

**Childhood Onset Eating Disorders: The Experience Of Parents**

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## **Abstract**

### **Childhood onset eating disorders: The experience of parents**

To date, there does not appear to be a study that has systematically examined the experience of parents who have a child with an eating disorder. It is essential to understand parents' perspectives because of their central role in the treatment of childhood eating disorders. This is a qualitative study that aims to address this gap in the literature. Of primary interest is parents' views on the impact of having a child with an eating disorder: how it affects their every day life, how it affects them personally and how it impacts upon the family as a whole. This study explores parents' understanding of their child's eating disorder, including their views of the possible causes of their child's illness and in terms of the help they feel they and their child need.

Semi-structured interviews were conducted with 11 mothers and 8 fathers. All participants had a child with a diagnosis of either anorexia nervosa or selective eating. In total, this concerned 8 daughters and 3 sons. Parents were also asked to complete several complementary questionnaires. These methods enabled individual parents' views to be explored in depth and retained within the analysis. All interviews were transcribed verbatim and were then analysed using Interpretative Phenomenological Analysis (IPA; Smith 1995). This is a qualitative form of analysis in which themes within the data are systematically identified. The results section describes how parents' accounts can be understood in terms of related themes. Themes are presented under the following domains: understanding the eating disorder; the impact of the eating disorder and managing the eating disorder. The analysis reveals that there are many commonalities between the accounts of the two sets of parents, but also some distinct differences. The discussion section examines the results of the study in relation to current eating disorder literature. It pays close attention to the similarities and differences in the accounts of parents who have a child with anorexia nervosa and those who have a child with selective eating. Methodological issues are examined. Following this, recommendations for clinical practice are outlined.

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## **Chapter 1: Introduction**

### **Overview**

Food and eating have always played a central role in the lives of human beings. Food sustains us physically, socially and spiritually. Physically the consumption of food and drink are integral to our existence, they are the fuel on which we survive. Socially, food is central to many activities from the giving of a birthday cake, the sharing of a wedding banquet to the 'doing of business over lunch'. Spiritually, it is a focal point for many different religions, be it wine and bread symbolising the body of Christ at a Christian mass, or the fasting during the Muslim period of Ramadam. To this degree food and eating pervade all areas of our lives. Therefore, when a person develops an eating disorder it has ramifications that extend beyond their altered physical state. It impinges upon all facets of their life.

Eating disorders are not a 'modern' disease in fact they have fascinated scientific thinkers for centuries. However, the last 30 years have witnessed a peak of interest into eating disorders in the clinical arena (Garfinkel, 1995). Most recently, increased attention has been focused on a distinct population of people with eating disorders, those with an onset below the age of 14 years (Lask and Bryant-Waugh, 2000).

Interest in childhood onset eating disorders has surged in the context of reports of increased dieting behaviour in children (Hill, 1993; Hill, 1998; Hill, Oliver and Rogers, 1992). This is a particular cause for concern because dieting behaviours have

been identified as a risk factor for the development of eating disorders (Wilson, 1993). There can be little doubt that as we enter the 21<sup>st</sup> century, eating disorders, including those of early onset, have become a major public health issue. Indeed referral rates for eating disorders continue to rise and as they do, the need for further specialist services that can cater for this population increases too (Lask and Bryant-Waugh, 2000).

The literature on eating disorders is vast. Nevertheless there is still much to learn about childhood onset eating disorders. This study hopes to make a contribution to one largely neglected area, namely the experience of parents who have a child with an eating disorder. Too often parents' experience of living with such illnesses and the treatment offered is overlooked. Research on the families of eating disorder patients has typically focused on two areas: the relationship between patients and their families and the role of the family in the aetiology and treatment of eating disorders (Vandereycken, Kog, & Vanderlinden, 1989). In contrast, no systematic attention has been paid to the experience of parents of children with eating disorders.

Parenting can be a difficult task at the best of times. However, the demands on parents are likely to be amplified when a child is ill with an eating disorder. Parenting can be conceptualised as "a 'process' that involves ongoing interactions between a parent and child that take place over the life span" (Brooks, 1991). The importance of parenting on a child's psychosocial development is clearly recognised. However; parenting is a challenging and complex process to understand (Bornstein, 1995). This is in part due to the fact that parenting does not occur in isolation. In fact the

interactions between any child and its parents are likely to be influenced by a large number of factors. These include the individual characteristics and temperament of the child and parent, the past experiences of the child and parent and other family relationships, as well as socio-cultural factors (Long, 1996).

The main goal of parenting is to provide a nurturing environment for children where the child's health, safety and financial economic security can be ensured to the best of the parent's ability (Brooks, 1991). Parents are also expected to provide a positive value system within social and cultural norms. It is argued that this kind of parenting will optimise a child's development, acting as a protective factor against the development and/or exacerbation of various child mental health problems (Bornstein, 1995; Downey, & Coyne, 1990; Forehand, & Long, 1988, 1996; Shaw, & Bell, 1993). However, the provision of 'positive' parenting is not an easy task. In particular, if a parent is distressed or irritable (for whatever reason) it is not surprising to hear that this may lead to "impatience, inconsistency, and or emotional unavailability as a parent" (Vondra, & Belsky, 1993). Furthermore, "without the psychological resources to understand, and consequently tolerate, the daily demands and frustrations (of a child or teenager) a parent will be hard pressed to demonstrate the patience, sensitivity and responsiveness that effective parenting requires" (Vondra, & Belsky, 1993). What therefore are the consequences for parents when their child develops an eating disorder, a serious, demanding illness that they may know very little about?

There is little doubt that parents can suffer enormously when a child has an eating disorder (Bryant-Waugh, 1992; Lask, & Bryant-Waugh, 1993). Parents are faced not only with the usual difficulties associated with growing up but also a potentially life-threatening illness (Sharkey-Orgero, 1999). After all, it is the parents “who have lived with and observed the anorexic child from birth, and who have to deal with the anorexic child’s problems first-hand, 24 hours a day” MacDonald (2000). Parents remain largely neglected within the eating disorder literature. This is in spite of research that suggests that effective treatment packages for childhood onset eating disorders must involve parents at some level (Lask, 2000). The views and experiences of parents may provide insight into understanding the impact of having a child with an eating disorder. For example, how do parents approach difficulties with their child? How can we engage them in treatment? Furthermore, when a child is ill, it is both the child and their parents that become consumers of health services, and as such they should be valued as reporters of their own experience (Harrison, & Barlow, 1995; Hope, Wells, Morrison, Gillmore, & Wilsdon, 1995).

This study seeks to consider the understandings and experiences of parents in relation to having a child with an eating disorder. Of particular interest are parents’ views on the impact of their child’s eating disorder on the family. The study explores parents’ understandings of their child’s eating disorder. This includes their thoughts on the possible causes and the help that they and the child may need. Fundamentally, it is hoped that this study will act as a voice for parents.

**Types of childhood onset eating disorders and epidemiology**

Generally, the descriptive terms applied to children do not easily translate into the diagnostic labels applicable to adults. This is due to the complexity of diagnosing eating disorders in children according to current diagnostic systems such as DSM-IV (American Psychiatric Association, 1994) and ICD-10 (World Health Organisation, 1992). Bryant-Waugh (2000) provides a detailed account of the issues related to the diagnosis of eating disorders in childhood. In particular, this account highlights the confusion arising from the complexity of applying adult diagnostic criteria to eating difficulties in children. It outlines the difficulties that are associated with distinguishing eating disorders from developmentally appropriate feeding difficulties and ‘phases’, as well as the impact of the lack of standardised instruments for the assessment of eating disorders in childhood. Finally, the myths promoted by the media that surround eating disorders in childhood are discussed.

‘Childhood onset’ or ‘early onset’ eating disorders’ generally refer to those eating disorders that emerge prior to 14 years of age (Bryant-Waugh, & Lask, 1995). Various childhood onset eating disorders have been described and are clearly distinguishable from developmentally appropriate feeding difficulties and eating problems such as food fads. It has been estimated that approximately half of children who attend eating disorder services do so with a symptoms characteristic of anorexia nervosa including a presentation of under-eating, food restriction, and avoidance of weight gain (Bryant-Waugh, 2000). Other children who present to eating disorder services have a range of different types of eating disorder or eating disturbance. These include selective eating, food avoidant emotional disorder, obesity, compulsive

overeating and in rare cases, pervasive refusal syndrome (Bryant-Waugh, & Lask, 1995).

There is distinct lack of empirical epidemiological research relating to childhood onset eating disorders. This makes it difficult to know precisely how many children are affected by the various eating disorders. Furthermore, existing epidemiological studies of eating disorders are hampered by a variety of problems, which create further difficulties in the interpretation of the findings. Doyle and Bryant-Waugh (2000) explore these methodological problems in relation to childhood onset eating disorders.

An overview of the childhood onset eating disorders that frequently present to specialist services is outlined below. However, childhood obesity and related eating problems will not be addressed here. Available epidemiological data will be discussed under each heading.

#### Childhood onset anorexia nervosa

The core physical, behavioural and psychological features of anorexia nervosa in childhood are very similar to those seen in adults (Bryant-Waugh, 2000). Therefore the key feature of anorexia nervosa in children remains the determined attempt to either lose weight or avoid gaining weight. This is often achieved by avoiding food, the abuse of laxatives, self-induced vomiting and over exercising. The weight or body mass of children with anorexia nervosa drops to below the level required to ensure that they can continue to develop and grow. Unlike in adulthood, failing to gain

weight in childhood is equal to weight loss, as children should be systematically growing and gaining weight. Furthermore, because children have lower levels of total body fat, they can become more severely emaciated and suffer the physical and psychological effects of starvation more rapidly than adults (Bryant-Waugh, & Lask, 1995).

A range of abnormal cognitions are found in children with anorexia nervosa. In particular, they have an intense fear of gaining weight or becoming fat even though they are underweight. Moreover they suffer from a major disturbance in the way their body weight or shape is experienced. Children with anorexia nervosa are highly preoccupied and dissatisfied with their weight and shape, often to the extent that they can think of nothing else but weight, shape and food (Bryant-Waugh, 2000).

Despite the clear similarities between the key features of anorexia nervosa in children and adults, difficulties exist in the application of some of the currently accepted diagnostic criteria for anorexia nervosa. While ICD-10 (World Health Organisation, 1992) acknowledges the existence of pre-pubertal anorexia nervosa and makes an allowance for this in its diagnostic criteria, the DSM-IV (American Psychiatric Association, 1994) does not. For example, criterion D of the DSM-IV states the “absence of at least three consecutive menstrual cycles”. However, this criterion is problematic for girls under the age of 14 who may not yet have started menstruating. It is also difficult to establish whether menstruation would “otherwise have occurred” in girls under the age of 14. Nevertheless, it is clear that childhood onset anorexia nervosa does exist and that it is a potentially life threatening illness with a poor prognosis (Bryant-Waugh, & Lask, 1995).

The incidence of childhood anorexia nervosa is not known. While young people have been included in a number of large-scale epidemiological studies, researchers in these studies have failed to distinguish between children and adults affected by anorexia nervosa (Neilson, 1990). Furthermore, studies that have reported incidence rates of anorexia nervosa in children (e.g. Joergensen, 1992; Lucas, Beard, O'Fallon, & Kurland, 1991) have significant methodological weakness. Despite the lack of reliable incidence figures it would appear that the incidence of childhood anorexia nervosa is lower than in late adolescence and early adult life. While there appear to be lower incidence rates in this younger age group, clinical audits do in fact suggest that referrals of children with anorexia nervosa to specialist clinics have been gradually increasing over the years (Bryant-Waugh, & Lask, 1995). However, one cannot conclude from this that the incidence of childhood onset anorexia nervosa is necessarily rising. Part of the increase in referrals may be due to an increased awareness of eating disorders in children and the availability of specialist services for such illnesses.

Who develops anorexia nervosa? In adults, anorexia nervosa is much more common in women compared to men. Men are thought to account for approximately only 5% to 10% of cases (Joergensen, 1992; Pasberg, & Wang, 1994). However, in childhood onset anorexia nervosa, boys account for a much higher percentage of cases, for example, 20% to 25% of clinical referrals are boys (Bryant-Waugh, & Lask, 1995). It remains unclear why this difference exists between early and late onset cases, but clearly it requires further thought and investigation.

It is now clear that children with anorexia nervosa appear to come from a range of different social and cultural backgrounds despite early reports that suggested the illness was virtually limited to middle class, white females (Prince, 1983). It now seems likely that previous estimates of the low prevalence of anorexia nervosa in non-whites were underestimated (Hsu, 1987). Cases of anorexia nervosa have now been described all over the world including Zimbabwe (Hooper, & Garner, 1986), Egypt (Okasha, Kamel, Sadek, Lotaif, & Bishry, 1977), Nigeria (Nwaefuna, 1981), Singapore (Ong, Tsoi, & Cheah, 1982), Malaysia (Buhrich, 1981) and Chile (Purnarino, & Vivanco, 1982).

