Cystic Fibrosis Queensland Quality of Life Survey Report – 2023

This year Cystic Fibrosis Queensland's Quality of Life survey had 54 responses:

- 19 Adults living with cystic fibrosis (18 years and older)
- 33 Parents/Guardians of a child living with cystic fibrosis
- 2 Incomplete responses

Basic Information Questions for Parents/Guardians of a child living with cystic fibrosis

84.38% of respondents were mothers of children living with cystic fibrosis, 12.50% were fathers and 3.13% were grandparents.

100.00% of respondents listed Caucasian as their child's race/ethnicity.

16 of the children were male and 16 were female.

93.75% of children were diagnosed with cystic fibrosis at less than 1 years old, while only 6.25% of children were diagnosed with cystic fibrosis between 1 – 5 years old. There were no later reported diagnoses.

Current marital status for parents

71.88% of respondents listed their current marital status as married, 9.38% are single, 3.13% are widowed, 3.13% are divorced and 12.50% are with a partner.

Education status

6.25% of respondents selected less than a high school diploma as their education status, 21.88% selected high school degree or equivalent, 31.25% selected diploma, 21.88% selected bachelor's degree and 6.25% selected master's degree.

12.50% selected other:

- Completed yr 10 and never went back.
- Still at primary school
- Post graduate diploma
- Cert 3

Employment status

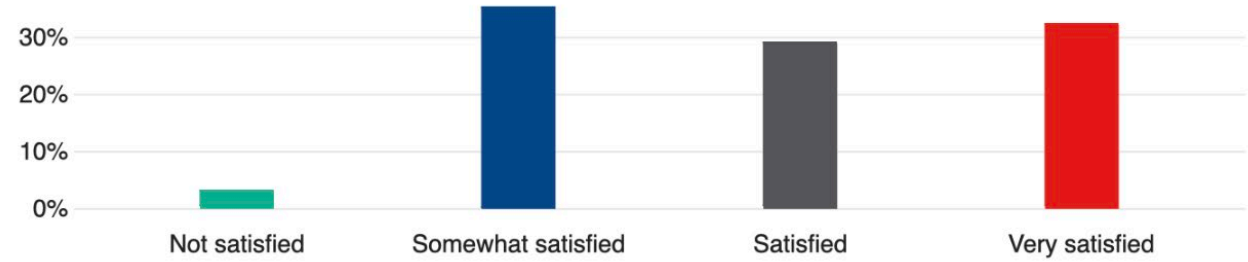
34.48% of respondents are employed full-time, 34.48% are employed part-time, 6.25% are self-employed, 3.00% are unemployed and not seeking employment and 12.5% are unable to work due to caring for their child living with cystic fibrosis and 9.38% are not working.

37.50% of respondents have participated in support groups or communities for parents of children living with cystic fibrosis, while 62.50% have not.

93.75% of respondents feel adequately informed about cystic fibrosis and its management, while 6.25% do not.

