



Fit to Eat: Media Briefing

INTRODUCTION

Caring for a child with cancer in hospital can be extremely worrying, stressful and exhausting. Helping the child to cope with their stay in hospital, making decisions about treatment or supporting siblings are major preoccupations. Concerns about food and eating would be expected to be relatively minor. But, parents are very concerned that their children are not eating food provided on cancer wards.

Children and young people with experience of cancer recently came together to tell CLIC Sargent what matters most to them. Hospital food featured highly on their list – they and their families said food is often inappropriate, unappetising, unhealthy – even totally inedible.

To investigate the extent of the problem CLIC Sargent carried out further surveys with both hospital staff and parents.

- **90% of hospital staff received complaints about food**
- **77% of parents described the food negatively: unappealing, poorly prepared, unsuitable for sick children, lacking in choice and not age appropriate**

More needs to be done to improve the quality of the service being provided.

Children and young people with cancer can be in hospital for weeks, sometimes months, undergoing painful and toxic treatment. Treatments can affect taste buds and the ability to eat, so food needs to be tailored to their particular needs.

When suitable food isn't available on the ward, parents are resorting to buying-in their own food, which can bring families, already stretched by the cost of caring for their sick child, to financial breaking point.

"He stopped even attempting to hospital food because he didn't like the look or smell, so I brought food in" Parent NW England

- **98% of parents took food into hospital for their child**
- **76% of parents spent more on food whilst their child was in hospital**
- **Parents brought extra food in order to encourage their child to eat, to counter the side effects of treatment or because the timing of delivery did not fit well with treatment**

CLIC SARGENT'S FIT TO EAT CAMPAIGN

The campaign aims to eliminate the inconsistencies in food provision. There are some great examples of innovative delivery models in some hospitals – we want to make sure that this happens everywhere.

We will be working collaboratively with NHS hospitals and the Government to ensure that existing guidelines are implemented to ensure that all children and young people in cancer wards are given decent, age-appropriate, nutritious food when they are in hospital.

"It's hard enough for a parent to see their child critically ill – they should not be faced with the added worry of seeing their child offered food they cannot eat"

Dr Carole Easton

A CHILD'S SPECIAL DIETARY NEEDS

Most children and young people will experience problems with eating and drinking at some point during their treatment. There are a number of causes including side effects of treatment and medication and the symptoms of the cancer itself. The food they eat can make a significant impact on their response to treatment.

Common problems include:

- Feeling of nausea and vomiting
- Sore throat or mouth ulcers
- Dry mouth which affects the taste buds
- Change in the sense of taste
- Craving and a very big appetite due to steroid treatment
- Diarrhoea and constipation

"I can't think of anything worse than mushy, tasteless food when your taste buds are shot to bit" Parent

Good nutrition is extremely important for children with cancer; but their needs are often distinct from those of other children and what is 'good' or 'healthy' food needs to be considered in the context of their illness. If food is unappealing or unappetising it can prolong a child's recovery time and length of time in hospital.

Nausea or sickness mean the child is eating very little and what they do eat needs to be packed with energy and nutrients. A child who needs to gain weight and build up their strength may want high-fat, high-sugar snacks. Some may only want bland foods and nothing else so their intake needs to be monitored to ensure they are getting the nutrients they need.

WHAT'S WRONG WITH HOSPITAL FOOD?

Standards of food provided to children with cancer vary hugely throughout the UK and a number of hospitals are providing very good services. Despite this, inconsistencies exist and children and young people are still reporting unappetising food that is not responsive to their needs.

- **The food provided is inappropriate:** either not suitable for sick children or children at all, or not age appropriate – either too 'childish' or too 'adult'.

- **The food is not appetising, or poorly prepared:** food is regularly served at the wrong temperature, over-cooked or even frozen.

".. the food was cold and sloppy. It smelt awful and was very unappetising" Parent

- **Meals are served at the wrong times:** set meals are often missed due to treatment. If food is not available outside of set times then the child will not have an opportunity to eat.
- **The eating environment is wrong:** children dislike eating in bed. If no alternative dining area is provided children struggle to eat or refuse food altogether.
- **The child's needs are not being met:** food being offered isn't what the child wants or needs to help them deal with the side effects of treatment.



THE CHALLENGE – HOW TO PROVIDE FOOD WHICH IS FIT TO EAT

CLIC Sargent wants all hospitals to provide food that is appropriate, nutritious and appetising on its children's cancer wards. The service needs to be flexible and responsive to a child's needs.

The challenge in making innovative changes without spending more money: using existing resources in a different way to make significant differences to the service that is being provided.

"... Food can make a big difference to children with cancer –which is all the more reason to try innovative ways to help them eat" Director of Nursing

CLIC Sargent recommends changes to the way hospitals provide food to children and young people with cancer. Our guidelines follow five key principles:

- **Flexibility:** offering a wide choice of food and drink in a social setting that appeals to the child. Involve children in their food selection.
- **24 hours:** available 24 hours a day to allow for appetite changes; without disruption to treatment times. Protected meal times to be preserved so that all non-urgent treatment does not interrupt eating.
- **A child's preferred food:** children should be consulted on a daily basis about their preferences and needs, and every effort made to accommodate them.
- **A child's age:** food should be appropriate to their age. Where possible, hospitals should provide the same level of service for a teenager or young adult not based on a children's cancer ward.
- **Working together:** all staff who come into contact with the child should work collaboratively

ON-WARD CHEF OR FOOD CO-ORDINATOR

The most effective models for providing food for children with cancer are those which have a dedicated children's service, in the form of an on-ward chef or a specialist kitchen. However, space and budgetary restrictions mean that many hospitals aren't able to provide this level of service.

A dedicated food coordinator could be the point of contact for any food requests and who is responsible for getting to know a child's needs and preferences and who employs a series of strategies to encourage children to eat. They would have a close relationship with dieticians, nurses and catering staff to ensure the child's needs are taken into consideration when providing meals and snacks.

"It very much works because Mick, and the way he interacts with the children and families. You have to have the right person in place"
Addenbrookes Hospital



Mick, Children's Cancer Ward Cook at Addenbrooke's Hospital