

# Ages and Stages: Living and Growing with Cystic Fibrosis

**Developmental Education for use with Parents  
and Patients living with CF**



**Kecia Nelson, MSW, LCSW  
Contributions from Ashley Gage, MSW  
University of Missouri Healthcare  
Cystic Fibrosis Center**

# Developmental Educational Program for Children with Cystic Fibrosis

## Initial Diagnosis

These are goals, issues, and expectations that the CF team would like each patient and family to discuss with the medical team and at home. Resources will be provided for many of these items. Questions are encouraged and welcomed. Please tell your CF team if any resources are needed to help meet these goals & expectations.

### Goals, Expectations, Issues

- Discuss Newborn Screening Process, understanding the Sweat Test
- Understanding genetics of Cystic Fibrosis
- Basic Review of Cystic Fibrosis
- Other test results
- Returning to CF Clinic- frequency of visits & purpose
- Team approach to CF
- Getting Information – tips for “safe” websites
- How to contact your CF Center

# Developmental Education Program for Children with Cystic Fibrosis

## First follow up visit after diagnosis

These are goals, issues and expectations that the CF team would like patient and family to discuss with the medical team and at home. Resources can be provided for many of these items. Questions are encouraged and welcomed. Please inform your CF team of any resources needed to help meet these goals & expectations

### Goals, Expectations and Issues

- Team approach to Cystic Fibrosis
- Enjoying your baby & their development
- Expecting normal growth and development
- Understanding the respiratory system- Infections
- Understanding the digestive system- Malabsorption
- Understanding treatments involved in Cystic Fibrosis Care
- Understanding Enzymes & how to give enzymes
- Philosophy of the CF center- Fitting CF into everyday life
- Sharing the diagnosis with family members
- Goals for outpatient management ( Clinic follow up, Respiratory, GI, assessments and baselines)

# Developmental Education Program for Children with Cystic Fibrosis

## Age – 2-4 Week Visit

These items are guidelines for your understanding of CF and are meant to assist parents in teaching a healthy lifestyle to their child. Please inform the medical team of any resources needed to help accomplish these goals & expectations.

### Goals, Expectations & Issues

- Assess understanding of CF
- Enjoying your baby & their development
- Cystic Fibrosis Care & Primary Care (well child care) – When to call
- Expect normal growth & development
- Sharing the diagnosis of CF with family & friends
- Review airway clearance, begin CPT
- Enzymes & nutrition
- Begin to determine child's respiratory baseline – Identifying signs & symptoms of Exacerbations
- Begin to determine child's GI baseline – Identifying signs & symptoms of malabsorption
- Good infection control (hand washing, antibacterials, avoid ill people)
- Fitting CF into everyday – Balancing a new baby, CF and your family

# Developmental Education Program for Children with Cystic Fibrosis

## Age – 6 to 9 Month Visit

These items are guidelines for your understanding of CF and are meant to assist parents in teaching a healthy lifestyle to their child. Please tell your CF team of any resources needed to help accomplish these goals & expectations.

### Goals, Expectations & Issues

- Networking with other CF Families, getting connected
- Comfort with CF care- airway clearance, medications & treatments
- Enzymes & nutrition – expecting normal growth and development
- Fitting CF into your daily routine, balancing CF & family
- Treatment of the “healthy” looking child
- Managing Lung problems, understanding illness
- Managing malabsorption, understanding signs & symptoms
- Child Care concerns
- Coping with diagnosis- Emotional Issues
- How a diagnosis of CF affects you and other family members

# Developmental Education Program for Children with Cystic Fibrosis

## Age – 1 Year

These items are guidelines for helping your child's understanding of their CF and are meant to assist parents in teaching a healthy lifestyle to their child. Please tell your CF team of any resources needed to help meet these goals & expectations.

### Goals, Expectations & Issues

- Discuss family planning for future
- Understanding the function & importance of airway clearance
- Understanding the function & importance of medications
- Comfort with airway clearance, manual CPT
- Comfort with medications & treatments
- Enzymes & nutrition- beginning toddler foods & eating habits
- Fitting CF into your daily routine, balancing CF & your family
- Development of child's respiratory baseline
- Development of child's GI baseline
- Child Care concerns
- Setting limits & discipline with your child
- Coping with diagnosis- Support systems & getting involved

# Developmental Education Program for Children with Cystic Fibrosis

## Age – 2 to 4 Years

These items are guidelines for helping your child's understanding of their CF and are meant to assist parents in teaching a healthy lifestyle to their child. Please tell your CF team of any resources needed to help meet these goals & expectations.