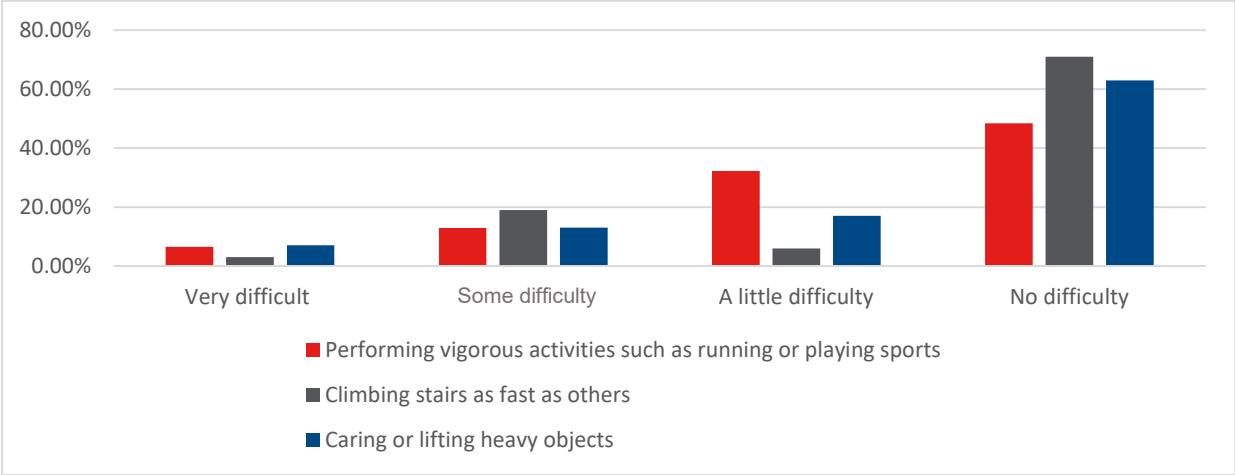
Physical Functioning

Graph 1: Satisfaction of child's physical health and well-being



32.26% of respondents were very satisfied with their child's physical health and wellbeing, 29.03% were satisfied, 35.48% were somewhat satisfied, and 3.23% were not satisfied.

Graph 2: Difficulty in performing basic activities

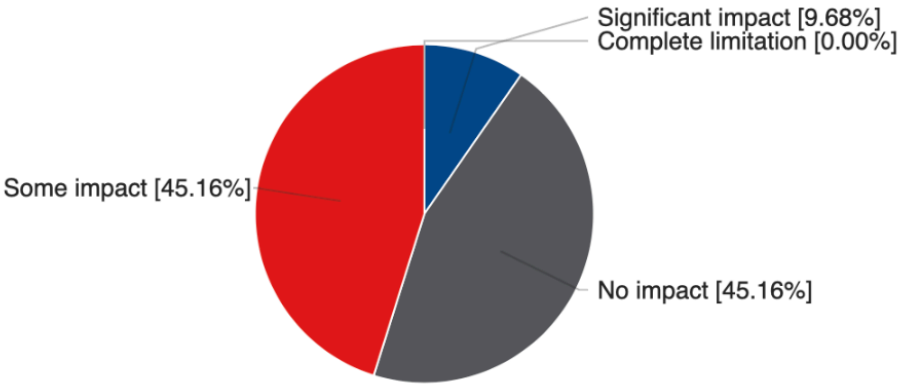


48.39% of respondents found their child had no difficulty performing vigorous activities such as running or playing sports, 32.26% responded a little difficulty, 12.90% responded some difficulty and 6.45% responded very difficult.

70.97% of respondents found their child had no difficulty climbing stairs as fast as others, 6.45% responded a little difficulty, 19.35% responded some difficulty and 3.23% responded very difficult.

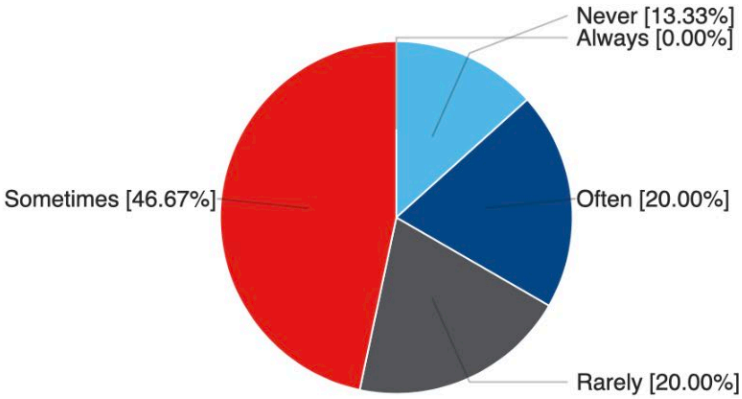
63.33% respondents found their child had no difficulty caring or lifting heavy objects, 16.67% responded a little difficulty, 13.33% responded some difficulty and 6.67% responded very difficult.

Graph 3: Impact on ability to pursue educational or extracurricular activities



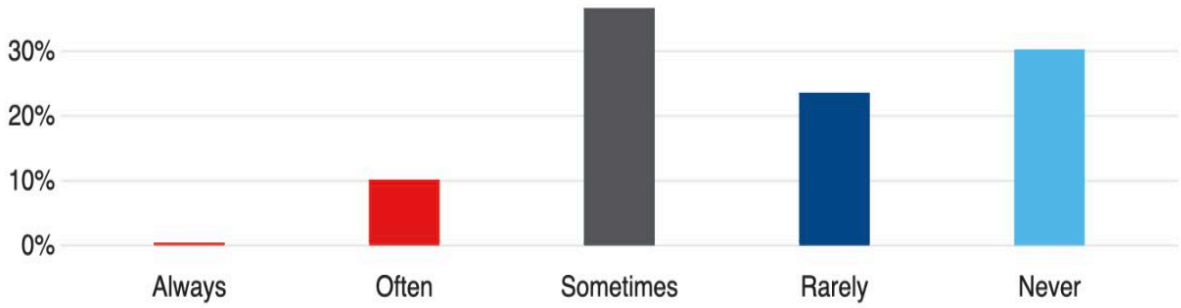
45.16% of respondents indicated that cystic fibrosis had some impact to their child's ability to pursue educational or extracurricular activities, 45.16% indicated no impact, and 9.68% indicated significant impact.

