Supporting Children with Cystic Fibrosis in ECCE Settings:

Information for Practitioners
A child is like a butterfly in the wind. Some can fly higher than others, but each one flies the best it can. Why compare one against the other? Each one is different. Each one is special. Each one is beautiful.

**What is Cystic Fibrosis (CF)?**

Cystic Fibrosis, or sixty-five roses as some children pronounce it, is an inherited disease that primarily affects the lungs and digestive system of approximately 1200 children and adults in Ireland. When a child is diagnosed with CF it means his or her cells are missing an essential protein, therefore chloride and sodium cannot be properly transported across the cell membrane. This means normal mucus secretions become thicker and stickier which directly affects the respiratory, pancreatic and gastrointestinal systems by obstructing the lungs. This leads to chronic lung infections which can permanently damage lung tissue. Malabsorption is also a complication of CF as mucus obstructs the pancreas by stopping natural enzymes from helping the body break down and absorb food.

**Symptoms of CF:**

- Chronic coughing
- Sputum production
- Shortness of breath or wheezing
- Pale appearance
- Excessive appetite but poor weight gain
- Frequent respiratory infections
- Poor growth
- Stomach cramping
- Small stature
Challenges facing children with CF:

- Hospitalisation
- Fatigue
- Excessive coughing
- Sinusitis

**Important**

It is important to remember that CF will vary significantly between each individual. Not all children with CF will have the same complications or symptoms, nor will they require the same amount of care. Each child must be treated as an individual.

**Medications**

Children with CF are on a daily intensive routine of medication, nebulisers and physiotherapy to control their illness. This routine must be followed closely to allow the child every advantage from their medication. However this routine can be time-consuming and fatiguing and is also subject to change depending on whether the child is experiencing an active infection (often during the winter months), or having a period of "wellness" (possibly the summer months).

Some examples of medications which a child may take include:

- Antibiotics
- Steroids (Anti-Inflammatory medications)
- Pancreatic Enzymes (Creon)
- Vitamin supplements
- Oral bronchodilators
- Insulin
Medications and the Pre-School

Depending on the age of the child, they may need more or less help in taking their medications particularly pancreatic enzymes which must be taken with all food to help aid digestion. Discuss with the parent(s) if there is a particular way the child takes these tablets. For example a baby may take their Creon tablets broken up into soft food e.g. apple sauce. While a toddler or older child may be used to taking their tablets whole.

It is important for a child to develop a sense of responsibility when taking their enzymes and other medications. As a practitioner, you can encourage the child to be confident about their illness and medication. Allowing the child to be imaginative when taking their medications is a good way of bringing fun and normality to the situation. Through discussions with the parent(s), allowing a child with CF to self-administer enzymes with their food can be a primary step in promoting responsibility and will serve to provide a sense of independence and privacy for the child.

The parent(s) will often put the number of enzymes to be taken with food into lunchboxes, however it is important to discuss with the parent(s) how many enzymes should be taken with food given out on special occasions during school time i.e. birthday party’s.

Though it is important for the child to become responsible for his/her enzymes when he/she reaches an appropriate age, it is also important to keep an eye on the child that they take their enzymes when they should as young children will be easily distracted by peers, activities or something shiny! Children should always be supervised when taking medications no matter how competent or compliant they may seem.
Different activities can allow a child to acknowledge their medical condition. This could be in the form of drawing e.g. “good” bacteria could be fighting “bad” bacteria. Or in the play area through medical equipment such as a stethoscope or blood pressure cuff. The main goal is to allow the child to gain every benefit from their preschool experience and this may mean re-evaluating how an activity is presented. Also be aware a child may be shy or nervous when returning to school after a period of prolonged illness and may need a helping hand to develop social interactions and friendships with peers.

A useful way of encouraging social interaction may be through the “buddy system” where children are paired up for 10-15 minutes of free play each day. This will expand the social and language skills of all children and will also encourage peer support.

Play is a very important way for children to make sense of the world around them as they use their imagination and creativity to role-play many different aspects of life. Play gives children opportunities to know their limits, to work through their anxieties, to work out their capabilities and a child with CF is no different.

Having an active partnership with the child’s parent(s) is a further means of supporting the child’s development if they are out of the setting for a prolonged period of time. As practitioners it may feel natural to give a child with CF extra attention or help doing a task. However to ensure that the child becomes independent and grows in confidence, it is essential that once it is recognised that he/she is capable of performing a task for him/herself, the adult should then remove themselves from providing unnecessary support for the activity. Otherwise the child may not feel comfortable performing tasks without support and look for help in everything they do.