### Goals, Expectations & Issues

- Importance & function of airway clearance (Begin Vest therapy)
- Teaching age appropriate involvement with CF care
- Comfort with medications & treatments, teaching child basic words
- Identifying Malabsorption- Development of child's GI baseline
- Identifying Exacerbations -Development of child's respiratory baseline
- Child care concerns
- Mealtime routines, enzymes and nutrition with toddlers
- Setting Limits & Discipline for your child
- Getting prepared for school

# Developmental Education Program for Children with Cystic Fibrosis

## Age- 5 Years

These items are guidelines for helping your child's understanding of their CF and are meant to assist parents in teaching a healthy lifestyle to their child. Please tell your CF team of any resources needed to help meet these goals & expectations.

### Goals, Expectations & Issues

- Child begins participation in clinic visits
- Child begins learning about medications (age appropriate slang terms) and their role in lung health
- Child begins to learn about airway clearance
- Identifying Malabsorption- Begin Child's understanding
- Identifying Exacerbations – Begin Child's understanding
- Begin PFT's- Pulmonary Function Testing
- Nutrition- Child learning basic understanding between nutrition & lung health
- Setting Limits & Discipline with your child
- School Issues
  - Entering School- 504 Health plans and legal rights
  - Telling teachers & friends about CF
  - Taking enzymes at school
  - Preparing for school lunch & snacks
  - Field trips
  - Bathroom needs
  - Water & Salt needs during school



# Developmental Education Program for Children with Cystic Fibrosis

## Age – 6 to 7 Years

These items are guidelines for helping your child's understanding of their CF and are meant to assist parents in teaching a healthy lifestyle to their child. Please tell your CF team of any resources needed to help meet these goals & expectations.

### Goals, Expectations & Issues

- Explaining CF to friends
- Sleepovers with friends & CF treatments
- Continue learning the importance & function of airway clearance
- Beginning independence with airway clearance (Vest)
- Identify medications & role with CF (age appropriate slang terms)
- Helping with treatment preparations
- Importance of Exercise & physical activity
- Identifying Malabsorption- Continue child's understanding
- Identifying Exacerbations – Continue child's understanding
- Understanding PFT's – Pulmonary Function Tests
- Nutrition & Growth- understand link between nutrition & lung function
- School Issues
  - 504 Health Plans & Legal rights
  - Telling teachers & friends about CF
  - Taking treatments & enzymes at school
  - Preparing for school lunch and snacks
  - Bathroom needs

# Developmental Education Program for Children with Cystic Fibrosis

## Age 8 to 10 Years

These items are guidelines for helping your child's understanding of their CF and are meant to assist parents in teaching a healthy lifestyle to their child. Please tell your CF team if you need resources to help you meet these goals.

### Goals, Expectations & Issues

- Naming medications and simple reasons for taking them
- Continue encouraging independence with Vest
- Explore other options for airway clearance (Flutter, Acapella)
- Explaining CF to friends
- Continue taking enzymes independently
- Exercise and sports including salt and fluids for physical activity
- Understanding why some people have CF and others do not- Basic Genetics
- Begin more active participation in clinic visits, answering independently
- Continue to help child understand respiratory baseline & changes that occur
- Continue to help child understand GI baseline & malabsorption
- Basic nutrition and CF, and the importance of it's role with lung health
- School Issues- 504 plan, friends, meals/snacks, bathroom use, activities
- Transition issues, encouraging more child participation in care
- Making a Health Care Notebook & transition worksheets
- Mental Health (Coping with chronic illness, identifying anxiety and depression)

# Developmental Education Program for Children with Cystic Fibrosis

## Age 11 to 12 Years

These items are guidelines for helping your child's understanding of their CF and are meant to assist parents in teaching a healthy lifestyle to their child. Please tell your CF team if you need resources to help you meet these goals.

### Goals, Expectations & Issues

- Continue to answer questions independently in clinic & in the hospital
- Child feels comfortable bringing up issues or concerns
- Naming medications (proper names) and reason for taking them
- Taking enzymes independently
- Independence with airway clearance
- Explore options for airway clearance (Flutter & Acapella)
- Exercise and sports including need for extra salt and fluids
- Continue to develop an understanding of respiratory baseline and when changes occur- identifying & treating exacerbations
- Continue to develop an understanding of GI baseline and when changes occur- identifying & treating malabsorption
- Begin to understand yearly tests (blood, sputum, X-Rays, PFT's, diabetes screening)
- Child understanding basic CF nutrition & it's importance for lung health
- School Issues- 504 plans, friends, meals/snacks, medications, bathroom use
- Mental health (coping with chronic illness, identifying anxiety and depression)
- Review Transition Issues- Keeping a Healthcare notebook

# Developmental Education Program for Children with Cystic Fibrosis

## Age 13 Years

These items are guidelines for helping your child's understanding of their CF and are meant to assist parents in teaching a healthy lifestyle to their child. Please tell your CF team if you need resources to help you meet these goals.

