to go to your GP for? *

67. How many of these chest infections did you need to get treated by your GP? *

68. How many of these chest infections did you need to go to your GP more than once for treatment? *

69. How many of these chest infections did you need to be admitted to hospital for? *

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