Graph 4: Absent or late for school due to illness or treatment



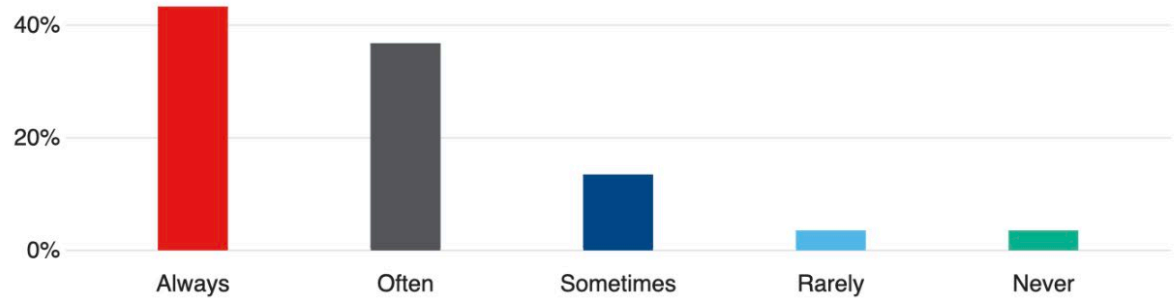
20.00% of respondents selected that their child was often absent or late for school due to their illness or treatment, 46.67% selected sometimes, 20.00% selected rarely, and 13.33% selected never.

Graph 5: Impact on social life and relationships with friends at school



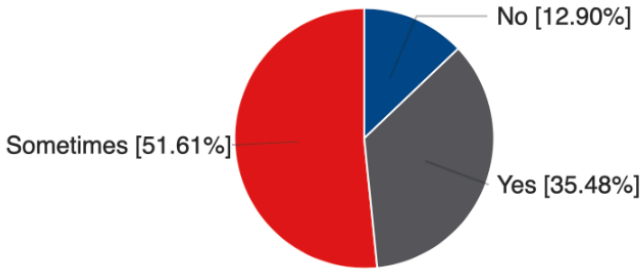
10.00% of respondents stated that cystic fibrosis often impacted their child's social life and relationships with friend at school, 36.67% stated sometimes, 23.33% stated rarely, and 30.00% stated never.

Graph 6: Impact on ability to keep up with school work



43.33% of parents stated that their child always kept up with schoolwork, 36.67% responded often, 13.33% responded sometimes, 3.33% responded rarely and 3.33% responded never.

Graph 7: Time spent completing treatments



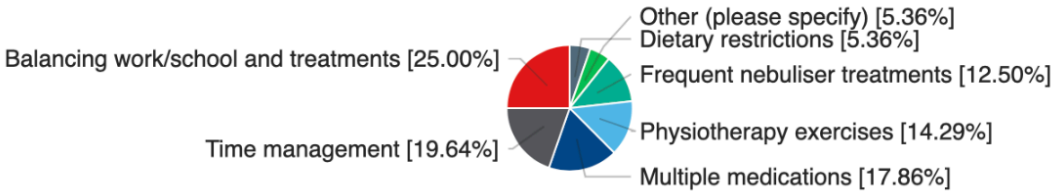
35.48% of respondents stated that their child spent a lot of time on their treatments, 51.61% stated sometimes, and 12.90% stated that their child doesn't spend much time on their treatments.

48.39% of respondents stated their child's treatment time was less than 1 hour, 41.94% stated treatment time was between 1 – 2 hours, 3.23% stated between 2 – 3 hours, and 6.45% stated the treatment was over 3 hours.

Modulator therapy

80.65% of respondent's children were currently on a modulator therapy, while 19.35% were not.

Graph 8: Challenging aspects of child's daily routine



Balancing work/school and treatments was ranked as the most challenging aspect of maintaining their child's daily routine at 25.00%. This was followed by time management (19.64%), multiple medications (17.86%), physiotherapy exercises (14.29%), nebuliser treatments (12.50%) and dietary restrictions (5.36%).

