PASSPORT

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Transition to CF Adult Care

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THIS PASSPORT BELONGS TO:

DATE RECEIVED:

ESTIMATED DATE OF COMPLETION:

DATE COMPLETED:

Welcome to your Transition Passport!

You are receiving this passport so we can begin working with you on becoming more independent with your CF care. The goal of this passport is help prepare you to be independent and take ownership of your life as a young adult.

Your passport includes several different areas of focus ranging from your daily CF treatment and nutritional/medication needs to career and future planning. As you master each section, just as in a passport, you can place a stamp on that particular page. Your CF team and parents/caregivers will be working with you during clinic visits, admissions and at home to support you in applying the information and skills needed for your transition to adulthood.

Once you have completed all the checkpoints in your passport, please review it with your CF team. Becoming an adult is an exciting time, and your CF team wants to help you make the most of it, which includes living the healthiest life possible.

Ready, Set, Go!

TABLE OF CONTENTS

HAVING CYSTIC FIBROSIS (CF)

☐ I am able to explain what CF is and how it affects my body

☐ I know the guidelines for having contact with others diagnosed with CF

☐ I know what precautions to take to decrease risk for infections

☐ I am aware of my specific CF mutations

☐ I am aware of the various CF studies and trials available to me

☐ I am aware that some people diagnosed with CF need a lung transplant, and I have discussed this topic with my CF doctors to determine if or when this might be a treatment option for me

RESPIRATORY TREATMENT

☐ I can describe what I should be doing for my recommended CF treatments and how often I should be doing them

☐ I know how to properly clean and sterilize all my treatment equipment

☐ I am able to describe why I am doing my CF treatments and how it helps me

☐ If I have questions about my respiratory treatments or need assistance with equipment, I know whom to contact

MEDICATIONS AND VITAMINS

☐ I know the names and dosages of the medications/vitamins prescribed to me

☐ I know why I am taking them and how they help me

☐ I am aware of any possible side effects of my medications

☐ I am aware of any allergies I have to specific medications

☐ I know why it is important for my CF team to check my vitamin A, D, and E levels annually

NUTRITION

☐ I know why good nutrition is important; why I need more calories; foods highest in calories; and how to include them in my diet

☐ I know what BMI stands for; how it is used to follow nutritional status; and the relationship between BMI and lung function

☐ I know why I need enzymes; how they work to help nutrient absorption and digestion; and how and when to take them

☐ I know what CFRD is; the importance of checking my glucose levels annually; and how blood sugar should be controlled with insulin and healthy meal planning if I have CFRD

☐ I am able to create and plan a week of meals/snacks for myself or my family including purchasing foods and cooking the meal

EXERCISE

☐ I am aware of the short and long term benefits of exercise

☐ I exercise for at least 30 minutes, 4 times per week

CF OWNERSHIP

☐ I know why it is important to take an ownership role in my CF care

☐ I know the benefits of taking care of my health and the consequences of not taking care of my health

☐ If I have a port, I have discussed the benefits and risks of having a port and proper port care with my pulmonologist

KNOWING YOUR BODY

☐ I know what symptoms my body has when it is sick and how this is different from when it is feeling well

☐ I know the importance of monitoring my stools

☐ I know what stool changes I should discuss with my CF team

☐ I know my blood type

☐ I know when I should go to the emergency room for CF symptoms and when I should schedule a sick clinic visit for non-emergency symptoms

RELATIONSHIPS AND REPRODUCTION

☐ I understand the difference between healthy, unhealthy and abusive relationships

☐ I feel comfortable talking about my feelings, wants and needs in relationships

☐ If I plan on becoming sexually active, I have discussed safer sex practices with my parents/guardians and/or my doctor

☐ I am aware of community resources if I have questions or need resources regarding relationships and/or safer sex practices

☐ I am aware of the possible effects of CF on fertility and the reproductive system

MENTAL HEALTH

☐ I am aware of community resources for food, clothing, employment, housing and mental health services

☐ I am aware of any history of family medical or psychiatric concerns

☐ I am aware of signs and symptoms of anxiety and depression

☐ I am aware of signs and symptoms of substance abuse

☐ I am aware of the effects illegal drugs, smoking tobacco and alcohol can have on my body (short term and long term)

☐ I am aware of how to seek help if I experience anxiety, depression, substance abuse/dependence or any other mental health concerns

☐ I know what self care is and why it is important

CF RESOURCES

☐ I know each member of my CF team and the role of each person

☐ I am aware of online supports and resources specific to CF

☐ I am aware of the CF legal hotline and how they can help me

SELF ADVOCACY

☐ I know what it means to advocate for myself and my needs

☐ I feel confident in being able to advocate for myself and my needs

☐ I know who I can count on for support as I transition toward adulthood, and I have talked with them about how they can support me as I transition

☐ I know that after I turn 18, I need to complete a medical release of information if I want my family or friends to be able to receive information about my medical care

☐ I have discussed advance directives with my CF team

☐ I am aware of how to request copies of my medical records and how to request a transfer of my records to another location if I move to another provider or another city/state/country

MEDICAL APPOINTMENTS AND REFILLING MEDICATIONS

☐ I have the contact information for my doctors and pharmacies used for my medications (names/numbers/addresses)

☐ I have practiced scheduling my own doctor and dentist appointments

☐ I know how often I should see my primary care doctor, eye doctor, dentist, CF team and any other specialty doctors

☐ I have practiced calling in my medication refills to the pharmacy

INSURANCE

☐ I know what type of health insurance I have, why it important to have health insurance, and at what age I will need to get my own insurance

☐ I know the current co-pays required for my doctor visits, medications, lab work, and hospital admissions

☐ If I had questions about my insurance coverage, I know whom to contact for answers

☐ I am aware of medication patient assistance programs

☐ I am aware of the CF services pharmacy and how can they help me

FUTURE PLANNING

☐ I have a sense of purpose for my life and know my spiritual beliefs about life

☐ I have thought about my future goals and where I want to be within the next six months, year and five years with my goals

☐ I have created a daily/weekly/monthly/yearly schedule to accomplish my CF tasks and personal goals (and I have scheduled time for fun)

CAREER AND EMPLOYMENT

☐ I have explored careers/jobs and discussed my interests with my school counselor/family/friends/CF Team

☐ I am aware of scholarships available and of the Disability Resource Center (DRC) in colleges and how they can benefit me

☐ I have created my resume

☐ I know how to search for employment and have practiced employment interviewing skills

☐ I know the importance of searching for jobs with benefits (i.e. time off, medical leave, insurance coverage)

TRANSITIONING FROM PEDIATRIC TO ADULT CARE

☐ I understand the different expectations between my CF pediatric care team and adult care team

☐ I have scheduled a time to tour the adult inpatient floor and meet the charge nurse and inpatient social worker

☐ I have scheduled a time to meet with the CF adult pulmonologist to discuss my ongoing adult CF care needs

CONCLUSION

Congratulations in preparing for your transition to adulthood!

Although this is the end of your transition passport to adulthood for your CF care, this is just the beginning of your young adult life. Just remember, part of being a responsible adult is asking for help if you need it. Your CF team is here to support you in your CF health care and growth, so feel free to ask questions and/or voice concerns.

You have an exciting life journey ahead of you.

Carpe Diem (seize the day)!

Questions?

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