### Bulimia nervosa

Children and young adolescents rarely present to specialist services with bulimia nervosa despite reports from bulimic women that their eating disorder started in early adolescence (Bryant-Waugh, 2000). Bulimia nervosa is characterised by episodes of overeating in which the person experiences a loss of control. This is accompanied by an endeavour to avoid weight gain by behaviours such as self-induced vomiting, laxative and/or diuretic abuse, or food avoidance. As in anorexia nervosa, weight and shape concerns are central. Bulimia nervosa frequently exists alongside other forms of self-harm (such as injuring skin, risk-taking behaviour) although a diagnosis can be made without these additional features.

Selective eating

Selective eating is a term used to describe children who persistently refuse to eat anything that is outside of their limited range of preferred foods (Bryant-Waugh, 2000; Nicholls, Christie, Randal & Lask, 2001; Timimi, Douglas, & Tsiftsopoulou, 1997). The diet of children with selective eating generally consists of five or six varieties of carbohydrate based foods such biscuits, chips or crisps. In addition to a highly selective diet, a number of accompanying behaviours may also be seen, such as extreme distress and resistance to try new foods, which can result in parents needing to always have the child's preferred foods at hand. Other disruptive behaviours at mealtime can also occur, including spitting out food, playing with food, excessively slow eating, as well as difficulties with swallowing or chewing food and also gagging (Bryant-Waugh, 2000; Sanders, Patel, Le Grice, & Sheperd, 1993; Werle, Murphy, & Budd, 1993; Williamson, Kelley, Cavell, & Prather, 1987). Children with selective eating are clearly distinguishable from children who suffer from anorexia nervosa or bulimia nervosa. Most prominently the pre-occupation with body weight and body shape is absent. Clinically, they are thought to be distinctly different from children with functional dysphagia, an extreme fear of gagging or choking (Bryant-Waugh, 2000).

On the whole, the extremely restricted diet of these children does not appear to adversely affect their weight and height, as most children with selective eating are within the normal range (Nicholls et al, 2001). However, social functioning does seem to be adversely affected. For example, these children can experience difficulties, as they grow older because their eating can interfere with their ability to engage in

social activities with peers (Bryant-Waugh 2000; Nicholls et al, 2001; Timimi et al 1997). As in childhood onset anorexia nervosa, there is often a great deal of anxiety within the family in relation to the child's eating habits and mealtime behaviour.

There is very little empirical research available on the epidemiology of selective eating. The incidence of selective eating in children is not known as the existing literature on these children remains virtually limited to case descriptions, clinical accounts and retrospective case note reviews (Nicholls et al, 2001; Timimi et al., 1997). However, children with selective eating appear to be presenting for treatment in ever increasing numbers (Bryant-Waugh, 2000; Timimi et al., 1997). This does not necessarily mean that the actual incidence of selective eating is rising as improved recognition of eating disorders and appropriate specialist services may in part account for this increase (Doyle, & Bryant-Waugh, 2000). This has already been noted in childhood onset anorexia nervosa.

Very little information exists regarding the characteristics of children who develop selective eating. However, clinical accounts suggest they come from a range of social and cultural backgrounds. In particular, preliminary research suggests that a high percentage of boys present with selective eating (Nicholls et al, 2001). For example, Timimi et al (1997) in a retrospective case note review found that out of the 33 selective eaters referred to a specialist eating disorder service 24 were boys. This contrasts with childhood onset anorexia nervosa where the proportion of boys is estimated at about 25% (Fosson, Knibbs, Bryant-Waugh, & Lask, 1987). The reason for the high percentage of boys presenting with selective eating remains unclear.

Food avoidant emotional disorder

Food avoidant emotional disorder (FAED) is a term that is used to describe children who have an emotional disorder in which food avoidance is a prominent feature (Higgs, Goodyer & Birch, 1989). Children presenting with FAED are likely to have a history of food avoidance, significant weight loss and impaired growth. These children are clearly distinguishable from those with anorexia nervosa, in that they do not present with either the pre-occupation with body weight and body shape, nor distorted body image. However, children with FAED do often experience mood disturbance including, including anxiety, obsessionality, phobias and depression (Bryant-Waugh, 2000). At present the precise incidence of children with FAED is unknown.

Functional dysphagia

Functional dysphagia is characterised by a marked avoidance of foods, often of a certain type or texture (Bryant-Waugh, 2000). The central feature of this eating disorder is a fear of swallowing, choking or vomiting. This anxiety usually underpins the child's resistance to eating. Often a clear precipitant to the fear and anxiety can be identified in the form of an aversive experience(s). The weight and shape concerns that are prominent in children with anorexia and bulimia nervosa are not found in children with functional dysphagia. The number of children currently affected by functional dysphagia is not known.

It is clear that a plethora of children present to services with a variety of childhood onset eating disorders. Yet there is a distinct lack of empirical epidemiological research available on this group. The increase in referral rates for childhood onset eating disorders suggests that further research is required. Despite the lack of systematic epidemiological research the area of aetiology in eating disorders has received much attention.

### **Aetiology**

A vast amount of research has attempted to address the nature of aetiological factors involved in eating disorders. As a result, an abundance of aetiological theories have been proposed from a variety of different perspectives including: familial, socio-cultural, cognitive-behavioural, psychodynamic, feminist and neurobiological (Brownell, & Fairburn, 1995). While many singular theories have been presented, there can be little doubt that eating disorders are multifactorial in causation. Multifactorial accounts emphasise the complexity of eating disorders and attempt to integrate a number of factors, including variables that may impact on the predisposition, precipitation and perpetuation of eating disorders (Wren, & Lask, 1993). For example, a variety of factors have been suggested to be important in both the development and maintenance of eating disorders. These include biological factors, cultural considerations, personality disturbances, cognitive styles, the role of the family and adverse sexual experiences (Lask, 2000).

The parents of patients with eating disorders have received some attention within the aetiological literature. In fact, family functioning was one of the earliest factors

suggested to be relevant to the causation of eating disorders (Lasegue, 1873 cited in Waller & Calam, 1994). Researchers and clinicians have presented a number of models of family interaction in an attempt to explain a link with anorexia and bulimia nervosa (Minuchin, Rosman, & Baker, 1978; Selvini-Palazzoli, 1974). These models generally portray the family in a negative light and suggest that family interaction may have a directly harmful effect upon the eating disorder patient. The fact that such research has been interpreted by some as meaning that families (and in particular, parents) have caused their child's eating disorder is extremely unfortunate. The "causality of any association between family function and eating psychopathology is certain to be complex" (Waller, & Callam, 1994). While in some cases family dysfunction may indeed precipitate or perpetuate an eating disorder, it is also highly likely that family interaction will be impaired by having a family member with an eating disorder (Waller, & Calam, 1994). It is clear that parenting is only one of a variety of factors that can influence food preference and food refusal in children and adolescents (Waller, & Calam, 1994). While family dysfunction has been advanced to explain the causation of eating disorders it is clear that no single variable model will be adequate to explain more than a small proportion of eating disorder cases. Multifactorial models are more likely to adequately represent the complex clinical picture of an eating disorder, as they consider the interaction of a number of factors (Hsu, 1983).

### **Parents' understanding of eating disorders**

The search for increased understanding of the aetiological factors in eating disorders is unlikely to be confined to researcher and clinicians in the field. Parents of children

with an eating disorder will undoubtedly consider the subject. Research has shown that when anything unusual, unpleasant or unexpected occurs such as an illness, people begin to search for causal explanations in an attempt to attribute the illness to a cause (Brewin, 1988). During the process of considering causes, people explore whether it is external or internal to them, whether it is uncontrollable or controllable and also whether it is permanent or temporary (Weiner, 1985, 1986). The opinions that people form about the causes of illness are thought to affect the person's perceptions of control over it. Therefore, this process of explanation can be regarded as "an attempt to re-establish control over the world and to determine what changes need to be made" (Brewin, 1988).

Beliefs about the causes and treatments of psychological problems are important to examine for several reasons. In the first instance people are more likely to do better in counselling approaches that are congruent with their own beliefs (Atkinson, Worthington, Dana, & Good, 1991; Brewin, & Bradley, 1989; Foulks, Persons, & Merkel, 1986). Therefore, parents' causal attributions about their child's eating disorder are likely to affect how they attempt to manage their child's illness, negotiate difficulties, and engage in treatment programmes. Understanding parents' beliefs about their child's eating disorder may therefore, help develop hypotheses about the relationship between parental attributions and treatment outcome. Moreover, knowledge about parents' accounts of how they explain their child's problem may also help the development of appropriate interventions for children with eating disorders and their families.

At present there do not appear to be any accounts which systematically examine how parents of children with eating disorders think about their child's illness. However, one can speculate that the increased coverage of 'eating disorders' in the media in recent years, which appears to reflect growing public interest in this area, will mean that parents of children with eating disorders will have had opportunities to acquire beliefs and opinions. They are likely to hold views on the course, cause and possible treatments of eating disorders in general and in relation to their own child.

Despite a distinct lack of studies that systematically examines parents' understandings of their child's eating disorder, informal surveys and clinical accounts give some insight into parents views. An informal survey, mothers of children with eating disorders described a variety of factors, which they felt contributed to their child's illness (MacDonald, 2000). They presented a range of factors including severe anxiety in early childhood, attention seeking, and the impact of trends in 'healthy eating'. Difficulties associated with school were also reported including difficulties with friends, teasing, bullying and the pressure of exams. Mothers' also identified problems at home for example; losses through death or separation and major life style changes, all of which were regarded as stress producing life changes (MacDonald, 2000).

While research has not systematically examined the understanding of parents in relation to their child's eating disorder, beliefs about eating disorders have been researched in young men and women (Furnham, & Hume-Wright, 1992; Furnham, & Manning, 1997; Huon, Brown, & Morris, 1988). Furnham and Hume-Wright (1992) examined the lay theories of male and female university students about anorexia

nervosa. Participants were given a questionnaire, which asked about “what anorexics are like”, the “causes”, and “cures” of anorexia. Their responses on questionnaires revealed that people hold elaborate and moderately accurate beliefs about the description, causes and possible cures of anorexia nervosa. The beliefs about “what anorexics are like” were broadly similar to clinical descriptions of the disorder. For example, participants emphasised that anorectics are obsessed with their weight and eating. Participants reported an extensive range of responses in relation to the causes of anorexia. However, on the whole, “scientific theories” received support, especially sociological theories that related to societal pressure in relation to the desirability to be slim. Factor analysis of the participants’ responses identified several clusters of causes. These included underlying factors of family, the stress of change, conflict in contradictory social roles, goals and demands, and also rebellion and security. In terms of “cures”, psychotherapeutic interventions were most frequently endorsed. Those interventions that emphasise the importance of increasing self-worth and developing coping strategies were the most popular. In contrast to clinicians, people did not rate hospitalisation as an important cure.

Furnham and Hume-Wright (1992) argue that the general consensus of participants’ responses suggests that lay beliefs are formulated and mediated by some kind of cultural transmission. Interestingly, no significant differences were found when comparing the beliefs of people who had experience of anorexia and those who did not.

## **Treatment**

### **Prognosis and outcome**

The prognosis for childhood onset eating disorders remains unclear due to the lack of systematic research in the area (Neiderman, 2000). However, cautious estimates from the current literature suggest that approximately two thirds of those receiving treatment for anorexia nervosa make a full recovery, while the remainder continue to experience persistent difficulties. While the outlook for the majority is positive, it is worrisome for those who continue to experience difficulties. This is because eating disorders like anorexia nervosa can have an adverse impact on nearly all areas of life and can also lead to premature death. Furthermore, the long-term risks for anorexia nervosa include infertility, delayed growth, osteoporosis, as well as other complications (Bryant-Waugh, & Lask, 1995).

Childhood onset anorexia nervosa can be conceptualised in three stages (Bryant-Waugh, & Lask, 1995). The first stage is characterised by the predominance of eating difficulties. During the second stage a gradual improvement can be noted in nutritional intake. This coincides with the emergence of a phase of intense negativism, manifested by rudeness, assertiveness, oppositional behaviour and sullenness. In the third and final stage a more appropriate eating pattern emerges and more socially acceptable ways of expressing feelings manifest. Children who successfully pass from the second to the third stage seem to have the best chance of

recovery (Bryant-Waugh, & Lask, 1995). However, what precise help a young person and their family need to successfully manage this transition remains unclear.

Information regarding the prognosis for children with other childhood onset eating disorders is extremely sparse. For example, clinical accounts of children with selective eating suggest that in many cases the problem will resolve during adolescence. However, some children will continue to eat selectively during adulthood. Selective eating is only likely to be problematic if it is associated with other emotional, social or physical difficulties (Bryant-Waugh, 2000).