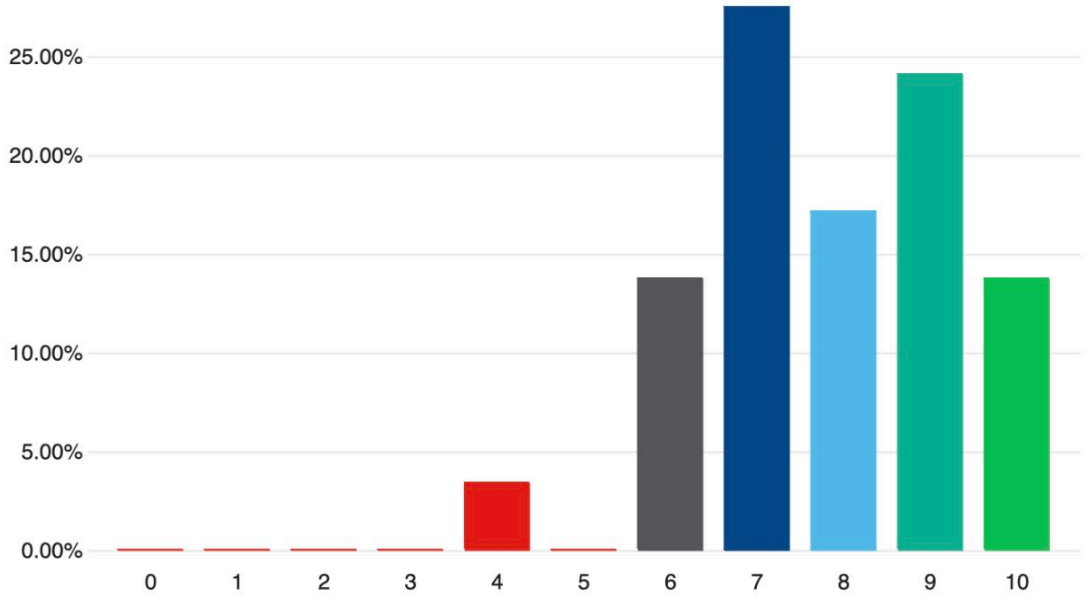
5.36% responded other:

- None really.

- Administration/Management and dealing with Pharmacy
- Soapy hazards to avoid

82.61% of respondents stated that their child had faced challenges in accessing healthcare for cystic fibrosis management, while 17.39% hadn't.

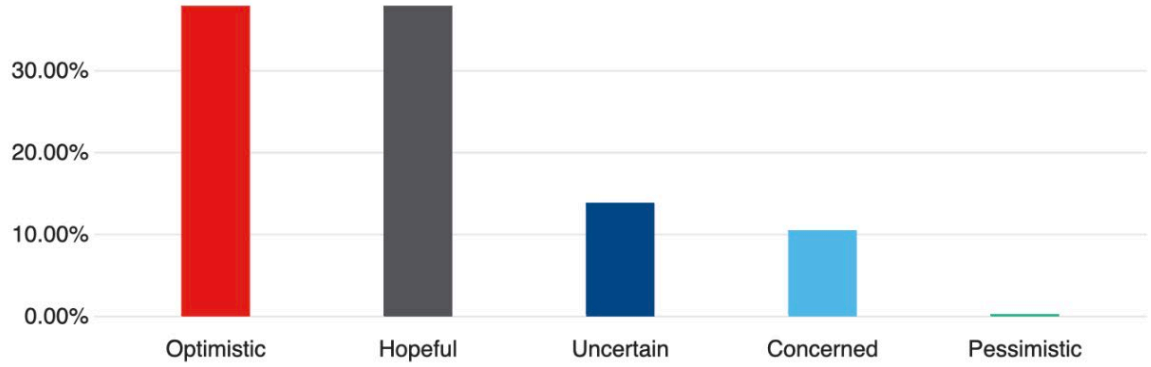
Graph 9: Rate of child's overall quality of life



(Rate of scale 0 Poor – 10 Excellent)