Exercise

Children with CF require chest physiotherapy to help remove the thick secretions in their lungs. This will usually be done at home, but aerobic exercise is also a great method of physiotherapy. The level of participation by a child with CF in sports or outdoor activities can vary greatly depending on many factors including; the intensity of the disease; how the child feels on a day-to-day basis; time of the year; and whether or not they have an active infection i.e. chest infection. However each child should be encouraged to participate to the best of their ability while consideration should be given to their endurance level compared to their classmates. If necessary a discussion between the parents and teacher can help identify appropriate levels of activity for the child.

Strenuous forms of exercise are likely to bring on coughing episodes, shortness of breath and wheezing. While this may cause some embarrassment to the child, the child should not suppress or stop coughing as this is a vital form of airway clearance. Instead to encourage good hygiene practice, all students should be taught to cough into an elbow or tissue and not their hands.

It may be necessary to keep a box of tissues or alcohol gel close in times of emergency as over exertion may cause nausea and dizziness which may lead to vomiting.

Children with CF are at a higher risk of dehydration, especially during warm weather. A child with CF may need to eat salty snacks and drink extra fluids during this time as large amounts of salt can be lost through their perspiration. Water should be easily accessible during physical activities.

Important

If a situation arises where another child inadvertently swallows a CREON tablet, there should be no adverse reactions from this. However the parent or guardian of the child should be notified.
Physical activity and physiotherapy can be disguised in many forms. Remember with a bit of imagination and creativity hopping like a bunny, leaping like a frog, dancing like a prince or princess or prancing like a pony are all entertaining physical activities which will allow a child to play as well as helping to manage their CF.

**Special Diet**

Maintaining an appropriate weight can be very hard for children with CF. Therefore they are encouraged to consume a high protein/high calorie diet which consists of sufficient daily amounts of fat, salt and calories. Although many early years' settings have a healthy eating policy, please be sensitive to the fact that children with CF need to consume more calories due to the body’s decreased ability to digest food. Although it may appear their diet is unhealthy by most nutritional standards, high-calorie foods and snacks are necessary in maintaining a healthy weight. Some children with CF may require a mid-morning or mid-afternoon snack to help maintain proper nutrition. Also during times of infection, a child may experience a decreased appetite and therefore may be required to have “build–up” drinks which provide their body with important vitamins, minerals and calories. Weight loss can be a significant problem for children during times of infection. Therefore it is very important during times of “wellness” that the child is given enough time to eat their lunch as well as being encouraged to eat as much as they can. However if they seem uninterested in their lunch/snacks they should not be forced to eat as a negative association with food should not be encouraged.

璀 If the child seems uninterested in food and positive encouragement has failed, explain to the child that they can be given a break from lunch now but at another stage of the afternoon (after they have played etc) they will be given a snack to eat.
Hygiene & Cross Infection

Children with CF are very susceptible to infection therefore a good hygiene routine is one of the first steps in preventing the spread of infection. Hand washing with soap and water is critical as it is the best way to prevent colds and flu. If another child is obviously sick (runny nose, fever, etc.), it is especially important to enforce the settings hygiene policy. While it is important to sanitise hands, particularly after completing group activities, it is vital not to over emphasise hygiene on one particular child, or expect a clinical standard of cleanliness within the setting. A balance is needed between letting children be children and supporting their needs in a safe environment.

**Important**

In reference to cross infection guidelines, children with CF should not interact with one another. It is not recommended to have two children with CF in the same classroom at any one time.

Teaching the Child with Cystic Fibrosis

CF does not have any negative neurological effects, however due to the nature of the disease including hospitalisations, appointments, fatigue, early morning medical routines, infections and absences from class, a child may need extra help in some areas of curriculum. This may be particularly true for literacy and numeracy as the foundation for learning in these areas may become ad hoc due to illness.

💡 Use everyday items to encourage numeracy and literacy in an informal way. For example counting the number of enzymes a child takes with food. Or spelling out the name of their enzymes i.e. C.R.E.O.N.

Be aware of the fact that a child may be frustrated by the fact that others in the class may be better or quicker at things that him/her. Be adaptable in how certain activities are presented if the child does not appear to understand or at times may be physically unable to complete certain tasks.
The main goal is to allow the child to gain every benefit from their preschool experience and this may mean re-evaluating how an activity is presented. Also be aware a child may be shy or nervous when returning to school after a period of prolonged illness and may need a helping hand to develop social interactions and friendships with peers.