### Goals, Expectations & Issues

- Teen answers questions independently in clinic – goal of independent visits
- Adolescent feels comfortable bringing up issues or concerns
- Naming medications & reason for taking them
- Independent with airway clearance, understanding why airway clearance is necessary
- Taking enzymes independently
- Identifying & treating exacerbations – Continue to develop your child's understanding of their respiratory baseline and when changes occur
- Identifying & treating malabsorption Continue to develop your child's understanding of their GI baseline and when changes occur
- Nutrition, osteoporosis, and calcium
- Exercise & sports including need for extra salt & fluid
- School Issues: Friends, meals/snack, & bathroom use
- Understanding quarterly visits– establishing baselines
- Begin to understand yearly tests (blood, sputum, X-Rays, PFT's, diabetes screening)
- Review Transition Issues– Healthcare Notebook, transition worksheets
- Mental Health (Coping with chronic illness, identifying anxiety and depression)

# Developmental Education Program for Children with Cystic Fibrosis

## Age – 14 to 15 Years

These items are guidelines for helping your child's understanding of their CF and are meant to assist parents in teaching a healthy lifestyle to their child. Please tell your CF team if you need resources to help you meet these goals.

### Goals, Expectations & Issues

- Independent clinic visits answers questions independently in clinic & the hospital
- Adolescent feels comfortable bringing up issues or concerns
- Naming medications and reasons for taking them
- Independent with airway clearance
- Taking enzymes independently
- Understanding why airway clearance is necessary
- Importance of exercise and sports, including salt and fluids
- Communication between adolescent, parent, & CF team
- Adolescent understands their respiratory baseline, identifying exacerbations
- Adolescent understands their GI baseline—identifying malabsorption
- Nutrition, osteoporosis, and calcium
- School Issues –504 plans, friends, meals/snacks, bathroom use, medications
- Understanding of yearly tests (blood, sputum, CXR, PFT's, diabetes screening)–  
Keeping a Healthcare Notebook
- Reproduction issues and CF
- Healthy Lifestyle Choices: Smoking, drinking, drugs, sexuality, & dating
- Mental Health (coping with chronic illness, identifying anxiety and depression)
- Transplant: Options, risks, & the transplant process

# Developmental Education Program for Children with Cystic Fibrosis

## Age 16 to 17 Years

These items are guidelines for helping your child's understanding of their CF and are meant to assist parents in teaching a healthy lifestyle to their child. Please tell your CF team if you need resources to help you meet these goals.

### Goals, Expectations & Issues

- Independent clinic visits. Answers questions independently in clinic
- Feels comfortable bringing up issues or concerns
- Naming medications and reasons for taking them
- Independent with all treatments
- Importance of exercise and sports, including salt and fluids
- Communication between adolescent, parent, & CF team
- Teen begins to monitor medications & supplies
- Teen begins to communicate directly with staff via the phone
- Continue to understand respiratory baseline
- Continue to understand GI baseline
- Nutrition, osteoporosis, and calcium
- School Issues- IEP, friends, sports & post High School plans- Scholarship information (if applicable)
- Understanding of yearly tests (blood, sputum, CXR), Health Maintenance Notebook
- Reproduction issues and CF
- Making Healthy Lifestyle Choices: Smoking, drinking, drugs, sexuality & dating
- Mental Health (coping with chronic illness, identifying anxiety and depression)
- Transplant: Options, risks, & the transplant process

- Work Issues and cystic fibrosis
- How to advocate for yourself
- How to be independent when on your own or in college
- Discussion of impact of CF on college & career choice
- Securing financial coverage/insurance and adult CF insurance

# Developmental Education Program for Adolescents/Adults with Cystic Fibrosis

## Age – 18-21 Years

### Goals, Expectations & Issues

- Independent clinic visits answers questions independently
- Feels comfortable bringing up issues or concerns
- Naming medications and reason for taking them
- Independent with airway clearance
- Importance of exercise and sports including salt and fluids
- Taking enzymes independently
- Monitors medications & supplies. Calls in refills
- Communicates directly with staff via phone calls
- Understands own respiratory baseline
- Understand own GI baseline
- Nutrition, osteoporosis, and calcium
- School Issues- Post High school plans
- Understanding of yearly tests (blood, sputum, CXR)- Health maintenance notebook
- Reproduction and CF
- Maintaining Healthy Lifestyle Choices: Smoking, drinking, drugs, sexuality & dating
- Mental Health (coping with chronic illness, identifying anxiety and depression)
- Transplant: Options, risks, & process
- Work Issues and cystic fibrosis- Post high school plans for career & college
- Understanding Advanced Directives
- Transition topics: How is it different/alike?

How to advocate for yourself?

How to be independent when on your own?