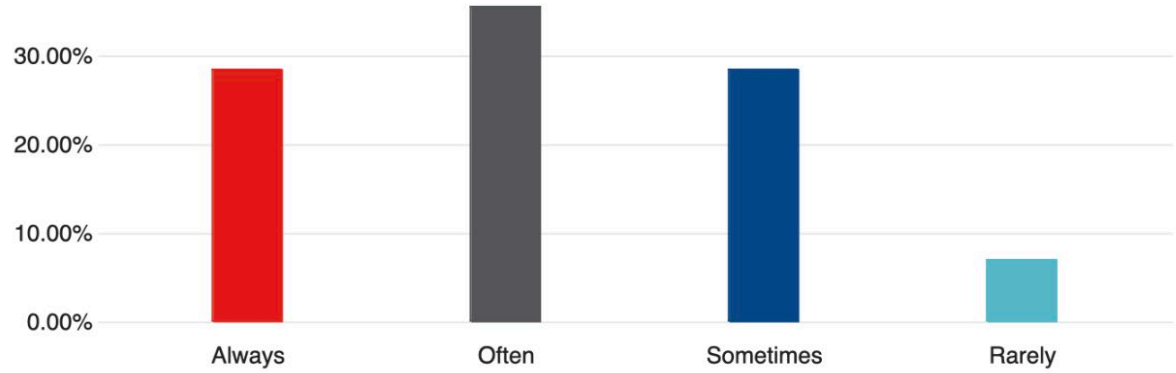
3.35% of respondents indicated that their child's overall quality of life as 4. 13.79% rated 6, 27.59% rated 7, 17.24% rated 8, 24.14% rated 9 and 13.79% rated 10.

Graph 10: Feelings about child's overall life expectancy



37.93% of respondents felt optimistic about their child's overall life expectancy, 37.93% felt hopeful, 13.79% felt uncertain, and 10.34% felt concerned. There is no respondents felt pessimistic.

Graph 11: Received enough emotional support



35.71% of respondents stated that their child often received enough emotional support, 28.57% stated sometimes, 28.57% stated always, and 7.14% stated rarely.

Respondents approaches to maintaining a high quality of life living with cystic fibrosis include:

- Routines, exercise, diet
- Having 2 children with Cf, keeping life real and normal, everything in life is achievable through love, support and positively
- Persistent routines
- Trikafta has changed our whole family's lives for the better
- The greatest impact for our family relating to CF management has been the inability of my wife to return to work for fear of putting our child into day-care where he is likely to pick up various illnesses. She's forced to be his full-time carer and our family is limited to a single income. The subsequent financial pressures are impacting us all and we have no option for any government support.
- Seeing a doctor with vision of just being healthy as well as having CF, keeping all Vitamin and blood levels in check

Basic Information Questions for Adults living with cystic fibrosis

77.78% of adult respondents were male, and 22.22% were female.

88.89% of respondents were diagnosed with cystic fibrosis at less than 1 year old, 5.56% were diagnosed at age 1 – 5 years, and 5.56% were diagnosed at age 10 years and above.

100.00% of respondents listed Caucasian as their race or ethnicity.

Current marital status

38.89% of respondents listed their current marital status as married or with a partner, 16.67% are single, and 5.56% are divorced.

Education status

38.89% of respondents listed their highest education status as a bachelor's degree, 33.33% as a diploma degree, 16.67% have high school graduate or equivalent level of education, and 11.11% have less than a high school diploma level of education.

Employment status

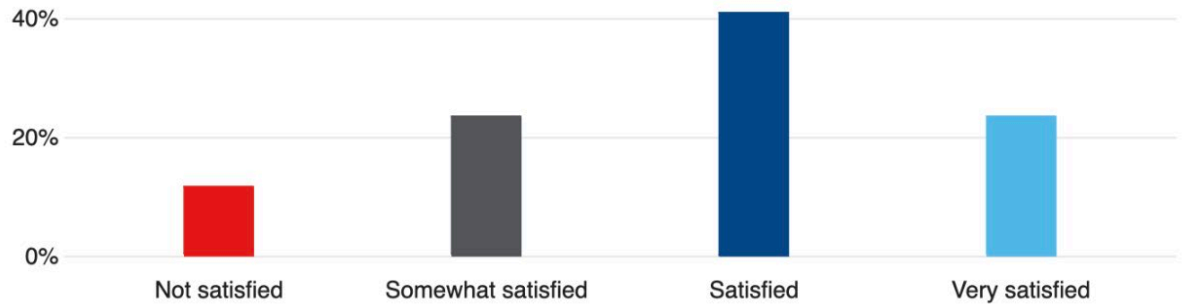
50.00% of respondents are employed full-time, 27.78% are employed part-time, 16.67% are self-employed, and 5.56% are seeking work.

