Simplifying the treatment burden in CF

Welcome to our survey

What are the effective ways of simplifying the treatment burden of people with Cystic Fibrosis?

This was recently chosen by the CF community as the most important question to be answered by research.

If you are a person with CF, a parent of children with CF, a relative or a health care professional who cares for people with CF, please help us begin to answer this question by taking part in the following questionnaire.

We understand that people with CF are asked to undertake a vast treatment routine each day. We would like to know more about how CF treatment routines impact people with CF (and those that care for them), to gain a better understanding of treatment burden.

We ask that you answer the questions honestly so that we gain a complete picture of your experiences. If you are a parent or relative of a person with CF you may want to complete this answering for yourself (about the burden you feel) or on behalf of your relative(s) (about the burden they feel). Therefore you may wish to complete the survey more than once. Please only answer the questions you feel are relevant.

Please be assured that this survey remains completely anonymous. This means that you will not be identifiable from the answers you provide. If you leave your contact details for further involvement activities these will be separated from your survey answers before they are looked at.

Many thanks,

The Evidence Based Child Health Team at The University of Nottingham, UK

Simplifying the treatment burden in CF

* 1. Are you

- ○ A person with CF?
- ○ A parent of a child or children with CF?
- ○ Spouse or partner of a person with CF?
- ○ Other relative or friend of a person with CF?
- ○ A health care professional or researcher working with CF?

Simplifying the treatment burden in CF

We are aware that living with CF brings different kinds of challenges and that there are times when things can be more difficult than others. These difficulties may or may not be directly related to your CF. We know that CF and the treatments that go with it (medicines/nebulisers/inhalers/physiotherapy/insulin/nutrition & feeds) bring significant physical, mental, emotional, practical and financial challenges for those living with the condition. While living an independent life, it can be difficult to get all the treatments done every day and prioritise your health while doing all the other things you need to do in the real world. We know that sometimes it can feel like the psychological aspects of CF and the burden of treatment are worse than the condition itself.

We are interested to hear about the perspectives on treatment burden on people with CF and how treatment burden affects family members as well.

2. I am answering

○ for myself (as a person with CF)

○ for myself (as a parent, spouse, other relative or friend of a person with CF)

○ on behalf on my child/relative

3. If treatments feel hard or get you down, is it everything overall or just specific aspects/treatments that cause problems? Please let us know what comes to mind?

4. Are there any aspects of daily treatment that make you feel worse?

5. Is it easier to do treatments when you feel they work?

○ Yes

○ No

○ Sometimes

How do you tell whether a treatment works or not?

6. Have you found a good routine that works or do you just do things when you can?

○ Yes I have found a good routine that works

○ No, I just do things when I can

○ Other (please specify)

7. Are there some treatments you feel work better than others?

○ Yes

○ No

If so which are these?

8. When you are very busy or feeling tired, are there some treatments you sometimes miss out?

○ Yes

○ No

○ Sometimes

Is it always the same thing(s)? Can you please tell us what they are.

9. Are there some aspects of your daily treatment that you find more difficult than others?

○ Yes

○ No

○ Unsure

Can you tell us why that is?

10. Overall, do you feel your treatment plan helps you?

○ Yes

○ No

○ Unsure

11. Unfortunately, there are certain aspects of CF treatment that just need to be done day-in/day-out but sometimes it can help CF teams to find a treatment plan that works for you if they understand what really matters to you. Do you feel that your treatment plan takes your own personal situation (including life plans, personal priorities, and goals) into account?

○ Yes

○ No

○ Unsure

Can you tell us more about this?

12. Do you ever have difficulties getting the medications you need from your GP/Pharmacist/hospital/homecare?

○ Always

○ Sometimes

○ Never

How does this affect you?

13. Is there anything that would make it easier for you to get the medications you need from your GP/Pharmacist/Hospital/Homecare?