On the whole there is a distinct lack of information about the prognosis and outcome of early onset eating disorders, and as a result relatively little is known about what treatment elements are most effective (Neiderman, 2000). Nevertheless, the limited literature available does suggest a positive treatment effect associated with the use of family therapy and/or family counselling (Le Grange, Eisler, Dare, & Russell, 1992; Russell, Szmuckler, Dare, & Eisler, 1987) and for multidisciplinary approaches to treatment (Bryant-Waugh, Knibbs, Fosson, Kaminski, & Lask, 1988; Crisp, Norton, Gowers, Halek, Bowyer, Yelham, Levett, & Bhat, 1991; Gowers, Norton, Halek, & Crisp, 1994; Hall, & Crisp, 1987).

### **Family therapy and family counselling**

While there is an increasing amount of empirical evidence against a family aetiological model for anorexia nervosa and related eating disorders, paradoxically, the evidence for the importance of involving the family in treatment has intensified

(Dare, & Eisler, 1995). The acceleration of clinical and research interest in family therapy for eating disorders arose primarily as a result of the major influence of two groups of family therapists; the Milan group (Selvini-Palazzoli, 1974) and the Philadelphia group (Minuchin, Baker, Rosman, Liebman, Milman, & Todd, 1975). These groups advocated a family systems viewpoint and emphasised the importance of the family in the development and maintenance of anorexia nervosa. The observations of Minuchin and Selvini-Palazzoli gave strong support to the belief that eating disorders originate in specific, pathogenic family processes. Despite this both identified other aspects too. Minuchin himself acknowledged the role of a variety of factors other than family processes in the aetiology of anorexia nervosa, while Selvini-Palazzoli also argued that social change was influential in the upsurge of anorexia nervosa cases in northern Italy. Nevertheless, the observations of these two groups led to a widespread commitment to using family therapy as a treatment for anorexia nervosa despite the fact that neither group empirically tested its therapies or theories (Blair, Freeman, & Cull, 1995).

In fact, in contrast to the findings of Minuchin and Selvini-Palazzoli, the research literature to date does not support the idea of a distinctive, consistent pattern of family structure and family functioning in eating disorder patients. The differences that have been reported between eating disorder families and control groups are not unique to these families, they are also seen with other severe or chronic illnesses (Ritchie, 1980; Schaffer, 1964). Thus these differences may not be related to aetiology but may be the product of the presence of a major illness in a child (Dare, & Eisler, 1995).

**Controlled studies of family therapy for eating disorders**

In recent years the Maudsley Hospital has conducted several large-scale randomised control trials of family therapy for eating disorders, which support the efficacy of family therapy in adolescent anorexic patients (Le Grange et al., 1992; Russell et al., 1987). Russell reported the first trial of family therapy in anorexia and bulimia nervosa. In this study 80 patients consecutively admitted to an inpatient re-feeding programme. They were at discharge, randomly assigned to a 1-year course of family therapy or individual supportive therapy. The results revealed that those patients with early onset anorexia nervosa (before the age of 19) and a short history of illness (less than 3 years at the time of presentation) had a significantly better outcome when treated with family therapy. This was in comparison to the individual supportive therapy, and the finding held constant at a 5-year follow-up. However, those patients with more chronic anorexia nervosa or a later onset of illness, along with those with severe bulimia nervosa, did not gain specific benefit from family therapy in comparison with the control treatment (Russell et al., 1987).

The apparent effectiveness of family therapy for adolescents with anorexia nervosa led to a further controlled study comparing two forms of family therapy. Le Grange et al (1992) conducted a study with 18 families in which ‘conjoint family therapy’, (where a whole family is seen together in a session), was compared with ‘family counselling’ (where parents are seen alone). These two forms of family therapy had similar aims and generally followed a similar course. Initially there was a strong focus on helping the parents manage their child’s symptomatic behaviour, which involved the clinician helping the parents mobilise the family’s resources to help themselves.

This was done in conjunction with the clear message that the family was not considered to be the source of the problem but rather the best resource for effective treatment. In the later stages of treatment, wider adolescent and family issues were explored. The results of the study suggest that both treatments gave rise to similar benefits in terms of weight gain and bringing about significant symptom relief in anorexia nervosa. Most pertinently, the results tentatively suggest that 'family counselling' helped reduce levels of critical comments within the family above those in 'family therapy'. The implication that family counselling may in fact be more effective for some families challenges the opinion that the efficacy of family therapy originates from its ability to shift the characteristic patterns of family interaction and organisation. The findings of Le Grange et al (1992) have also been supported by other studies such as Robin, Siegal, Moye, Gilroy, Dennis, and Sikand (1999). This group also found that conjoint family therapy or individual adolescent therapy with collateral parental counselling could be used to effectively to treat young adolescents with anorexia nervosa.

The results of these recent studies have important practical and theoretical implications. It is clear that parental involvement is essential to the success of interventions for younger adolescents with anorexia nervosa. However, intervening with the whole family present is in many cases not necessary (Le Grange et al., 1992). In clinical practice, the use of family therapy is now widespread for patients with anorexia nervosa. Under this umbrella of treatment a variety of theoretical approaches are employed. This suggests there is a need for further research to consider the efficacy of the different models of family therapy (Dare, & Eisler, 1995).

**The importance of parents in treatment**

Involving parents in the treatment of children with eating disorders is now considered the “sine qua non of management” (Lask, 2000). This notion clearly stems from the research presented that suggests no child should be treated for an eating disorder without parental involvement at some level. Ideally in any treatment package for childhood onset eating disorders such as anorexia nervosa, family therapy or parental counselling should form the mainstay of therapeutic input (Bryant-Waugh, & Lask, 1995). For the parents of children with anorexia nervosa the major focus of family therapy or parental counselling is likely to focus on the importance of helping parents “take charge” (Lask, 2000). This is based on the premise that children with eating disorders feel out of control. To enable parents to take firm control, it is useful to highlight the importance of parents working together on a consistent plan of management, as well as offering mutual support to each other throughout the process. Parents often require some support in doing this, as it is common for parents to be in conflict over the management of their child’s eating disorder. Quite obviously, parents cannot be in charge while they are in disagreement (Lask, 2000). Family therapy or parental counselling may best be achieved within a comprehensive treatment package that gives due consideration to the social, psychological and physical facets of the illness. An effective framework should also include individual therapy for the index patient and the monitoring of the child’s physical health by a medical clinician (Magagna, 2000). In this way, support groups for parents are often a useful adjunct to treatment, providing a forum for parents to explore their own feelings and vulnerabilities and giving parents an extra space to regain their mastery of parenting (Nicholls, & Magagna, 1997).

The study of the situation of families gives an insight into any characteristics that are prevalent among families who have a child with an eating disorder.

### **Family characteristics of eating disorder patients**

The family characteristics of patients with eating disorders have been extensively investigated. Vandereycken, Kog and Vanderlinden (1989) in their study provide a comprehensive overview of this area. They show that it is clearly important to examine the family characteristics of patients with eating disorders as they are likely to be highly relevant to the planning of treatments. This is particularly apposite if a family orientated intervention is to be used.

The evolution of family focused studies has undergone many changes. Early studies of the families of eating disorder patients focused almost exclusively on the mother-child relationship (Bruch, 1973), mirroring the myth that ‘parenting’ means ‘mothering’. Research later shifted to examining the ‘absent’ father, before turning to focus on the family as a system (Minuchin et al., 1978, Selvini-Palazzoli, 1974). Systems theorists primarily focused on the interaction between the parental subsystem and the children. Research generally analysed these interactions in terms of communication, problem solving, and boundary setting.

Methodologically, studies examining the families of eating disorder patients tend to take two different stances. They adopt either an “insider” or an “outsider” perspective (Vandereycken, 1995). Insider perspectives tend to take the form of self-

report studies, describing the family's view of themselves. For example, self-report studies have found that anorexics tend to perceive their families as stable, non-conflictual, cohesive and with no lack of nurturance. The parents of eating disorder patients tend to report similar perceptions but are often less extreme in their reports (Vandereycken, 1995).

In comparison, "outsiders" perspectives focus on how the family interacts from an observer's point of view. These observational studies only partially correspond with the findings from self-report studies. For example, compared with non eating disorder families, anorexic families show more rigidity in their family organisation, have less clear interpersonal boundaries, and have a tendency to avoid open discussions of disagreements between parents and children (Vandereycken, 1995). The one problem with research that shows distressed parent-child interactions is that it is impossible to decipher whether these are a cause or a consequence of the eating disorder. On the whole, the literature to date does not allow us to describe typical patterns of family dysfunction or parenting in eating disorders (Waller, & Calam, 1994).

Only in recent years have researchers started to focus more specifically on the role of parents and parenting styles in eating disorders. From a clinical point of view, lack of joint parental authority is commonly observed (Lask, 2000). This means that parents often appear to find it difficult to establish an adequate balance in the control of their child. This may often be related to a more general difficulty in negotiating a basic agreement regarding child rearing and working together as parents (Honig, 2000). Studies of attitudes and parental rearing practices have revealed a broad array of

results. These do not at present suggest a connection between an eating disorder in adolescence with a particular model of parental relationship in childhood (Vandereycken, 1995).

In summary, parents of eating disorder patients generally remain only marginally discussed in their own right. This is despite the fact that information about their experience may provide us with the necessary knowledge to help parents in a family orientated treatment approach.

### **The Experience of Parents**

Given the importance of parents in the treatment of children with eating disorders, very little is known about their experiences. Within the eating disorders literature, there does not appear to be a study which systematically explores the experience of parents or the impact of having a child treated for an eating disorder. To date, parents' experiences have mainly been reported anecdotally via reports of treatment or support groups. While this gives an important insight into some of the issues for parents, it does not allow parents to tell their own side of the story. In contrast, the experiences of eating disorder patients are well documented.

There are very few accounts of parents' experiences during their child's treatment. In one of the few descriptions Bryant-Waugh and Lask (2000) include a poignant account written in their comprehensive book on childhood onset eating disorders. In this chapter Maryann MacDonald (2000) writes from the perspective of being the

mother of a child with anorexia nervosa. She emphasises the turmoil that she went through and in particular her pre-occupation with questioning herself about “what went wrong”. MacDonald describes being affected “profoundly and irrevocably” by the rejection of her child, and describes her despair when she reached out to the literature on anorexia only to find blame. Unfortunately many descriptions of parents in the literature are discussed in a negative way. Throughout her account, MacDonald combines her views as a parent with those of 27 other mothers who were recruited on a voluntary basis via an advertisement in Sign Post (the Eating Disorders Association’s newsletter). They completed a questionnaire, which posed several questions to parents in terms of what they found helpful and unhelpful about their experience (also reported in Bryant-Waugh, 1992).

McDonald’s (2000) informal survey revealed that mothers experienced a huge emotional impact to having a child with anorexia. In fact, 52% reported “detrimental changes” in themselves since the onset of their child’s eating disorder (Bryant-Waugh, 1992). A range of prominent feelings were described by the mothers, including a feeling of blame, increased guilt, anxiety, depression, anger and resentment towards their child. Simultaneously they experienced a loss of trust in their child and a sense of hopelessness for the future. Mothers typically reported that they experienced their own difficulties around food, which often manifested in feeling guilty. Despite these negative experiences mothers reported that their “refusal to give up” and their “good marriages” gave them the strength and courage to go on.

To ascertain further views mothers were asked to rate a variety of treatments as either “very helpful”, “moderately helpful”, or “unhelpful”. Approximately 3/4 of

mothers who had experienced group therapy rated it as helpful while only 2/5 of mothers who had experienced psychotherapy rated it as helpful. Over 1/4 of mothers who had experienced family therapy rated it as helpful, despite also experiencing it as considerably distressing. In part this was due to parents feeling manipulated and frustrated at not always knowing the purpose of sessions. Hospital care was rated helpful by 1/3 of mothers. Mothers also listed the factors other than the treatment approach that they found helpful which included parental contact with the child's (preferably female) therapist and continued support from their GP. In spite of this it was also noted that their children did not always fair well following discharge, and that mothers felt that follow-up care was inadequate.

The survey also highlighted dissatisfaction in several areas. For example, over half of the mothers surveyed felt that there was a lack of information and support from the professionals they encountered. In fact mothers felt that there were not enough specialist services available to them which catered specifically for children with eating disorders. Mothers described being particularly disturbed by the lack of parental involvement in treatment when their child was over the age of 16. Moreover that the needs of parents often went unrecognised by services. Whilst reporting that the treatments offered were generally helpful, mothers did identify that frequent changes in therapists and a lack of follow-ups after discharge felt unhelpful. Some mothers then went into detail on improvements that could be made.