22.22% of respondents have participated in support groups or communities for people living with cystic fibrosis, while 77.78% have not.

100.00% of respondents feel adequately informed about cystic fibrosis and its management.

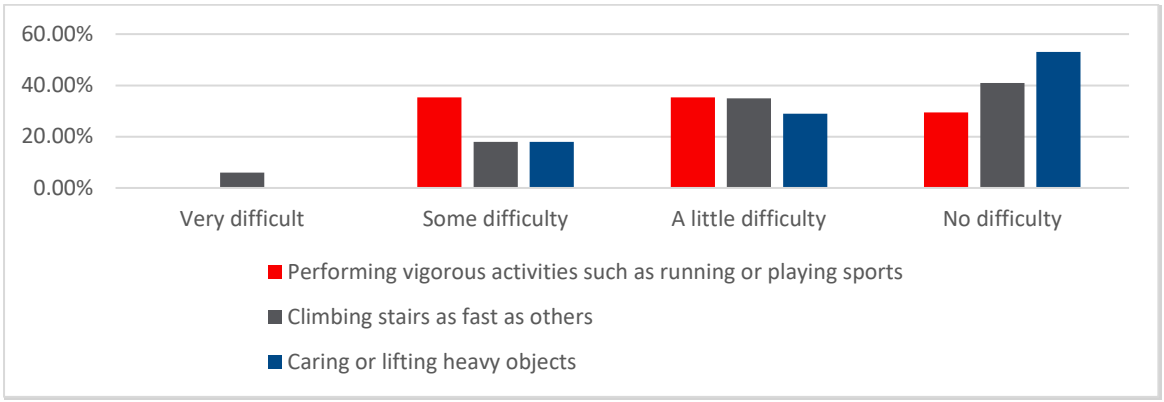
Physical Functioning

Graph 12: Satisfaction of physical health and well-being



41.18% of respondents felt satisfied with their physical health and well-being, 23.53% were very satisfied, 23.53% were somewhat satisfied, and 11.76% were not satisfied.

Graph 13: Difficulty in performing basic activities

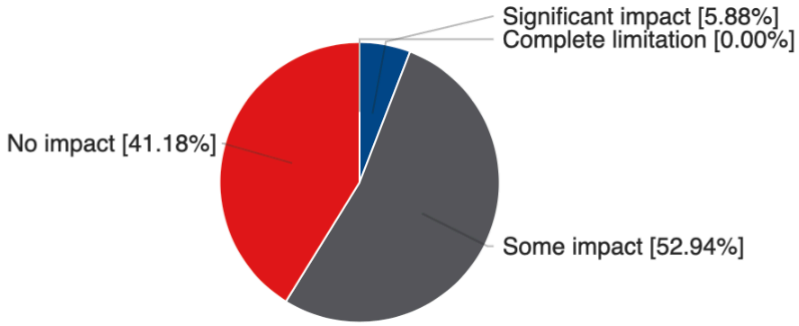


35.29% of respondents found they had a little difficulty performing vigorous activities such as running or playing sports, 35.29% has some difficulty, while 29.41% had no difficulty.

41.18% of respondents found they had no difficult when climbing stairs, 35.29% had a little difficulty, 17.65% had some difficulty, and 5.88% found climbing stairs very difficult.

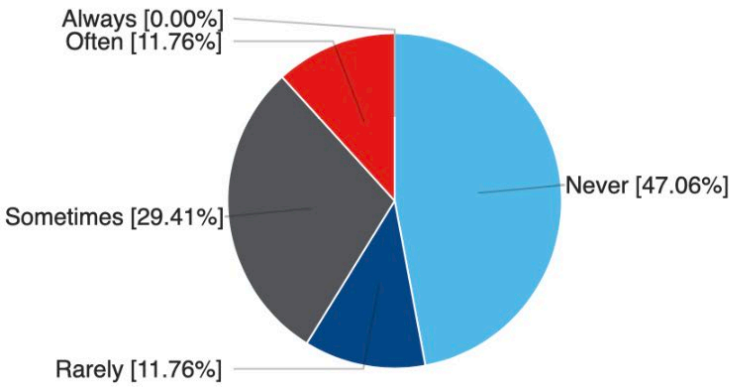
52.94% of respondents found they had no difficult carrying or lifting heavy objects, 29.41% had some difficulty, and 17.65% had some difficulty.