14. Are there any ways in which technology could make your CF treatments easier or less disruptive to your life?

15. Have you developed any tricks, tips or techniques that have made treatments easier to manage?

16. Do you have any other ideas that you feel could make treatment plans less demanding for people with CF?

17. Please tell us if your treatments get in the way of the following

	Yes	No	Sometimes	Not applicable
Family relationships	○	○	○	○
Relationship with partner/spouse	○	○	○	○
Relationships with friends	○	○	○	○
School/college/university	○	○	○	○
Job/career	○	○	○	○
Sports or hobbies	○	○	○	○
Socialising	○	○	○	○
Other activities you enjoy	○	○	○	○

18. Please tell us more if you would like to about this

To help us understand your answers it would be really useful to know about the current level of treatments and how you feel your/your child's/relative's CF health is at the present time. Please feel free to only answer the questions you feel are relevant.
If the question asks about 'you', please answer for the person you are completing the survey for i.e. yourself or on behalf of someone else.

19. In order to understand which treatments people find particularly burdensome, it would be helpful for us to know how common each is amongst all the people completing this survey. Please tick any treatments which are prescribed as part of your/your child’s usual routine, no matter how many times per day (tick any that apply).

☐ Pancreatic enzymes

☐ Vitamins

☐ One regular long term antibiotic e.g. flucloxacillin (don't count azithromycin) (by mouth)

☐ More than one long term antibiotic (don't count azithromycin) (by mouth)

☐ Azithromycin

☐ Ivacaftor/Orkambi

☐ Ursodeoxycholic acid

☐ Corticosteroids e.g. prednisolone

☐ Antifungals e.g. itraconazole

☐ Anti-Reflux e.g. omeprazole, ranitidine

☐ Nutritional supplements e.g. drinks/shakes

☐ DNase

☐ Hypertonic saline

☐ Mannitol

☐ One long term nebulised antibiotic (tick this option if you rotate antibiotics in different months but are only ever taking one at a time)

☐ More than one regular long term nebulised antibiotic

☐ Dry powder inhaled antibiotic (e.g. Podhaler)

☐ Inhalers (e.g. salbutamol or inhaled steroids)

☐ Exercise and physical activity

☐ Aiway clearance techniques

☐ Gastrostomy/ Naso-gastric feeds

☐ Insulin

☐ Regular intravenous ("IV") antibiotics (planned e.g. every 3-4 months)

☐ Psychological support

☐ Oxygen

☐ Non-invasive positive pressure ventilation (BIPAP)

☐ Other (please specify)

20. Are you/your child currently taking additional medication because you/they are more unwell than usual?

○ No

○ Yes, taking extra/different medicines by mouth

○ Yes, currently receiving intravenous ("IV") antibiotics

○ Other (please specify)

21. How many different treatments in total are you/your child/relative currently on? (please count all different treatments including e.g. medicines/nebulisers/inhalers/physiotherapy/insulin/nutritional supplements/oxygen/psychological support)

22. How many hours a day do YOU spend on managing the CF treatment routine? (including doing all the medicines, nebulisers, inhalers, physio, insulin, feeds, nutritional supplements AND cleaning nebs, setting up equipment etc.)

23. How many courses of IV antibiotics, either at hospital or home, have you/your child/relative had in the past 12 months?

24. What is your/your child/relative's most recent % predicted FEV_1?

○ 100+%

○ 80-99%

○ 60-79%

○ 40-59%

○ 20-39%

○ less than 20%

○ Post-transplant

○ too young

○ Unknown

25. Are YOU currently

○ in full time employment?

○ part time employment?

○ school?

○ a student?

○ looking after dependents?

○ unemployed?

○ off sick?

Other (please specify)

☐

26. How well do you feel YOU are coping with CF and the treatment plan at this moment in your life (with 100 being the best you've ever felt and 0 not coping at all)

0 100

☐

Simplifying the treatment burden in CF

27. What do you see as the most important treatment?

☐

☐

28. Why this?

☐

29. In an ideal world, without consequence, If you could choose to stop one aspect of regular CF treatment what would it be?

