



NUTRITION

Helping Children to Eat a High Fat, High Calorie Diet for CF

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Good nutrition is vital to people with CF. Studies conducted over the past 20 years have confirmed that there is a clear link between a high fat high calorie diet and weight gain that contributes to improved lung function and longer survival. Many children now born with CF live into their 30's and 40's compared with thirty years ago when death usually occurred during teenage years.

In order to achieve good nutrition for children with CF, it is now recommended that they eat a diet comprising 120-150% of recommended daily energy allowance for age and 40% of this allowance should come from fats. In addition, children are required to have enzymes with all but a few foods. Although this diet is important for their health and survival they do not always follow these recommendations. The result of this is poorer health due to weight loss and chest infections. When children have inadequate diets begin to lose weight, it is necessary to give them supplemental meals and snacks with high calorie drinks like milkshakes. If they continue to lose weight they may require tube feeding, which is usually given at night during sleep.

For children who are not eating the required diet for weight gain and who may be difficult to feed (e.g. dawdling with food, refusing food, spitting it out) psychologists have developed behavioural programmes to help parents modify children's mealtime behaviours. However, there is little known about the long-term effectiveness of such programmes in terms of increasing children's dietary intakes. In practical terms, it may be difficult for parents to modify their child's eating behaviours without their co-operation. Children make choices about what they do and do not want to eat, and their food choices may not always be what parents or health care professionals advise them to eat. Also, children eat at times other than mealtimes which may be outside the home and without parental supervision.

Rather than concentrate on parents as the principal persons in getting children to eat the recommended diet for CF, it may be better to work more directly with children in order to:

- # help them understand why diet is important to their health
- # listen to the difficulties they experience with CF diet
- # tailor dietary messages in ways that are relevant to their day to day lives

An interview study carried out with 32 Irish school aged children (aged 6 to 14 years) and their parents on managing diet for CF provides important findings on how children could

be helped to meet the required calorie and fat intake. Part of this study was published in the Archives of Diseases in Childhood in March 2005 (Savage, E. and Callery P. (2005) Weight and energy: parents' and children's perspectives on managing CF diet. *Archives of Diseases in Childhood*. 90: 249-252). A message highlighted in this study was that parents and health care professionals focus on weight gain as a key to good health whereas children focus on being active and energetic when describing their sense of health and well-being. The children did not make the connection that maintaining their weight ensured that they had good energy levels for example to play football or go out dancing. The study found that children make little sense of weight gain as being important to their health. Weight was not something they could experience changing in their bodies from day to day. In contrast, children did notice changes in their energy levels. They described being very active and having lots of fun when "full of energy" or feeling tired and having to lie down when they had little energy.

Sticking to diet for CF can be difficult for children, especially when expected to eat foods they dislike. Some children in the Irish study described it as a chore to eat the amount of food expected of them and they spoke of their annoyance with health care professionals who were insistent about eating when they were losing weight. For example, a 12 year old girl said that sometimes "they'd be talking to you about food forever...just eat, eat, eat and eat." They also described their annoyance with health care professionals who might not believe that they were trying their best to eat as much as possible. Children who were losing weight described having arguments with their parents because of not eating enough food.

Other children spoke of difficulties in eating a high fat diet because they had learned at school that fatty foods were not good for their health. Information on good nutrition for the general population was not relevant or helpful to children with CF.

When parents were asked their views in the study, some spoke of their difficulties in getting their children to eat the recommended diet for weight gain. Some parents described it practically impossible to get children to eat the amount of food that they were expected to "ladle into them". Other parents questioned the relevance of a high fat diet if children were steadily gaining weight. These parents believed in giving children a 'balanced and all round diet' similar to the general population of children.

Parents of children who were losing weight believed it necessary to increase their fat intake. These parents described their experiences of seeing their children lose weight as one of the most distressing aspects of managing diet for CF because they worried about their children's health "starting to go downhill". Parents in this situation spoke of increasing their efforts at getting their children to eat by "getting strict with them" and some parents described "battling" every day with their children to the point of almost using physical force with them. As one mother said: "all I'm short of doing is shoving it down her throat". While these efforts worked for some parents, other parents described having little success in getting their children to eat in which case children were commenced on tube feeding because of continuous weight loss. Parents in the difficult situation of having "battled" with their children to eat welcomed tube feeding because of



fears that their children might die if they continued to lose weight and have recurrent chest infections.

For parents, a priority in feeding their children was “keeping the weight up” in order to protect them from chest infections. They spoke of health care professionals reinforcing the importance of weight gain when advising about diet such that they were told to “pile on” a high fat diet and “the more the better”. One mother explained that: “...it was driven into you to get the food into them...to try and keep their weight up”

A key message from this study is that *encouraging children to eat a high fat diet for weight gain may not be the best approach to take, whereas explaining that they need food for energy to play games or go dancing may motivate them to stick with their diet*. Rather than talk to children about food in terms of its nutritional or calorie value, it may be a better approach to talk to them about food in terms of providing more or less energy. Children should understand that fatty foods give them most energy for their activities and that it is important for them to have more fatty foods for energy than their peers because children with CF lose energy from their bodies quicker than peers without CF. Likewise, a child’s need to take enzymes could be explained as helping food to be broken down so that its energy can be taken into their bodies and used for everyday activities. *Focussing on energy may a meaningful health message for children because it was something they could experience changing within their bodies from day to day*, whereas they had difficulties knowing whether they were gaining or losing weight.

When helping children understand the importance of diet for CF and for their health, it is important to talk openly and directly with them. Children are not always directly consulted when they attend clinics for check-ups. This study with Irish children found that health messages about diet were mainly targeted at parents. For example, an eight year old girl mentioned that the clinic was “boring” because:

“you just have to sit there and listen to all this information about me. I don’t like it. (pause)...it is not interesting and they just talk to my Mum and Dad”

The problem with not directly involving children in consultations is that they may “switch off” from what is being said about their diet and their health. When children were asked who health care professionals should talk to about their diet and their health, and they believed it was important that children themselves were consulted rather than being ignored. *Health care professionals would therefore be advised to be more inclusive of children during clinic visits by asking them what their views and concerns might be in trying to eat the recommended diet for CF*.

Colourful, child-friendly information booklets with pictures of children being active and energetic linked to pictures explaining dietary needs in terms of energy for activities would be a useful way of engaging with children and of working with them in ways that are relevant to their day to day needs. This more child-friendly approach may also be

helpful to parents in gaining children's co-operation with eating a high fat high calorie diet for CF rather than focussing on weight gain.

The messages from this Irish study are important. If dietary messages are tailored in ways that are relevant to children's every day lives, they may be motivated to eat the recommended diet for CF which in turn has important clinical implications for their long terms health because of the links between a high fat diet and survival.

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