Graph 14: Impact on ability to pursue educational or extracurricular activities



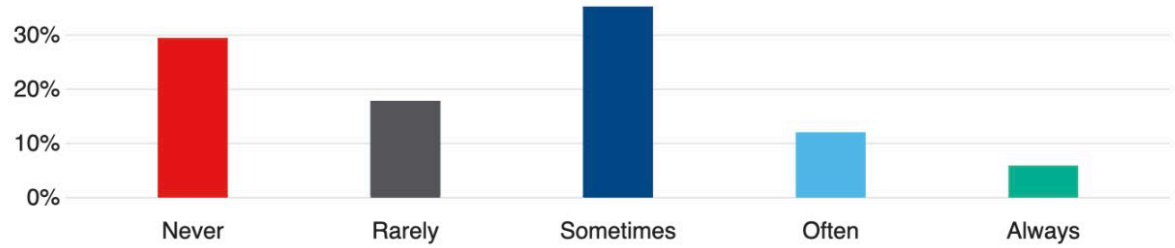
52.94% of respondents stated that they had some impact in their ability to pursue educational or extracurricular activities, while 41.18% had no impact, and 5.88% had significant impact.

Graph 15: Absent or late for school/work due to illness or treatment



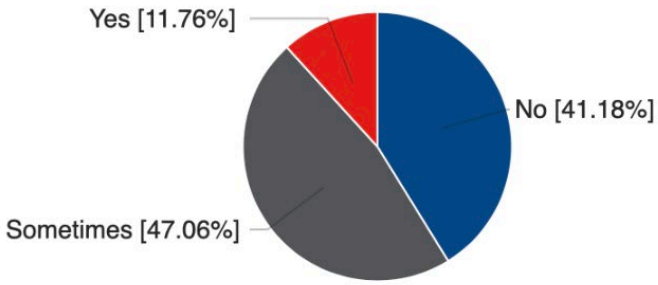
47.16% of respondents stated they are never absent or late for school/work due to illness or treatment, 29.41% stated sometimes, 11.76% stated often, and 11.16% stated rarely.

Graph 16: Impact on social life and relationships with friends at school/work



35.29% of respondents stated sometime cystic fibrosis will impact their social life and relationships at school/work, while 29.41% stated never, 17.65% stated rarely, 11.76% stated often, and 5.88% stated always.

Graph 17: Time spent completing treatments



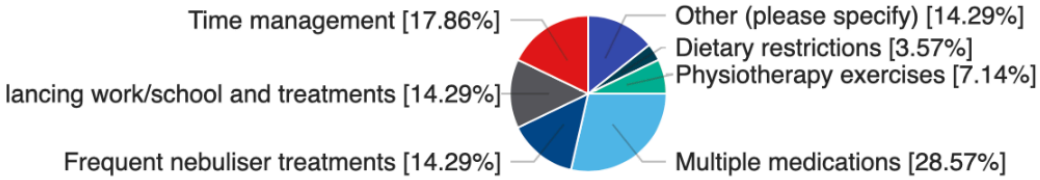
41.18% of respondents stated they did not spend a lot of time completing their treatments, while 47.06% of respondents stated sometimes, and 11.76% stated they spent a lot of time completing treatments.

64.71% of respondents stated their treatment time was less than 1 hour each day, 29.41% spent 1 – 2 hours, and 5.88% spent between 2 – 3 hours.

Modulator therapy

70.59% of respondents were currently on modulator therapy, while 29.41% were not.

Graph 18: Challenging aspects - Daily routine due to living with cystic fibrosis



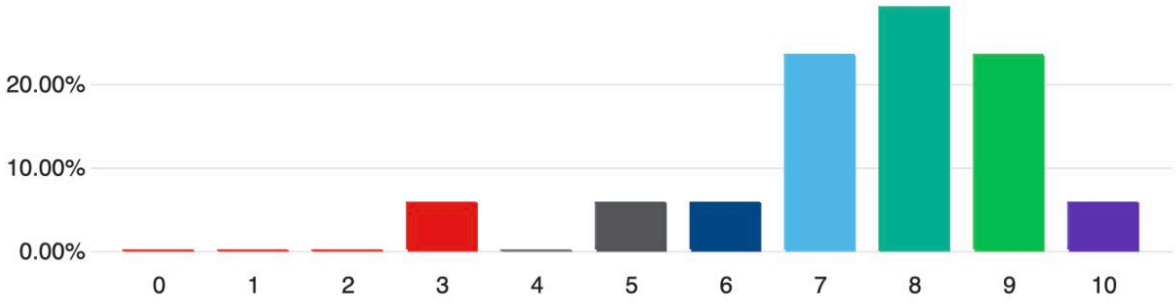
Multiple medications were ranked as the most challenging aspects of maintaining their daily routine at 28.57%. This was followed by time management (17.86%), balancing work/school and treatments (14.29%), frequent nebuliser treatments (14.29%), physiotherapy exercises (7.14%), and dietary restrictions (3.57%.)