Mothers listed a number of improvements, which they felt would make a difference to children and families affected by eating disorders. Firstly, they expressed a need to increase the awareness of eating disorders amongst GPs. The GP is most often the

first port of call for any worried parent. Consequently mothers felt that it was therefore essential that GPs be aware of the importance of early recognition and speedy referral to specialist services for children with eating disorders. Secondly, mothers suggested that more information regarding the course, treatment and likely outcome of eating disorders should be made readily available to eating disorder patients and their families. It was felt that this need could best be met via recommending relevant reading and/or support networks. Thirdly, the importance of active parental involvement in treatment of children with eating disorders was noted, regardless of the patient's age. Finally, the need for better service provision and a more "sensitive approach" to the eating disorder was described as vital by mothers (Bryant-Waugh, 1992).

Insights such as these are vital for clinicians in terms of developing services for children with eating disorders and their families. Such studies provide valuable insights into the experience and impact on parents' lives when living with a child suffering from anorexia nervosa. However, they do not go far enough in terms of the depth or quality of research. There are distinct limitations to how parents relate their experience within the constraints of a questionnaire. In previous studies, all those who completed the questionnaires were mothers. This ultimately means the voice of fathers remains largely unheard.

As part of an exploratory study to examine the parenting styles of families with an anorexic or bulimic patient, Perdnia and Vandereycken (1989) also explored the emotional well being and marital satisfaction of parents. Questionnaires were administered to the parents of 16 female patients. The Symptom Check List-90

revealed that both parents showed high scores in comparison with a normal population. However, mothers, in contrast to the fathers, scored higher on depression and somatisation scales. Both parents also completed the Maudsley Marital Questionnaire, which measures marital satisfaction. Whilst mothers reported more dissatisfaction with their marriages than their husbands, parents described their relationships as more similar to “normal” couples than to “distressed” ones. Perdnia and Vandereycken (1989) reported that parents often viewed the causality of the patient’s eating problem being due to issues that are encountered by most adolescents, such as “discontent with weight and physical appearance”, “problems at work or school”, and “changes due to puberty”. Interestingly the issues described by parents are those that are encountered by almost all adolescents. The authors noted their surprise that while parents did not directly consider the family as a factor related to the development of the eating disorder, many parents did in fact report strong feelings of guilt that they may have done something wrong.

### **Groups for parents of children with eating disorders**

The literature on support groups for parents of children with eating disorders is limited despite the recognition that they can be a useful adjunct to treatment (Jeammet, & Gorge, 1980; Lewis, & MacGuire, 1985; Rose, & Garfinkel, 1980). The themes that emerge during studies of support groups for parents of eating disorder patients offer an insight into the experience of these parents. Nicholls and Magagna (1997) present a detailed account of a support group for parents of children with eating disorders. The group is described as a useful forum for bringing parents together to share their experiences in a supportive environment. In particular, the

group's capacity to provide a safe space for parents to explore their own feelings and any vulnerabilities is emphasised. This is particularly pertinent since many parents who enter the group initially express feelings of guilt, defeat, hopelessness and a loss of parenting skills. The group also appears to act as an arena in which parents can rebuild the skills they may feel they have lost. This can be achieved in part through the opportunity that the group provides for parents to learn from each other's experiences.

In addition to presenting the advantages of running a parents support group, Nichols and Magagna (1997) go on to describe a number of prominent themes arising from the groups they held. Several themes related to the emotional impact of having a child with an eating disorder, in particular, the guilt that parents feel about their child's illness and the propensity to blame themselves in some way for the illness. These feelings appear to be exacerbated by questions about the reasons why the child has an eating disorder, which are posed to parents by the wider network. Despite the expression of powerful feelings on the whole, parents reported it was important to not spend too much time exploring their own feelings. Instead they focus on attempts to "keep going". Nevertheless, parents recognised the need to remember to look after themselves as well as their ill child. In this way defeating the eating disorder was not a purely food focused issue but a holistic battle.

One issue described by Nicholls and Magagna (1997) related to the effect of parents' attempts to deal with both the child and the eating disorder. Many parents described their distress at feeling unable to control their child's difficult behaviour. The anxiety they experienced when they attempted to stand firm in relation to their child's

demands, whether or not they were driven by the eating disorder, was paramount. Parents discussed the difficulties associated with not colluding with the eating disorder and the difficulties with managing conflict. They reported that the hardest task of parenting was to being able to tolerate their child's depression without feeling either attacked or hopeless. Nevertheless, when parents felt that had reached positive turning points, sharing these successes appeared invaluable in confirming their achievement.

Finally, Nicholls and Magagna (1997) discuss the role of fathers. This is important as fathers receive limited attention in previous literature. They report that fathers attended the group less frequently than mothers. This lack of attendance by fathers was most often explained in terms of work commitments. However, Nicholls and Magagna report that this is unlikely to be the only reason. They hypothesise that fathers feel they are being asked to be the "strong anchor providing structure and guidelines" for other family members. Thus fathers feel under greater pressure to keep 'normal life' going rather than take time out for themselves. When fathers were present in the group it was noted that they participated less when the discussion turned to issues relating to food and eating. This may be related to the tendency for mothers to be primarily responsible for the task feeding. While this provides some insight into the experience of fathers it is clear that more information is needed.

### **Is the experience of parents of children with eating disorders unique?**

Whilst there is very little information on the experience of parents of children with eating disorders, there are numerous published accounts on the experience of parents

of children with chronic illnesses. In a comparison of the families of anorectics, cystic fibrosis patients, and well controls, Blair et al (1995) found that both anorectic and cystic fibrosis families were more over involved than well controls. This suggests that some of the reactions of parents of children with eating disorders may be similar to the reactions of any parent to the presence of a major illness in their child.

Differentiating between the groups it was noted that the families of anorectics were slightly more enmeshed, over-protective and poorer at problem solving than cystic fibrosis families. The researchers propose that this difference is most likely to be due to the fact that the families with a member with an eating disorder are more likely to be facing much more problematic behaviour. This may be related to the more robust psychological health of children with chronic illness in comparison to patients with eating disorders (Blair et al, 1995). Furthermore, in contrast to those families with a member with cystic fibrosis, the parents of children with eating disorders are much more likely to be facing the adverse affects of the stigma that is associated with mental illnesses. In this respect a huge difference exists.

Similarly, Barlow, Harrison and Shaw (1998) examined, via a focus group methodology, the experience of parenting in the context of juvenile chronic arthritis (JCA). The themes that emerged from parents of children with JCA closely echo those revealed from groups for parents of children with eating disorders. Parents typically described the emotional impact of parenting in terms of guilt, anxiety, frustration, helplessness, powerlessness and isolation. As with parents of eating disorders, they felt that lack of information and inadequate support hindered their efforts to cope with their child's illness. Furthermore, discussions around 'dealing

with parenting dilemmas' closely resembled the views of eating disorder parents. For example, parents expressed difficulties in coping with the child's symptoms and namely with the effect on the family. Social and attitudinal barriers were experienced these were often attributed to ignorance, lack of knowledge, and failure to understand JCA. Parents with JCA suggested that more information and support would be helpful, as have parents of children with eating disorders.

Generally, parents of children with a chronic illness do appear to have an increased risk for psychosocial problems (Daniels, Moos, Billings, & Millar, 1987; Timko, Stovel, & Moos, 1992; Vandvik, & Eckblad, 1991). However, the majority of parents do not experience significant difficulties (Elander, & Middence, 1997; Silver, Bauman, & Ireys, 1995). In comparison to fathers, mothers appear to experience poorer mental health than fathers do (Eiser, 1990; Timko et al., 1992; Wallander, Varni, Babani, DeHaan, Wilcox, & Banis, 1989). This may be related to the perceived differences in roles, since mothers are most often responsible for the day to day caring of children. In terms of the parental marital relationship, both Eiser (1993) and Middence (1994) suggest that there may be adverse effects. Despite this, divorce rates for couples with chronically ill children are no higher than national average although higher levels of dissatisfaction and conflict are reported. On the whole, the limited literature to date suggests that many of the reactions of parents of children with eating disorders maybe similar to those who have other major illness in childhood and adolescence.

While research to date indicates there may be some similarities between the experiences of parents of children with eating disorders and those of children with

chronic illness, there are also likely to be aspects of their experience that are unique. For example, Jarman, Smith, & Walsh, (1997) examined the experiences of therapists treating children with anorexia nervosa. The issue of control was highlighted as extremely important to both understanding a child's illness and also in terms of its impact on treatment. They found that even trained clinicians find dealing with children with anorexia nervosa a personally demanding experience. It is highly likely therefore that this experience is much more stressful for parents, who are emotionally involved and have no formal training in how to deal with such matters.

### **Summary and Aims of The Present Study**

#### **Summary**

It is clear that parental figures are fundamental to the psychosocial development of all children. When a child develops an eating disorder they are no less vital in fact parents are often the best resource. Research suggests that working with families is an essential component to any successful treatment package. Despite recognition that parents are vital to the treatment of childhood onset eating disorders literature on their experience is scarce.

#### **Aims**

To date, there does not appear to be a study that has systematically examined parents' experiences of having a child with an eating disorder. The current study aims

to address this gap in the literature. Of particular interest are parents' views on the impact of their child's eating disorder: how it affects them personally, how it affects their everyday life, how it impacts on relationships and how it affects other family members. The study will also explore parents' understanding of their child's eating disorder, including their views of the possible causes of their child's illness and of the help that they and their child may need.

It is essential to understand parents' perspectives because of their central role in treatment of childhood eating disorders. The views and experiences of parents may provide important information about how they approach difficulties with their child and how professionals might engage them in treatment. This information could then be used to guide and develop interventions for children with eating disorders and their families.

## **Methodological Approach**

### **The rationale for utilising a qualitative discovery-orientated approach**

The present study adopts an exploratory, discovery-orientated. It is based around a set of research questions that are fundamentally descriptive in nature. This approach contrasts with the confirmatory stance of the hypothetico-deductive model. In that it does not emphasise the use of previous research or theory to generate testable hypothesis (Barker, Pistrang and Elliott, 1998). A discovery-orientated approach is particularly suited to areas where little information is known or when the subject

matter is complex (Barker et al, 1998). Qualitative methods are particularly suited to discovery-orientated research.

Qualitative methods aim to capture the complexity of individuals' experiences. The use of a qualitative methodology is advantageous in that it lends itself to allowing the research participants to identify the important issues relevant to the topic being investigated. This is in contrast to quantitative lines of inquiry, which can restrict the voice of participants with pre-determined criteria for measurement. A qualitative approach can provide a richer, insider's view of the subject under investigation, which in turn can help us to understand how participants construct their internal worlds (Payne, 1997). In this manner the present study's orientation is parent focused.

A number of qualitative methodologies have evolved from a phenomenological perspective (for a summary see, Barker et al, 1998). 'Interpretative Phenomenological Analysis' was the method chosen for this study.

### **Interpretative Phenomenological Analysis**

'Interpretative Phenomenological Analysis' (IPA) was developed by Jonathan Smith and his colleagues (Smith, 1995; Smith, Harré & Van Langenhove, 1995; Smith, Flowers & Osborn, 1997; Smith, Jarman & Osborn, 1999). IPA is 'phenomenological' in that it is concerned with eliciting and exploring individual, personal accounts of an experience. It assumes that individuals' verbal reports reflect their underlying cognitions. It thus aims to use this 'insider' knowledge to present an

individual's personal account or perception of a phenomenon, while making the researcher's role in the process explicit. It recognises that the research exercise is a dynamic process and emphasises the importance of acknowledging the 'interpretative' activity of the researcher with the research data. Therefore, the term 'interpretative phenomenological analysis' illustrates the dual facets of this qualitative approach.

IPA was chosen as the method of analysis for this study for several reasons. First and foremost, it is a systematic approach and its procedures have been clearly described (Smith, 1995; Smith et al, 1997). It is therefore an extremely accessible approach. Moreover, while it represents a relatively new approach, it has been widely used within the area of health psychology (Smith et al, 1997; Osborn & Smith, 1998; Smith et al, 1999). It is also being increasingly applied within clinical psychology, for example in the area of anorexia nervosa (Jarman, et al, 1997) and sexual health among gay men (Flowers, Smith, Sheeran, & Baeil, 1997; Flowers, Smith, Sheeran, & Baeil, 1998). It is hoped that this study will further illustrate the value of qualitative methods in clinically relevant research.

### **Research questions**

The research questions for this study are as follows:

- What is the nature of the experience of parents who have a child with an eating disorder?
  - How does the eating disorder impact on their everyday life?
  - How does it affect them personally? And practically?

- Does the eating disorder impact on relationships in the family?
- Does it affect the family as a whole?
  
- What is parents' understanding of their child's eating disorder?
  - What do they think are the possible causes of their child's illness?
  
- What is parents' experience of the services that have been offered to them and their child?
  - What help do parents feel they and their child need?
  - What have parents found helpful or supportive?

