



CF Responsibilities Checklist

1: Working with the CF Care Team and other Healthcare Providers (HCP)

Name: _____

Note: There are no right or wrong answers to this survey.

Date: _____

Please provide your honest feedback below so that we can work together to improve the management of your CF over time.

1 The person with CF is completely responsible	2 The person with CF is primarily responsible	3 The person with CF and I are equally responsible	4 I am primarily responsible	5 I am completely responsible	NA Not Applicable
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Please indicate the person in your household responsible for each of the following healthcare behaviors by placing the appropriate number from 1 to 5, or NA for Not Applicable, in the boxes below:

1. Scheduling CF Center appointments	
2. Arranging transportation to CF Center (drive, walk or take public transportation)	
3. Asking questions about medicines, treatments, or health concerns	
4. Answering questions about medicines, treatments, or other health concerns	
5. Meeting with the CF care team to review test results and changes to treatment plan	
6. Participating in health insurance discussions with the CF care team	
7. Calling the CF care team if experiencing symptoms or changes in health status	
8. Making sure the CF care team is made aware of visits with other healthcare providers (e.g., primary care physician, endocrinologist, ENT, etc.)	

Add all individual numbers entered for each row above and insert the total on the line below. Divide the total by 8 and enter the result in the box.

_____ / 8 = **Average Responsibility Reported:**



CF Responsibilities Checklist

1: Working with the CF Care Team and other Healthcare Providers (HCP)

Name:

Date:

Note: There are no right or wrong answers to this survey. Please provide your honest feedback below so that we can work together to improve the management of your CF over time.

1 The person with CF is completely responsible	2 The person with CF is primarily responsible	3 The person with CF and I are equally responsible	4 I am primarily responsible	5 I am completely responsible	N A Not Applicable
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Please indicate the person in your household responsible for each of the following healthcare behaviors by placing the appropriate number from 1 to 5, or NA for Not Applicable, in the boxes below:

1. Scheduling CF Center appointments	<input type="text"/>
2. Arranging transportation to CF Center (drive, walk or take public transportation)	<input type="text"/>
3. Asking questions about medicines, treatments, or health concerns	<input type="text"/>
4. Answering questions about medicines, treatments, or other health concerns	<input type="text"/>
5. Meeting with the CF care team to review test results and changes to treatment plan	<input type="text"/>
6. Participating in health insurance discussions with the CF care team	<input type="text"/>
7. Calling the CF care team if experiencing symptoms or changes in health status	<input type="text"/>
8. Making sure the CF care team is made aware of visits with other healthcare providers (e.g., primary care physician, endocrinologist, ENT, etc.)	<input type="text"/>

Add all individual numbers entered for each row above and insert the total on the line below. Divide the total by 8 and enter the result in the box.

/ 8 = Average Responsibility Reported:



CF Responsibilities Checklist

2: Responsibility for CF Treatments

Name: _____

Note: There are no right or wrong answers to this survey.

Date: _____

Please provide your honest feedback below so that we can work together to improve the management of your CF over time.

1 The person with CF is completely responsible	2 The person with CF is primarily responsible	3 The person with CF and I are equally responsible	4 I am primarily responsible	5 I am completely responsible	NA Not Applicable
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Please indicate the person in your household responsible for each of the following healthcare behaviors by placing the appropriate number from 1 to 5, or NA for Not Applicable, in the boxes below:

1. Taking prescription CF medicines as prescribed	
2. Doing CF treatments as prescribed	
3. Setting up equipment to take treatments (e.g., vest)	
4. Cleaning medical equipment and devices as recommended by the CF care team	
5. Disinfecting/sterilizing medical equipment and devices as recommended by the CF care team	
6. Bringing along medicines when at school, traveling, or away from home	
7. Maintaining a nutritional plan recommended by the CF care team	
8. Monitoring the number of prescription refills that remain	
9. Asking for new prescriptions from the CF care team before they run out	
10. Filling new prescriptions at the pharmacy	
11. Implementing changes to treatments based on input of the CF care team	

Add all individual numbers entered for each row above and insert the total on the line below. Divide the total by 11 and enter the result in the box.

_____ / 11 = **Average Responsibility Reported:**



CF Responsibilities Checklist

3: Living With Cystic Fibrosis

Name: _____

Date: _____

Note: There are no right or wrong answers to this survey.
Please provide your honest feedback below so that we can work together to improve the management of your CF over time.