14.29% responded other:

- Fitting in treatment around busy family life
- I have difficulty keeping up my food intake while working and struggle with maintaining a healthy body weight
- Diabetes control
- Find time to exercise

66.67% of respondents haven't faced any challenges in accessing healthcare for cystic fibrosis management, while 33.33% have faced challenges.

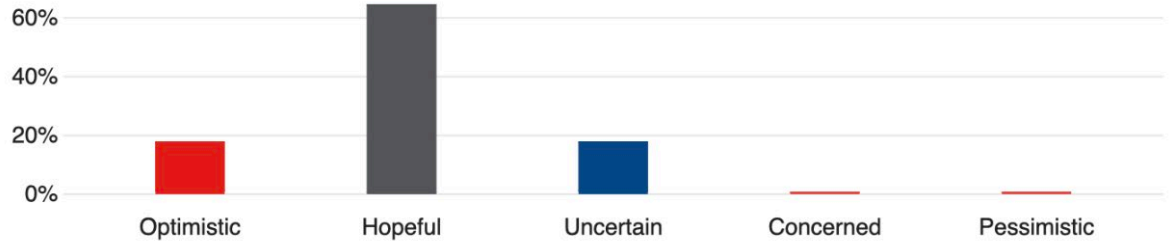
Graph 19: Rate of overall quality of life



(Rate of scale 0 Poor – 10 Excellent)

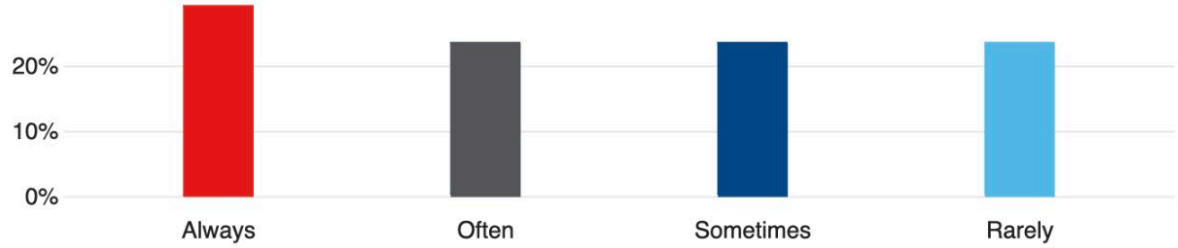
5.88% of respondents indicated that their overall quality of life as 3. 5.88% rated 5, 5.88% rated6, 23.53% rated 7, 29.41% rated 8, 23.53% rated 9, and 5.88% rated 10.

Graph 20: Feelings about overall life expectancy



64.71% of respondents felt hopeful about their overall life expectancy living with cystic fibrosis, 17.65% felt optimistic, and 17.65% felt hopeful.

Graph 22: Received enough emotional support



29.41% of respondents stated that they always received enough emotional support, 23.53% stated often, 23.53% stated sometimes, and 23.53% stated rarely.

Respondents approaches to maintaining a high quality of life living with cystic fibrosis include:

- Staying positive is very important.
- Mainly it affects my mental health and my ability to gain weight which has often makes me feel self-conscious and sad. Modulator therapy has significantly changed my life, I never thought I could be at this level of health, although it isn't a cure and I still face difficulties.
- I've only felt out of breath during a coughing fit
- The cost of medications is what I struggle with most. This affects me financially every month.
- Modulator therapy has enabled me to fully laugh without breaking into coughing. I can laugh uncontrollably which is another benefit to my mental health. love it.

- Continuous glucose monitor access would make day to day management much easier
- Trikafta has changed my life and given myself, my wife and kids hope i can grow old with them.
- Thanks to the modulator medication I can live and function extremely well
- TRIKAFTA has saved me and changed all aspects of my life