## **Chapter 2: Method**

### **Ethical Approval**

The Research Ethics Committee of a central London based Teaching Hospital granted ethical approval for this study. A copy of the notification of ethical approval can be found in Appendix A.

It was not envisaged that participation in this study would cause distress over and above that normally experienced by parents in the context of a visit to an eating disorder service. However, in line with good practice, certain precautions were taken. The researcher continuously monitored the effect of the interview on participants and at the end of the interview checked out how participants felt about the meeting. The researcher also asked whether any of the issues raised by the participants during the interview required any further action. In the event of any participants experiencing distress during the interview a system was set up to refer them to the Service Co-Ordinator of the eating disorders clinic.

### **Participants**

#### **Method of recruitment**

All participants for this study were recruited through a specialist eating disorders clinic at a central London based Teaching Hospital. At the time of this study the

clinic provided a service for children with a range of different eating disorders and their families.

All participants were 'parents' of children who were currently in treatment or had been recently assessed within the clinic. 'Parents' were defined as the parent(s) that lives and/or cares for the child. The inclusion criteria for this study were that the child should have a clinical eating disorder<sup>1</sup> (no particular eating disorder was excluded), and that the parent(s) speak fluent English (as in-depth interviews would be difficult to carry out with an interpreter).

Initially a senior member of staff from the eating disorder team or the researcher made contact with potential participants in the clinic. Parents who were attending an appointment at the clinic were given an introductory letter, information sheet and consent forms. These included a full explanation of the study, its purpose, the participants' right to withdraw and issues of confidentiality. (A copy of the letter, the information sheets and consent forms given to parents can be found in the Appendix B). The researcher was available on clinic day to answer any further questions regarding participation in the study.

Parents were asked to give their consent to participate in the study by completing the consent forms that were provided and returning them to the researcher in a pre-paid envelope. Parents were asked to reply within the next two weeks. Several parents

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<sup>1</sup> A clinical eating disorder is defined as "a persistent disturbance of eating or eating-related behaviour that results in the altered consumption or absorption of food and that significantly impairs physical health or psychosocial functioning. This disturbance should not be secondary to any recognised general medical disorder or any other psychiatric disorder"(Fairburn & Walsh, 1995).

gave immediate verbal consent following a discussion with the researcher. However, they were also asked to complete and return the consent forms.

The researcher telephoned those parents who did not reply to the initial letter of invitation within three/four weeks. If parents declined to participate in the study at this point they were not approached again.

In total, 33 parents were invited to participate in the study. A total of 14 parents (7 mothers and 7 fathers) declined. Little information on the reasons for non-participation is available. However, two parents who met separately with the researcher reported they did not wish to participate in the study due to “feeling too stressed” and “reservations that the study may be used to place blame on the families of children with eating disorder”.

### **Description of the sample**

Eleven mothers and 8 fathers participated in the study. These comprised 8 couples plus a further 3 mothers. The participants' ages ranged from 36 to 65 years, with a mean of 46 years. All participants described their ethnicity as White or British. Ten participants described their religion as Church of England or Protestant, two as Jewish, and seven gave no information about religion. The majority of participants were living with their partners in the marital home (16 out of 19). The majority of participants living with a partner (13) reported high levels of satisfaction with their relationship (mean of 121.2, S.D. 17.4, on the Locke-Wallace Marital Adjustment Test (1959). (Scores greater than 100 on this measure are thought to indicate high

levels of satisfaction in the relationship, see 'Measures' section for a detailed description of the measure). Only two participants scored below the cut-off of 100. The remainder (3 participants) were separated and/or divorced but continued to share the care of their child. The majority of participants (15), were in professional occupations or had partners who were, while 4 participants or their partners were in semi skilled occupations.

All participants had a child with a diagnosis of a clinical eating disorder. In total, this concerned 8 daughters and 3 sons. The majority of children received a clinical diagnosis of anorexia nervosa (6 females). One child received a clinical diagnosis of anorexia nervosa but was later diagnosed with bulimia nervosa. (Throughout the study, this child is grouped with those children diagnosed with anorexia nervosa). The remainder received a clinical diagnosis of selective eating (3 males and 1 female). The current age of the children ranged from 8 to 16 years, with a mean of 13 ½ years. The age at onset for those children with anorexia nervosa ranged from 9 to 13 years, with a mean of 11 years. The age at onset for those children with selective eating ranged from 1 to 3 years, with a mean of 2 years. The length of contact with the service ranged from 2 to 66 months, with a mean of 16 months. Table 1 presents an overview of this information for each child, along with their scores on the Strengths and Difficulties Questionnaire (SDQ). (See the 'Measures' section for a detailed description of this measure).

**Table 1: Overview**

Child and Parent Identification	Child's Gender	Child's Clinical Diagnosis	Age of child (in years)	Age of onset of eating disorder (in years)	Length of contact with service (in months)	Strengths and Difficulties Questionnaire (SDQ)					
						Hyper-activity 1	Emotional Symptoms 2	Conduct Problems 3	Peer Problems 4	Pro-Social Behaviour 5	Total Difficulties Score 5
1 / M	Male	SE	8	3	5	3	2	0	0	9	5
1 / F						Missing					
2 / M	Male	SE	16	2	13	2	4	0	2	10	8
2 / F						3	6	1	1	10	11
3 / M	Female	SE	15	2	12	0	2	0	3	7	5
3 / F						1	1	0	1	6	3
4 / M	Male	SE	10	1	3	5	0	6	0	7	11
4 / F						3	0	5	1	8	9
5 / M	Female	AN	15	13½	12	4	5	2	3	10	14
6 / M	Female	AN	16	9	20	0	4	4	0	9	8
7 / M	Female	AN/BN	14	12	16	5	3	3	5	2	16
8 / M	Female	AN	15	9	66	3	2	0	0	10	5
8 / F						0	2	0	0	10	2
9 / M	Female	AN	13	13	2	3	3	0	2	9	8
9 / F						5	2	1	1	8	9
10 / M	Female	AN	13	9½	19	1	7	0	0	10	8
10 / F						Missing					
11 / M	Female	AN	13	11	14	5	3	1	1	8	10
11 / F						5	3	3	2	9	13

**Key:**

**Identification:** First number = family identification; M = Mother; F = Father.

**Clinical diagnosis:** AN = Anorexia Nervosa; BN = Bulimia Nervosa; SE = Selective Eating

**SDQ:** The following scores indicate the child is judged to be within the clinical/abnormal range:

1 Score of 7+; 2 Score of 5+; 3 Score of 4+; 4 Score of 4+; 5 Score of < 4; 6 Score of 17+.

The overall mean scores on the five sub-scales of the SDQ are given in Table 2. The scores from the SDQ reveal that the majority of parents view their children as being within the normal range.

**Table 2. Strengths and Difficulties Questionnaire, Means and Standard Deviations.**

Strengths and Difficulties Questionnaire	Mean Score	s.d.
Hyperactivity <sup>a</sup>	2.8	1.5
Emotional Symptoms <sup>b</sup>	2.8	1.4
Conduct Problems <sup>c</sup>	1.5	1.6
Peer Problems <sup>d</sup>	1.3	1.6
Pro-Social Behaviour <sup>e</sup>	8.4	1.5
Total Difficulties Score <sup>f</sup>	8.5	2.9

<sup>a</sup> Score of 7+ indicates clinical/abnormal range; <sup>b</sup> Score of 5+ indicates clinical/abnormal range; <sup>c</sup> Score of 4+ indicates clinical/abnormal range; <sup>d</sup> Score of 4+ indicates clinical/abnormal range; <sup>e</sup> Score of < 4 indicates clinical/abnormal range; <sup>f</sup> Score of 17+ indicates clinical/abnormal range.

A detailed break down of the scores that each child obtained on the sub-scales of the SDQ is presented in Table 1. These reveal that while the majority of parents considered their child to be within the ‘normal’ range, on some of the sub scales a few of the children were judged to be within the ‘borderline’ and/or ‘abnormal’ range. For example, two children were viewed as having emotional symptoms; two were deemed to have conduct problems; and one child had peer and pro-social difficulties. However, the total difficulties score suggests that overall the majority of children were thought to be within the ‘normal’ range.

## Procedure

Those parents who gave their consent to participate in the study were each given a set of questionnaires to complete. These were either handed to participants in clinic or posted to their home address. Participants were instructed to complete the questionnaires prior to the interview, handing them to the researcher on this date or returning them in a pre-paid envelope. Partners were asked to complete the questionnaires independently.

Interview dates were generally set with participants over the telephone; they were arranged at the participants' convenience. All parents were interviewed separately, at their choice of location. However, several participants chose to sit in on their partner's interview, although they made very little comment. The majority of parents (13) chose to be interviewed in their own homes; one mother was interviewed at her place of work, while the remainder (5) chose to be interviewed in the psychology department at the hospital. The interviews lasted approximately 1-1½ hour/s. All interviews were audiotaped and later transcribed for qualitative analysis with all identifying information removed.

Participants' general practitioners were informed of their participation in the study by letter, a copy of which can be found in Appendix C.

## Measures

### Questionnaires

Two questionnaires were administered in order to obtain descriptive data about the sample.

#### The marital adjustment test (Locke and Wallace, 1959)

The Marital Adjustment Test (MAT) was used to assess the marital satisfaction and adjustment of participants. A copy of the questionnaire can be found in Appendix D.

The MAT is a well-established and widely used instrument (Freeston & Plechaty, 1997). It continues to be used despite the development of other scales. The MAT is a reliable and valid scale that has been highly correlated with other relationship indices such as the Dyadic Adjustment Scale (Spanier, 1976). It was chosen for use in the current study because of its relative brevity.

The MAT consists of 15 items. The items measure both general marital satisfaction or quality (item 1, 13, 14), as well as relationship style (leisure, outside interests, conflict resolution and confiding) and also agreement or disagreement on a number of issues (finances, recreation, affection, friends, sex, conventionality, philosophy, and in-laws).

The MAT is rapid to administer and score. The summation of scores for all 15 items gives a total score. Using the suggested cut off of 100 from the empirical literature on the MAT, total scores of 100 or more indicate good marital adjustment (Locke & Wallace, 1959).

The strengths and difficulties questionnaire (Goodman, 1997).

The Strengths and Difficulties Questionnaire (SDQ) was used to assess how parents view their child. The SDQ is a brief behavioural screening questionnaire that is rapid to administer and score. A copy of the questionnaire can be found in Appendix E.

Studies indicate that the SDQ is psychometrically sound (Goodman, 1997). It has been found to correlate highly with the Rutter Parents' and Teachers' Scale which are "long established and highly respected behavioural screening questionnaires that have proved valid and reliable in many contexts" (Elander and Rutter, 1996).

The SDQ comprises 25 items that are equally divided into the following 5 scales: Hyperactivity; Emotional Symptoms; Conduct Problems; Peer Problems and a Pro-Social Scale. Each item can be marked 'not true', 'somewhat true' or 'certainly true'. Items are then scored 0, 1, or 2. 'Somewhat true' is always scored 1 but the scoring for 'not true' and 'certainly true' varies between 0 and 2 for each item depending on the scale. Summing the scores for the five items that make up the scale produces the score for each of the five scales. This generates a scale score ranging from 0 to 10. The score for Hyperactivity, Emotional Symptoms, Conduct Problems

and Peer Problems are summed to generate a Total Difficulty score ranging from 0 to 40; the Pro-Social scale is not incorporated in this.

Scores from the SDQ were used to describe whether children were judged to be within the 'normal', 'borderline' or 'clinical' ranges by using cut-offs from the empirical literature (Goodman, 1997). The cut-offs vary for each sub scale; the clinical range for Hyperactivity is 7+; Emotional Symptoms, 5 +; Conduct problems, 4 +; Peer problems 4 +; whilst for pro-social scale, higher the score the more pro-social the child.

A third questionnaire was administered to parents, it was intended as a complement to the qualitative data.

The causal dimension scale (Russell, 1982).

The Causal Dimension Scale (CDS) is a measure of attributions. It examines how an individual perceives causes of an event or situation. The scale is based around three causal dimensions; Locus of Causality, Stability and Controllability, that have been described by Weiner (1979). A copy of the questionnaire can be found in Appendix F.

The CDS consists of nine items: Three measure locus of causality (items 1, 5, 7), three measure stability (items 3, 6, 8) and three measure controllability (items 2, 4, 9). Each item is scored on a scale from 1 to 9. A score for each causal dimension is obtained by the summation of the 3 items that constitute the respective sub-scale. A

total score for each of the 3 sub-scales is generated by the summation of the responses on the individual items. High scores on these sub-scales indicate that the causes are perceived as internal, stable and controllable (Russell, 1982).

Participants were asked to complete the following three questions prior to filling out the CDS:

- 1) Briefly describe your child's eating problem as you see it.
- 2) What do you think are the main causes of your child's eating problem?
- 3) If you have mentioned more than one cause above, what do you think is the most important cause?