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Children should always be supervised when taking medications no matter how competent or compliant they may seem.

Helping Classmates Understand CF

Young children have a lot of questions and are typically not satisfied until they are given an answer! Do not try to avoid questions about CF or hide the illness from the child’s playmates as this is their way of understanding the world in which they live. It is important to answer any questions other children may have in an appropriate way which suits their age and understanding. By being open and honest about CF allows any mystery or negativity about the illness to disappear. It encourages the whole class to accept difference as part of life and something to be embraced. It also teaches the child with CF that CF is part of who they are and it is not something they should hide. For example:

**Why does Sarah take tablets with her lunch?**

Sarah has to take tablets called enzymes with her lunch to help her tummy break down the food she eats.

**Why does Sean cough so much?**

He coughs because he has something called CF which means his lungs get a little sticky. He coughs to try and help clear his lungs and keep them healthy.

**Does that mean I could get sick?**

No Sean was born with CF so that means you can’t get sick from being around or playing with him even though he may be coughing.

(Useful Resource — Getting Nosey about CF with Oli and Nush
http://www.youtube.com/watch?v=WuI72eMrIqI )
**Important**

Although it is important to be open and honest with the class, it may be a sensitive issue for both the child and his/her parent(s). In collaboration with the parents, discuss in advance what information can be shared with the class which will help include the class but also respect the child’s privacy.

**Confidentiality**

It is important to recognise an individual’s privacy both inside and outside of an early years setting. It may be appropriate to discuss the specific needs of individual children between practitioners during working hours. However, it is essential to uphold the privacy and confidentiality of every child, both with and without additional needs, outside of the setting.

**Expert Advice**

Don’t be afraid to ask for extra advice or information from the medical experts dealing with CF on a day to day basis. These could include the child’s parents, specialist nurse, physiotherapist, dietician or doctor. There may even be opportunities for the parent(s) to come into the early years setting and discuss CF with the class. This encourages a relationship with the parent(s) as well as promoting to the children that difference is normal. It also takes away any mystery surrounding CF.

 כדאי שתהיה כלег基礎י ומקבילה לגבי ילד עם CF. עימם יש庾 להיאבק וערה מידע מומחיית, כגון הורים, רופאי ילדים, פיזיותרפיסט, טיפולוגים או רופאים. possono להיות הזדמנויות ביצוע ביקורים של הורים במעגל החינוך לחגיגת אספקטים של CF עם הקהל. זה מחזק את הקשר עם הורים, כמו גם מעניקה.FragmentManager להורים ומאפשר למידה לקอุปים כי השונות היא תקינה. זה גם מוציא מההתבלט הסודות שבקשר לCF.
“We know that equality of individual ability has never existed and never will, but we do insist that equality of opportunity still must be sought” F.D Roosevelt.

Remember although CF is a serious illness and should not be treated lightly, the most important thing to consider when evaluating your practice around a child with CF, or with any disability, is to treat the child first and the condition second. A child should not be defined by their disability. Instead if they are treated with support and guidance to overcome the many challenges they will face in life, they will grow up with a confidence to control and manage their disability instead of it controlling them and their experiences.

Most Important

….HAVE FUN!!!!
Useful Resources and Numbers:
Cystic Fibrosis Association of Ireland
CF House
24 Lower Rathmines Road
Dublin 6
01 496 2433
Lo-Call 1890 311 211
www.cfireland.ie

Your local Childcare Committee

Resources:
How to Support a Child with Cystic Fibrosis (CF) in Pre-School: A Guide to Help Parents Navigate the First Steps into Pre-School Settings
Available at: www.corkcitychildcare.ie

“Can you see what I see?” (2011) by Louise Byrne.
Contact Author: louisebyrnebooks@gmail.com

“School/Daycare Information on Cystic Fibrosis”
Handouts for Teachers - “Cystic Fibrosis in the Classroom”
Available at: www.iuhealth.org/riley/pulmonology/cystic-fibrosis/school-daycare-information-on-cystic-fibrosis

“Letter to Preschool Teachers about Cystic Fibrosis Care”
Available at: www.peterspavementpounders.org/2010/08/letter-to-preschool-teachers-about.html

“Caring for your toddler and pre-schooler: A parent’s guide to healthy living with cystic fibrosis”
Available at: www.cysticlife.org/downloads/ToddlerBooklet.pdf