1 The person with CF is completely responsible	2 The person with CF is primarily responsible	3 The person with CF and I are equally responsible	4 I am primarily responsible	5 I am completely responsible	NA Not Applicable
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Please indicate the person in your household responsible for each of the following healthcare behaviors by placing the appropriate number from 1 to 5, or NA for Not Applicable, in the boxes below:

1. Identifying someone with whom psychological and emotional issues can be discussed	
2. Telling close friends, family members, teachers, administrators, etc. about CF	
3. Knowing how to answer or having prepared answers for questions about CF from others	
4. Making sure to follow infection control standards	
5. Making healthy lifestyle choices related to drugs, alcohol, and cigarettes	
6. Recognizing limits (e.g., days you may need extra sleep)	
7. Making time for exercise	
8. Making time for fun and hobbies	
9. Preparing for hospital visits/tune-ups	

Add all individual numbers entered for each row above and insert the total on the line below. Divide the total by 9 and enter the result in the box.

_____ / 9 = **Average Responsibility Reported:**



CF Responsibilities Checklist

4: CF Transfer

Name: _____

Note: There are no right or wrong answers to this survey.

Date: _____

Please provide your honest feedback below so that we can work together to improve the management of your CF over time.

1 The person with CF is completely responsible	2 The person with CF is primarily responsible	3 The person with CF and I are equally responsible	4 I am primarily responsible	5 I am completely responsible	NA Not Applicable
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Please indicate the person in your household responsible for each of the following healthcare behaviors by placing the appropriate number from 1 to 5, or NA for Not Applicable, in the boxes below:

1. Identifying a preferred adult CF care team	
2. Finding adult primary care and specialist physicians	
3. Determining a specific transfer date with pediatric and adult care teams	
4. Confirming that paper or e-copies of medical history are sent from the pediatric to adult team	
5. Scheduling an appointment to meet with adult care team before transfer	
6. Scheduling and attending appointment to review medical history with the adult care team	
7. Answering questions about medical history with the adult care team	
8. Managing any health insurance changes when moving from the pediatric to adult Center	
9. Scheduling appointments for future visits with the adult CF care team	

Add all individual numbers entered for each row above and insert the total on the line below. Divide the total by 9 and enter the result in the box.

_____ / 9 = **Average Responsibility Reported:**



CF Responsibilities Checklist

5: Insurance and Financial Planning

Name: _____

Note: There are no right or wrong answers to this survey.

Date: _____

Please provide your honest feedback below so that we can work together to improve the management of your CF over time.

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Please indicate the person in your household responsible for each of the following healthcare behaviors by placing the appropriate number from 1 to 5, or NA for Not Applicable, in the boxes below:

1. Carrying an insurance card	
2. Reviewing medical bills and calling the appropriate person with questions	
3. Reviewing and appealing insurance claims	
4. Contacting the health insurance company and identifying a Case Manager to address questions	
5. Working with financial assistance programs to secure/access discounts on treatments	
6. Choosing the right type (commercial or government) and amount of health insurance coverage	
7. Researching a back-up plan/safeguards if personal circumstances impact current insurance plan (e.g., COBRA and how to maintain continuous coverage)	
8. Managing money including cash, credit cards, bank accounts, and budgets	

Add all individual numbers entered for each row above and insert the total on the line below. Divide the total by 8 and enter the result in the box.

_____ / 8 = **Average Responsibility Reported:**



CF Responsibilities Checklist

6: Education and Career Planning

Name: _____

Note: There are no right or wrong answers to this survey.
Please provide your honest feedback below so that we can work together to improve the management of your CF over time.

Date: _____

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Please indicate the person in your household responsible for each of the following healthcare behaviors by placing the appropriate number from 1 to 5, or NA for Not Applicable, in the boxes below:

1. Establishing short-term and long-term goals after high school graduation	
2. Knowing the steps for applying for admission and financial aid for college or post-grad program	
3. Talking to the CF care team about what to consider before going to college	
4. Deciding on a care approach if moving away from home (role of away vs. home CF Center)	
5. Contacting the Office of Disability and Support Services at college/university/technical school	
6. Planning and thinking through logistics for living in a dorm or living off-campus	
7. Developing a realistic class schedule that provides time to do treatments and take medicines	
8. Knowing the steps involved in seeking and applying for a job	
9. Considering a career that accommodates the specific needs of someone with CF	
10. Researching and understanding personal rights under the Americans with Disabilities Act (ADA) and the key elements of Section 504	

Add all individual numbers entered for each row above and insert the total on the line below. Divide the total by 10 and enter the result in the box.

_____ / 10 = **Average Responsibility Reported:**