30. Why this?

Simplifying the treatment burden in CF

31. Which professional group are you a member of?

- ○ Physiotherapist
- ○ Respiratory Paediatrician
- ○ Respiratory Physician
- ○ General Practitioner
- ○ Junior Doctor
- ○ Nurse
- ○ Dietitian
- ○ Psychologist
- ○ Pharmacist
- ○ Researcher
- ○ Social worker

Other (please specify)

32. We are conscious that treatment burden can include a number of different experiences. Can you tell us what treatment burden means to you as a professional that looks after people with CF?

33. What factors do you think influence how much treatment burden a person with CF feels?

34. Are there any ways in which technology could make CF treatments easier or less disruptive to your patients?

35. Do you have any other ideas that you feel could make treatment plans less demanding for people with CF?

36. Often it's difficult for people to keep up with all the CF treatments prescribed. How often do you think your patients manage to do exactly all you have asked them to?

○ Always

○ Most of the time

○ Half of the time

○ Less than half

○ Never

37. What do you see as your patients' most important treatment?

Why this?

38. What treatment do you think your patients find the most burdensome?

Why this?

39. How do you think we should measure if a treatment is worth taking?

40. With the advent of CFTR modulators it may be possible to stop or reduce some existing treatments for those patients taking these drugs. Would you support a stopping trial if this was to be carried out?

○ Yes

○ No

○ N/A

○ Other

41. Have you stopped any treatments for patients on CFTR modulators? (please maintain patient confidentiality)

○ Yes

○ No

○ N/A

If so, what treatment have you stopped?

Simplifying the treatment burden in CF

42. Age in years of person filling in survey

43. Age in years of person with CF (if parent/family)

44. Which country do you live in?

45. Would you be interested in continuing to be a Question CF contributor by taking part in future surveys?

○ Yes (please leave your email in the comment box below)

○ No thank you

46. Would you be interested in becoming a member of the Question CF advisory group for the opportunity to take part in more in depth discussions and designing of research trials? (via phone or internet)

○ Yes (please leave your email in the comment box below)

○ No thank you

47. email address

48. If you don't want to take part in the advisory group, but would still like to suggest an idea for a research trial, please feel free to write your suggestion here

Thank you so much for helping us by completing this questionnaire.

Please click below to submit your answers

P1

P2

Q1 Skip logic

- A1. A person with CF?
  - TOP OF PAGE 3
- A2. A parent of a child or children with CF?
  - TOP OF PAGE 3
- A3. Spouse or partner of a person with CF?
  - TOP OF PAGE 3
- A4. Other relative or friend of a person with CF?
  - TOP OF PAGE 3
- A5. A health care professional or researcher working with CF?
  - TOP OF PAGE 8

P3

Q2	No logic
Q3	No logic
Q4	No logic
Q5	No logic
Q6	No logic
Q7	No logic
Q8	No logic
Q9	No logic

Q10	No logic

P4

Q11	No logic
Q12	No logic
Q13	No logic
Q14	No logic
Q15	No logic
Q16	No logic

P5

Q17	No logic
Q18	No logic

P6

Q19	No logic
Q20	No logic
Q21	No logic
Q22	No logic
Q23	No logic
Q24	No logic

Q25	No logic
Q26	No logic

P7 Skip logic

After the current page is completed…

Skip to P11

Q27	No logic
Q28	No logic
Q29	No logic
Q30	No logic

P8

Q31	No logic

P9

Q32	No logic
Q33	No logic
Q34	No logic
Q35	No logic

P10

Q36	No logic
Q37	No logic
Q38	No logic

Q39	No logic
Q40	No logic
Q41	No logic

P11

Q42	No logic
Q43	No logic
Q44	No logic
Q45	No logic
Q46	No logic
Q47	No logic
Q48	No logic
Text	No logic

You have reached the end of the survey.