These questions intended to help participants identify the causal attribution they would have in mind when completing the CDS scales. For the purposes of this study minor adjustments were made to the CDS including replacing 'yourself' with 'your child'. The scoring was reversed from 9 – 1 to 1 – 9, this was done for 'ease of reading' on the recommendations of the ethics committee to which the study was submitted.

The intention in using the CDS in this study was to assess how participants perceived the causes of their child's eating disorder. The CDS was chosen as it appears to be a marked improvement over previously used measures of attribution. Estimates of validity and reliability obtained by Russell (1982) seem to confirm this assertion.

The CDS was not included in the final analysis due to the large amount of missing data. Many parents did not fill in the questionnaire, as they could not identify 'one main cause' for their child's eating problem, while other parents attempted the questionnaire but only partially completed it. The majority of parents complained about the scale, reporting that they found it "unclear" or "confusing".

### **Semi-structured interview**

The main part of the study consisted of a semi-structured interview. The aim of the interview was to elicit information about parents' views and experiences of having a child with an eating disorder. An interview schedule was developed using the 'good practice' guidelines that are proposed by Smith (1995). The interview schedule covered a number of areas. The impact of having a child with an eating disorder was explored in relation to its effect on the parent personally, practically, in terms of their relationships with their partner and other family members. Parents' understandings of their child's eating disorder were also explored, including their thoughts on the possible causes of their child's illness. Parents were also asked about their experience of treatment, including their views on the help that they thought both they and their child needed.

The questions set out in the interview schedule were used as a guide to explore the areas of interest; they did not dictate the interview. Flexibility was essential to ensure that participants were given "maximum opportunity to tell his or her own story" (Smith, 1995) and thus have room to introduce an area of interest that the researcher had not previously thought of. Neutral, jargon-free, open-ended questions

were used along with prompts to encourage participants to elaborate on their experiences. The interview schedule can be found in Appendix G.

## **Analysis**

### **The personal perspective of the researcher**

In qualitative studies, it is good practice for the researcher to disclose their own perspective on the research topic (see Stiles, 1993; Elliott, Fischer and Rennie, 1999). This can assist the reader in understanding the researchers' interpretation of the data and encourages the consideration of possible alternatives.

The researcher has never had an eating disorder or a close family member with an eating disorder. The researcher is not a parent. However, clinically the researcher has worked with many parents who have been trying to cope with a child with an eating disorder. This has led the researcher to hold a belief that eating disorders are often serious chronic illnesses that can have a significant impact on the lives of those that they touch. The researcher is currently a trainee clinical psychologist working in a Paediatric setting; the narrative therapy field and cognitive-behavioural models heavily influence her clinical work.

**Analysis of qualitative data**

All interviews were transcribed verbatim. The interview transcripts were stored electronically with any identifying information being removed so that participant anonymity was protected.

The transcripts were then analysed using the method of Interpretative Phenomenological Analysis (IPA; Smith, 1995; Smith, et al 1997; Smith, Jarman and Osborn, 1999). This is a qualitative form of analysis in which themes within the data are systematically identified.

Initially the process of analysis involved reading each of the parents' transcripts, in turn. Each transcript was read several times, and initial ideas were noted in the left-hand margin. During this early stage of the process, statements that appeared relevant, in terms of each parent's understanding and experience of having a child with an eating disorder, were noted. Following this, each transcript was re-read and potential themes that emerged from the data were noted in the right-hand margin. 'Themes' were specified as key words or phrases that captured the essence of the data. Each of the transcripts was coded in this way and then the themes were re-examined in each transcript to see if they could be grouped together meaningfully into themes and sub-themes. When a cluster of themes had been identified for the first transcript, the process was then repeated for each transcript. This process was repeated until clusters of themes were generated for all of the transcripts.

Once shared themes were identified for all of the transcripts, the quotes within each theme were then re-checked to ensure that the themes correctly represented what was said in the transcripts. This cyclical process of analysis allows the researcher to check that their own bias does not affect the selection of themes, as they can ensure that themes are reflected in the verbatim transcripts. A transcribed interview with examples of associated working can be found in Appendix H.

The transcripts of the mothers and fathers were compared and contrasted in order to identify any differences in themes. Following this, the transcripts of parents with children with anorexia nervosa were compared and contrasted with the transcripts of parents with children with selective eating. Once again, the aim was to identify any differences in themes. In the first instance it was noted if any of the themes or categories within each group were absent. Secondly, the verbatim data extracts, which made up each theme, were compared and contrasted across the groups and any differences were noted.

Quality control is of vital importance in qualitative studies and there are now several recently published guidelines that provide a description of 'good practice' (see Smith 1996; Turpin, Barley, Beail, Scaife, Slade, Smith, & Walsh, 1997; Elliott, et al, 1999; Reicher, 2000). During the stage of analysis, 'credibility checks' are recommended to examine the trustworthiness of the categories, themes or accounts of the researcher (Elliott et al, 1999). In line with this recommendation, three other qualitative researchers were enlisted to check the analysis. One researcher examined the transcripts, searched for potential themes and compared the fit of the themes that were elicited from the original data. The researcher's comments were then used to

modify the themes. In addition, two other researchers conducted “an audit of the paper trail” (Smith, 1996). This involved checking that a coherent chain of argument ran from the initial raw data to the final list of themes. The aim of the audit was not to reach consensus between the researchers but to validate one particular interpretation of the data. These procedures were used to safeguard the validity of the themes by checking that the themes were a good reflection of the verbatim accounts. Further issues relating to ‘good practice’ will be described in Chapter four.

## Chapter Three: Results

### Overview

This chapter describes the themes that emerged from the participants' interviews. The results are structured around three broad domains: firstly, understanding the eating disorder; secondly, the impact of the eating disorder; and finally, managing the eating disorder and its impact. The domains relate in part to the questions asked in the interview schedule but also reflect the issues that were brought up by the participants themselves. Within each domain the central themes are described in turn.

Table 3 presents an overview of the themes within each domain. There were many commonalities, but also some differences between the accounts of parents with a child with a diagnosis of anorexia nervosa and those with a child with selective eating. Table 3 presents the themes for each group. As the majority of themes apply to both groups, the themes are described for the sample as a whole; any variation between the two sets of parents is highlighted within the description of individual themes. No systematic differences emerged in the accounts of mothers and fathers, so the themes described apply to both.

Each theme is illustrated with the participants' own words. These appear in italics. Following each quote is the participant's research identification number and either *M*, denoting mother; or *F*, denoting father. Where the interviewer's comments are

also included these are differentiated from participants by the following: *I* denotes the interviewer; and *P* denotes the participant.

**Table 3: Overview of Themes.**

<b><u>Parents of Children with Anorexia Nervosa</u></b>	<b><u>Parents of Children with Selective Eating</u></b>
<b>Understanding the Eating Disorder</b>	<b>Understanding the Eating Disorder</b>
Slow recognition Analysing it Complex and puzzling	Slow recognition Analysing it Complex and puzzling
<b>The Impact Of The Eating Disorder</b>	<b>The Impact Of The Eating Disorder</b>
<i>The impact on the child</i> The dreadful monster High stakes Missing out	<i>The impact on the child</i> Normal apart from their eating  Missing out
<i>The impact on everyday life</i> Life stops – Disruption	<i>The impact on everyday life</i> Life goes on – Restriction
<i>The impact on the parent</i> A living nightmare	<i>The impact on the parent</i> Easy if you know how
<b>Managing The Eating Disorder And Its Impact</b>	<b>Managing The Eating Disorder And Its Impact</b>
<i>Attempts to manage the eating disorder</i> You can lead a horse to water ... Adapting - Taking control	<i>Attempts to manage the eating disorder</i> You can lead a horse to water ... Adapting and accepting
<i>Managing personally</i> Sharing experiences Support and understanding Time out	<i>Managing personally</i> Sharing experiences
<i>Experiences of Treatment and Services</i>	<i>Experiences of Treatment and Services</i>
Battling for services Speed Specialist understanding and knowledge Solutions and advice	Battling for services Speed Specialist understanding and knowledge Solutions and advice

## Understanding the Eating Disorder

The majority of parents discussed and provided examples about their understanding of the eating disorder. This section of analysis relates to the themes that capture this experience. Three themes are described in turn: Slow recognition, Analysing it, Complex and puzzling. While these themes emerged as common across both sets of parents, subtleties between the two sets will be described within each theme.

### Slow recognition

For the majority of parents, recognising the eating disorder was a slow process. While all parents began to notice differences in their child, most did not initially attribute these to an eating disorder. The parents of children with anorexia nervosa started to notice changes in their child's eating habits or general behaviours. However, despite pondering the possible reasons for these changes they did not initially associate them with an eating disorder. This is illustrated in the quotes below.

*"Then I thought well this is what being a teenager's all about, ... she's decided she can take more control she's decided she wants to be a vegetarian ... so again I didn't take an awful lot of notice" (9M).*

*"I didn't know enough about the illness at the time to put the two together .I knew that she was losing weight and wasn't well and was behaving oddly but it's ... you know ... I suppose I was praying that it wasn't really anorexia I suppose that you know you don't believe until you're actually diagnosed" (11M).*

The parents of the children with selective eating recognised early on, often at the introduction of solid foods, that their children were extremely selective in their food

preferences compared to other children. Initially, however, they too did not view this as a clinical eating disorder. Instead many parents thought it might have been part of the child's own idiosyncratic preferences.

*"Well I think a lot of young children probably do have you know likes and dislikes and some are more selective than others and a lot of them it just fades into insignificance when they are 7 or 8, they just grow out of it or they extend their diet and I think it is difficult to know whether there is a problem" (2F).*

Many parents appeared to link their lack of knowledge about eating disorders with the slow recognition of their child's eating problem. Both sets of parents described not knowing "enough" about eating disorders at this early stage to be able to associate either their child's presentation or the changes witnessed in their child with a disorder. For the parents of children with anorexia, recognition eventually came when the changes in their child escalated. For some, unusual behaviour became more evident and, for most, dramatic weight loss was witnessed.

*"P: We had to try and get her to eat something and it was almost impossible and I think she had just one tiny little bit of melon and we really, that particular incident really sort of pinpointed what had been building up for some time and it really sort of focused on the problems we were facing and obviously became more acute in some ways after that .. but that I think was the first time it really really came home to me that there was a particular problem about actually almost eating anything*

*I: So that was when the first sign really hit you?*

*P: That was when the first sign of the actual manifestation of the anorexia actually hit me although I was aware she was getting thinner but it really really hit me in that particular incident" (8F).*

Most parents of children with selective eating initially assumed their child's presentation was a "phase" or a "fad". They hoped it would be a variant of normal developmental fussiness that the child would "grow out" of. For most parents recognition of a more serious problem came when their child showed no signs of growing out of it and in most cases became more selective as they got older. Some

parents also described how their child's expressed desire to eat a wider variety of foods, but their obvious inability to do so, precipitated them to contact services.

*"I think the mistake that I probably made earlier on was the fact that I felt it was just [child] just being [child] and not wanting to try things and just being awkward, I mean, I feel guilty to that extent but that was just because of complete lack knowledge and I wasn't aware ... I think he said ...he just wished he could eat [pizza], so I got him a pizza and he wouldn't touch it and at that stage I thought ok he really does genuinely want to ... and but that was the first time that I realised that there was something a little bit more deep than just him being stubborn and not wanting to do it because it was quite obvious to me that he did want to do it" (2F).*

In hindsight, a lot of the parents described wishing that they had been aware that their child was suffering from an eating disorder earlier on. They wished they had recognised the magnitude of the problem or at least seen the warning signs so they could have acquired treatment sooner. There was an overwhelming sense of guilt about this from parents.

*"I felt I should have picked up on it earlier or if I'd have caught it earlier it wouldn't ever have developed as bad as it was, but I just, we didn't see it, we just couldn't see it, it was very complicated, very hidden I think, quite a secretive illness" (5M).*

Parents described how the slow recognition of the eating disorder was often exacerbated by general practitioners. For the majority of parents this was their first port of call when they became concerned about their child. However, initial visits often resulted in the general practitioner attributing the child's condition to something other than an eating disorder.

*"Her eating problem developed slowly. .. we weren't really aware of her cutting down food as such 'cause I think it just wasn't so obvious ... I went to the GP in July saying I was concerned that she wasn't putting on weight ...I went back to the GP and he said wait 'til puberty sets in...I'm still cross that the GP hadn't confirmed it early on because I kept saying to him" (10M).*

*“I think he didn’t believe she was going to be anorexic, I think he just thought she was going through a stage you know. I don’t think he for saw what was going to happen” (11M).*

Parents of children with selective eating recounted that when they expressed concerns about their child’s selective diet they were frequently given the message not to be concerned because their child would grow out of it.

*“Between about the age of 2 and 4 he was very very fussy...so I was concerned but I kept thinking he’ll grow out of it, he’ll grow out of it...I mean I had mentioned it, the doctor and the health visitor they all said he’ll grow out of it and he’ll come to it .. but as he got older instead of getting better it got worse ... in that the type of foods he would eat just diminished” (2M).*

*“I made various trips to my GP most of which were always started with the ‘first child’ line, you know the condescending look that goes with it and ‘this is your first baby is it Mrs [name]’, I was [age] years old you know I wasn’t 16 but um they were as sympathetic as could be expected I suppose you know convinced there was nothing actually wrong with him, go away and it will sort itself out” (1M).*

Some parents felt more aggrieved than others at the failure of health care professionals to “pick up” on the eating disorder. This seems in part related to the beliefs of parents. Those who had a strong sense that something was very wrong were angrier that their doctors did not take them seriously. Similarly the speed at which parents were able to access services as a result of recognition of the eating disorder was important. For some a lack of recognition resulted in a delay in receiving appropriate treatment. The idea of recognising the eating disorder and then accessing specialist services is closely linked with the theme ‘Speed’. This will be discussed in a later section with particular attention to the importance of quick recognition for good prognosis.

### Analysing it

All parents described a desire to fully understand the eating disorder. The majority of parents described spending a great deal of time and effort thinking about and discussing the possible reasons behind the development of their child's problem. Most often parents appeared motivated by a desire to find solutions to their child's problem and wanting to prevent further harm.

*"I mean [my wife] and I keep discussing this and have done time and time again" (11F).*

*"Particularly at the beginning we were thinking why, why, what is it, and we changed absolutely everything we could possibly change but whether it was too late when we changed it all or whether it didn't matter if we changed it or not I don't know" (5M).*

Analysing the eating problem appeared to be very much an ongoing process for parents. In their attempts to further their knowledge, parents read books; watched T.V. programmes; joined organisations; and talked to others, both lay and professional, with experience of eating problems.

During the process of analysing it most parents developed their own picture of their child's eating disorder. They also focused on the possible influential factors in its development. While all parents appeared to have carefully considered a host of possible causes some were more confident than others as to how the disorder evolved. Despite some variations, the overriding sense was a 'complex' and 'puzzling' picture.

Complex and puzzling

'Complex', captures the accounts of those parents who had formed distinct ideas about potential influential factors in the development and maintenance of their child's eating disorder. Parents described a multitude of different possible inter-related factors. They emphasised that they could not "pinpoint" any one cause that appeared to account for the eating problem.

*"I truly believe that it wasn't my fault, it was a set of circumstances that became too heavy a burden on the child and nothing I could do could alleviate those, but that sense of loss that she had found that I couldn't protect her from ... very traumatic events coupled with somebody who is sensitive. I don't think every child in that circumstance would fall prey to that, I think she is, she is a person and there are many people who are likely to have mental problems" (7M).*

*"[Child's] eating problem wasn't just one thing, ...low self esteem...the whole, everything, the whole mixture of things" (10M).*

*"You have an original cause and then that is reinforced by a natural conservatism and perhaps you get into a vicious circle" (3F).*

Parents often presented complex explanations, involving triggers and maintaining factors. Traumatic or stressful events were frequently seen as having precipitated the problem, which was exacerbated by the child's personality and/or a predisposing vulnerability. Many parents described personality as a maintaining factor that ran parallel with the idea of the child not knowing how to get out of the situation.

*"I mean I can't really pinpoint what's caused [child's]...[child] is actually fairly stubborn ... and once he's dug his heels in that's it, it takes a lot of persuading to change his mind, I mean whether. I don't know whether it was the way I approached him and weaning him onto solids I mean ... I don't know. Whether he thought that was a way he could control me or gain my attention, and if you ask him, he doesn't know why but I think, I think initially it could have been some of those reasons, but I think as he's got older because of his stubborn*

*nature and because we've said to him look [child] you've got to try these things ... he ... it's just grown with him and he's just sort of dug his heels in" (2M).*

In addition, the parents of children with selective eating also considered the role of parenting in the development of the problem.

*"I have questioned is it something we have done or said or you know why is he like this or is it part of his genetic make up and that that he genuinely doesn't like these things, I don't think that is the case but yeah I think parents, as parents you question, well I have questioned you did I wean him the right way, did I introduce solids the right and the answer is I don't know" (2F).*

Although many parents put a lot of effort into 'analysing' their child's eating disorder and developed a 'complex' picture of it, they generally appeared to feel no nearer to the truth and remained puzzled. Thus the majority of parents felt that they could not fully understand why their child had developed an eating disorder and found it very puzzling.

*"I mean I still don't really know the reasons, I mean you know you don't know the reasons do you really, I mean it's just what you think could be the reason, and if any body asks her or I sit and discuss it with her she says there's nothing wrong mum, you know it's just that I don't want to be fat" (6M).*

*"You know if you speculate on you know, we have tried speculating on this or that may be the cause but each of those speculations run up against that point where as a very young child she was so extremely conservative .... Now if you look at her brother he'll eat anything ... So even if you were to test the theory well it's the parents diet, it is very constrained or the diet that they would offer to their children is very constrained, or pressure would be put on, you know particular foods would be more beneficial ... I think again that theory would be negated by looking at her brothers diet, so it's very hard to say ... One can describe a variety of symptoms but to try to discover a cause, a prime cause which would fit in with all of those symptoms across the time spectrum has confounded us" (3F).*

Some parents tried to discuss the issue with their child but found their child had no clearer a view on the matter than they did.

*“I get frustrated sometimes as he’s getting older because I’d like to get better answers from him. I’ve always pinned my hopes on sort of between sort of age four and when he talks more we’d probably get a bit more of an answer rather than just “I don’t like the look of it” ... I find that a little bit frustrating but it’s obviously something psychologically there that makes him clam up about it ... Why do you choke or gag, what is it that ... I feel at [child’s age] you should be able to explain that there’s either a lump there or .. but you don’t get an intelligent answer” (1F).*

*“If you ask him, he doesn’t know why ...I wish I knew what the problem was I think [child] wishes he knew what the problem was” (3M).*

Most parents reported receiving little spontaneous feedback from professionals on the potential influential factors in the development and maintenance of their child’s eating disorder. Some parents directly consulted professionals but remained ‘puzzled’ despite these discussions. Thus the majority of parents appeared to form their ‘complex’ picture through observing their child and the events in its life.

*“We’ve mentioned at [the hospital] do you think it could be this, do you think it could be that? And everyone says ‘well it varies with individuals and we don’t know, so no not really’.. I think it would be nice if someone could say this was the cause, well it would be because if you could tell us what the cause was we could obviously change it and get rid of it” (5M).*

*“I don’t know ... I mean I think we’ve been through the stage where we’ve questioned ourselves over what we’ve done and the way we’ve treated him has contributed to the problem, but I don’t ever think, I think we thought that when we went to [the hospital] we would hopefully find some magic answer but we haven’t” (3M).*

For many parents their search for clarity was often related to their desire to do what ever they could to help their child. In an ideal world parents reported that they would “love to know why it arose or what caused it”. However, many reported that the ‘complexity’ of eating disorders did not lend itself to this. Therefore, parents seemed to be resigned to continue to ‘wonder’ while at the same time they have to find a way of managing the eating problem and its impact.

## **The Impact Of The Eating Disorder**

One of the prominent topics of discussion in the interviews was the impact of the eating disorder on the day to day lives of parents and their children. While some of the themes in this section are common across both sets of parents, others are unique to each group (see Table 3).

### **The Impact On The Child**

#### **The dreadful monster**

Parents reported that anorexia nervosa had a dramatic negative effect on their child. All parents described a process through which the eating disorder appeared to entirely take over their child. A commonly expressed view was that the disorder seemed to assert control of their child's thoughts, feelings and behaviour. Parents described witnessing a complete change in the child's personality to the extent that they were virtually unrecognisable as the child they once knew. This was extremely upsetting for parents, as they felt like they had lost their child to the disease.

*"Your child is possessed by this eating disorder, it is not your child in the same way, they are not responding in normal ways.... It does seem like a person possessed ... What you've got is an impostor sitting in your child" (7M).*

*"There was definitely this dreadful monster, it's just unbelievable when I think back to how she was I mean you couldn't reason with her you couldn't, she was just a different person" (11M).*

Many parents talked about their children engaging in uncharacteristically devious behaviour in an attempt to avoid weight gain. Parents reported their sadness at the growing distrust in their child that resulted. They described the difficulty in trying to manage this difficult behaviour, whilst simultaneously trying to maintain a positive relationship with their child.

*“She also became quite devious. You know you’d say have you eaten the biscuit ...and she’d look me in the eye and say I’ve eaten it and then I’d say what’s up your sleeve and it was awful and there was the biscuit up the sleeve.... You never think that your own children will behave like you know ... but ...this anorexia was so strong it was awful” (8M).*

*“This anorexia controlling her and anorexia would do everything possible to avoid being beaten, or you know she had to exercise, she had to avoid eating ...and there was such a kind of fight in her” (11M).*

However, parents reported that the changes observed in their child were not permanent. As the child began to “get better” and gain weight, parents described witnessing the reassertion of the child’s pre-morbid personality. For some this was a slow process. Several parents recounted that despite “having the child returned” to them, anorexia had left its “legacy”. Some described this as a “nagging voice” at the back of the child’s head, while for others it was the fear that the “monster” could return. All parents were alert to this possibility.

*“I do worry about the fact that she might go back, you know she’s done so well that and I feel as though I’ve got my daughter back, I don’t want that monster back again (11M).*

**Normal apart from their eating**

In stark contrast to the dramatic changes witnessed in children with anorexia nervosa, the parents of children with selective eating primarily described their children as ‘normal apart from their eating’. The longstanding nature of the child’s eating problem appeared to lead parents to see it as a small part of their child.

*“There’s no other problems apart from just this limited range he eats” (4M).*

Selective eating gives the sense of a normal child who eats a restricted range of foods. Whilst parents described ‘difficult behaviour’, they saw this as a direct result of the eating problem. This was in contrast to children with anorexia nervosa because these characteristics do not appear to “take over” the child.

*“He does get these strops but again I think that’s food orientated” (4F).*

*“He has had behavioural problems when he’s not been able to eat enough or not be near where we can supply the right foods, so he’ll just decide not to eat altogether” (1F).*

The ‘difficult behaviour’ appeared to be confined to episodes when the children could not eat the food that they liked. They were otherwise viewed as “happy” enough children.

### High stakes; missing out

Fundamentally all parents were concerned about the wellbeing of their children. However, when a child has an eating disorder these concerns become accentuated. Both sets of parents described a variety of concerns that emerged as a result of the eating disorder. The principal concern related to the health of the child.

### High stakes

For the parents of children with anorexia nervosa, concern ran 'high'. The risk of mortality meant that some parents were faced with the possibility of losing their child. Understandably this is an extremely distressing possibility that no parent wants to face.

*" The doctor who was on duty had actually called us into the sisters office and she said you know this child is extremely ill she may die .....,which really knocked us for six ... It was very, very traumatic" (8F).*

The seriousness of anorexia nervosa appeared to relate to parents' fear of relapse. No parent wants their child to become unwell again no matter what the illness. But more so when the "stakes are high" and there is a risk of death. Anorexia was like an overwhelming timeless spectre over the child.

In contrast, the parents of children with selective eating did not see the stakes as high: they acknowledged that their children did not run the risk of starving themselves to death, as in the case of anorexia nervosa. Nevertheless, parents of

children with selective eating were concerned that their child's restricted diet may generate health problems for them in the future.

*"If he was away he wouldn't starve ... He would buy what he wanted to buy and he would just survive on, well he has survived on a restricted diet so he wouldn't starve... So try not to worry, that's not easy though because I think all parents do worry about what their children eat, and I mean on the telly, you are bombarded by the whole healthy eating thing (2M).*

*"We are just concerned that he's getting the right nutrients and he's not damaging his health for later on" (4M).*

These fears were linked to the types of food the children eat, which were typically high in fat or sugar based. For several parents their fears were heightened by the current societal drive for "healthy eating" and the promotion of "good" and "bad" foods. Parents generally felt their child's entire diet was limited to those foods regarded as "bad", which are generally recommended only in moderation.

### **Missing out**

The majority of parents described concerns about their child missing out on social aspects of life not only in the present but also later on in life. This was a view held by both groups of parents. Typically their children avoid social situations because of their eating problem. Parties, sleepovers at friend's homes, restaurant outings and school trips were frequently cited examples.

*"Food is wonderful really I feel, and it's part of everything isn't it ... It's a social thing ... I just feel that she's missed out on all that for so many years really ... and if she's got to struggle like that for the rest of her life, worrying about what she's eating, it doesn't make you a very happy person really does it" (6M).*

*“ I do wonder if this food problem has sort of narrowed her, her range of social activities quite a bit... .. it wasn't just the fact that she was missing out on the actual nutrition from the food but she was missing out from a sort of a joining in sort of thing as well” (3M).*

*“It doesn't affect his social life too much at the moment because he's still that young but give him a couple of years when he starts going out more” (4F).*

Parents gave a variety of possible reasons for this social avoidance. These ranged from: embarrassment; the child not wanting to eat in front of others; and fears that foods within the range would not be available (this applied to both groups, as some children with anorexia eat a fairly restricted range of foods).

The majority of parents gave examples of situations where their child have 'missed out' due to their eating problem. These ranged from school trips, to “normal” social activities for their age group. Essentially parents did not like to think of their child as being disadvantaged or 'missing out' in anyway because of the eating disorder. To this end parents 'felt for their child', regardless of whether they were personally concerned.

*“I just feel for her ... I just feel poor child, you know she has such a lot to contend with” (8M).*

*“I mean I do, I worry about, I feel sorry for her that those restrictions are there in her life” (3M).*

Parents felt that it was their responsibility to alleviate their child's suffering and to try to ensure that they did not 'miss out' as a result of their eating problem.

*“It would be incumbent on me as a parent to try to help in as much as I could” (3F).*

*“To try to ensure that he is not disadvantaged in any way as a result of the problem” (2F).*

Schooling was another area of concern for parents. Several parents reported that often their child would not eat while at school. Therefore following breakfast, their next meal would be dinner at home. Several parents questioned the possible effect of this on their child’s concentration and thus their school performance.

*“I wonder if he was eating properly would his schooling improve” (4F).*

Parents were therefore concerned that their child may not be getting the full benefits of education.

Fundamentally the ‘concerns’ of parents appeared to drive their bid to rid their child of the eating problem.

### **The Impact On Everyday Life**

#### **Life stops – Disruption**

The impact of the eating disorder on every day life varied significantly between the two sets of parents. The lives of parents of children with anorexia nervosa were severely disrupted. Essentially normal family ‘life stops’. The eating disorder seemed to rule parents’ entire lives. As a result parents felt they had to change their priorities to make sure the child came first.

*“As far as possible keep your life going .... but inevitably everything stops” (7M).*

*"I mean I think it ruled our lives really when it was at it's height" (8M).*

*"You've got something else to think about on top of everything else and you know you obviously have to change your priorities ... So it has made a big impact" (9F).*

Many parents described trying to hold on to some level of normality in their lives but found this extremely difficult to do. Fundamentally, life began to revolve around attempts to feed the child. As a result parents were forced to make major life style changes. This involved giving up many of their activities or putting things on hold in order to care for their child. Many parents had to continue to hold down jobs, so when they were not at work, they felt they had to be at home to care for the child.

*"From a very practical point of view I'm supposed to be doing a [course] this year and I haven't because I didn't think I could cope with [the child] being ill and studying as well...It is quite time consuming at night time, and planning meals and shopping and just stupid little things that you don't even think about" (5M).*

Looking after a child with anorexia nervosa took up an incredible amount of time.

Paramount was the time taken up trying to feed their children.

*"Undoubtedly it took up a lot of time, ...particularly when we were getting her to eat. ...The evening would be gone because she would you know not eat and we'd sit with her... and it was dreadful!... It did take a long time and supper would go on to 10 o'clock at night by which time everyone was exhausted and went to bed. So I mean there was no evening really and all activities stopped, ...because you just couldn't afford not to be here ... We had to be here every evening" (8M).*

Parents described mealtimes as extremely stressful for everybody in the family. It was not unusual for mealtimes to take a couple of hours, after which time the whole family was exhausted.

*"Scenes at meal times were absolutely horrific, you know I suppose it took anything from one and a half hours every meal time basically with horrendous scenes" (11M).*

Meal times became a 'battleground' as opposed to the family gathering and the forum for social interaction that they once were.

*"It's just been awful for everyone really because meal times are usually quite fraught, even if we try not to make it. Occasionally they are fine, but if [the child] refuses to eat her meal, when she was very ill, then I'd shout, everybody else would cry and it's just the knock on effect to the whole family. It's been really, really devastating" (5M).*

Many parents talked about the impact of difficult mealtimes on siblings. Often siblings were left feeling very upset by "dreadful scenes" at mealtimes. Moreover, parents had less time for their other children, as some much energy had to be invested into the ill child. Try as they might to keep the lives of siblings as normal as possible, disruption appeared inevitable.

*"At her worst .. absolutely ghastly because you had no time at all for the other two, ... because she was the one that was ill you had to give her all the attention that she needed, which deprived every one else in the family of any really" (11M).*

There is little doubt that the eating disorder impacted on the lives of the whole family unit.

*"I think the biggest surprise that I've had is how much it actually effects the whole family. I'm sure with any illness it will effect the family but with an ongoing illness like this it has massive effects ...Its stressful for the whole family" (5M).*

In almost all cases the activities that families did together had to be adjusted. This was often related to the precarious weight of the child, which meant that families had to look for more sedentary pursuits.

*"I mean we did lots of sports and because [the child] has to restrict the amount of sport that she does, that's the first thing really that went, family sports and then team sports" (5M).*

The social lives of families were often severely disrupted by the eating disorder. At the height of the eating disorder, it was virtually impossible to attend a social gathering that involved food, as it was perceived as too difficult for the child. Furthermore, some parents mentioned that wider family and/or friends often found it too traumatic being around a child struggling with food. Since the majority of social events revolve around food, it was inevitably easier and less painful for all concerned to stay at home.

*“I mean we’ve spent a fair bit of time as a family out socialising and we’d have people round for Chinese or go out for meals with people ... that ...side of it, which was all good fun for everybody, .. that’s stopped because ...she found it difficult” (9F).*

Families appeared to adapt their lives as best they could to cope with the eating disorder. For most they did this by putting their lives on hold and concentrated on surviving one day at a time. Anorexia nervosa is such an all-encapsulating disease that it did not just effect the patient but impacted on the whole family. It is nothing more and nothing less than ‘a living nightmare’.

### **Life goes on - Restriction**

Conversely, the descriptions of daily life for the parents of children with selective eating generally indicate that ‘life goes on’ despite the problem. While the parents reported that the eating disorder did have an impact on their lives, they emphasised that it was not a significant one.

*“Well it has had an impact but I wouldn’t say the impact is of any great significance” (3F).*

In comparison to the ‘all encompassing’ influence of anorexia nervosa, the impact of selective eating is on a much smaller scale.

*“I mean [the child’s] eating problem isn’t anywhere near as bad as some of the other ones we sat in on a group session and I feel extremely relieved. I mean I even said in the group there that I’m absolutely staggered that my problems don’t even fit into a thimble in comparison to the problems that you lot seem to be having ... I mean [the child] is a selective eater and that’s really all it is and you can get by easily enough” (2F).*

At home the impact was very small. On the whole parents ensure that they are well stocked in the precise brands favoured by their child. If this was the case mealtimes were uneventful and were not considered a ‘nightmare’. However, problems could arise out side of the home if the specific brands of food were not available. For example, eating out at restaurants, particularly in foreign locations was cited as the biggest hassle.

*“When it is difficult is when you go out for a meal or when you are staying with relatives and the worst bit is when you go on holiday” (3M).*

*“It doesn’t stop us doing major things ....It’s just that very small inconveniences of having to take a packed lunch. Where ever you are you have to think where you’re going to be at what time of the day ‘cause you can’t always guarantee you can get the food that he needs, so it’s inconvenient I’d say more than anything” (1F).*

*“From a practical point of view it limits us to where we can go to restaurants if we want to go out, ... I mean certainly on holidays .. then you know you’ve got to be very careful where you stop for something to eat and if you stop in a little bay somewhere and there’s only one little restaurant .. you know we’ve got a major problem on our hands, so we’ve got to be a little bit careful from that point of view so we are a little bit limited ..but that’s very, very minor. Its not a major issue, you just have to be a bit careful” (2F).*

If parents wanted to have a ‘family meal out’ for everyone, this generally meant they were highly restricted in their choice of venues. Otherwise the options for parents were to take food out with them for the child or alternatively, let the child “get on

with it". On the whole this was seen as an inconvenience rather than insurmountable problem. Whilst it was nowhere near as inhibiting as anorexia nervosa, parents were resigned to the fact that eating out as a family could never be a spontaneous affair, some planning for the child was always required.

*"It's all this inconvenience whereas other families just go along for the day and don't worry .. I've got to always think about my family" (4M).*

Generally, life goes on despite the eating problem. This was highlighted in the family life, whilst it could be frustrating to manage it was 'easy if you know how'.

### **The Impact On The Parent**

While both 'eating disorders' impact on parents they do so with a different intensity. Parents experienced anorexia nervosa as pervading and overwhelming; it is 'a living nightmare'. In contrast the parents of children with selective eating regarded the problem as a frustrating addition to the hassles of everyday life.

### **A living nightmare**

For the majority of parents having a child with anorexia nervosa was 'a living nightmare'. The strain on parents was enormous, sometimes beyond comprehension. This ordeal was unique to the parents of children with anorexia nervosa; parents of children with selective eating described a very different experience.

*"Awful! Absolutely awful!" (5M).*

*"A nightmare! How else can I describe it, just as a nightmare really" (6M).*

The level of stress on parents is almost unbearable. It can feel like a never-ending problem with no light at the end of the tunnel.

*"I think you've got to bear in mind that the level of frustration a parent is feeling is extreme, ... because you might be living through this nightmare for a year, 18 months, longer you know who knows how long some parents go on for and it's a level of torture that is unimaginable" (7M).*

Anorexia nervosa dominated parents' lives. As parents they felt totally responsible for their child's well being, they were thus living and breathing the problem 24 hours a day.

*"I was ....living and breathing it the whole time ... I'd persuade my self not to worry about the work, that can wait, but [my child] and[ my wife] were more important" (11F).*

*"I do feel terrifically responsible you know. I do feel I don't want her to go back so much because I know that at the end of the day it falls on me to be there when she is that ill you know, [my husband] was a tremendous support but you know he still had to go to ... work ...where as my life did change hugely" (11M).*

Parents were left dealing not only with the eating disorder but also their own personal physical and mental exhaustion.

*"I mean I'm sure it put a tremendous strain on everyone ....As the mother you ...try to be there to listen to your husband's problems and your children's and sometimes that takes up so much time that you get no space at all and you end up feeling totally drained, exhausted and want to kind of just go and lock yourself in the bath and think just leave me alone! But there wasn't much time for that". (11M).*

Thus 'support and understanding' and 'time out' to take care of themselves emerged as vital to parents survival. These related themes are described in the final section of the results.

**Easy if you know how**

Aside from the 'concerns' that parents had about their child's restricted diet, day to day life was not considered terribly difficult by parents. This appears to be in stark contrast to the parents of children with anorexia nervosa who described their day to day lives as a 'living nightmare'.

*"Having a fussy eater makes it very easy to serve meals because you know exactly what brand to buy, and exactly how to cook it, and exactly what to serve it with ... so from that point of view it's very easy" (3M).*

*"I just literally gave him the same old dinner day in day out because it wasn't worth giving him anything else, he never ate it so in one respect I have to say it was probably easy" (4M).*

The fact that parents of children with selective eaters described day to day life as relatively easy, should not in any way undermine the frustration and practical difficulties that did arise at times because of the child's problem.

*"I think frustration would be the main thing I experienced" (3M).*

*"It is hard work because you have to carry [the food], make sure you have got it with you and if you've gone out without it you have to come back for it or find some that you can buy somewhere ... when its good you just get on with it you're organised ....then on bad days you sit there thinking why do I have to do this, why can't we just be normal?" (1M).*

Parents would obviously rather their child did not have an eating problem and some day's felt upset about this. The feelings exposed appeared to be one of resigned acceptance of the difficulties.

*“I suppose I feel cheated when I hear other mothers say that their children eat them out of house and home, and mine don't. I say, oh you must be joking it doesn't happen in my house and they can't sort of believe it really” (4M).*

While both ‘eating disorders’ impact on parents they do so with a different intensity. Anorexia nervosa was experienced as pervading and overwhelming, while selective eating was a frustrating addition to the hassles of everyday life. To this degree learning to manage the respective eating problems necessitates different approaches.

### **Managing The Eating Disorder And Its Impact**

‘Managing the eating disorder’ was of paramount important to all parents. The majority of the themes presented in this section are common across both sets of parents; any subtleties that emerged between the two sets of parents are described within each theme. Again, themes unique to each set of parents are presented separately (see Table 3 for the themes for each group).

The themes are presented in three sections: parents’ attempts to manage the eating problem; their attempts to manage personally (unique to the parents of children with anorexia nervosa); and parents’ experiences of treatment and services.

Attempts To Manage The Eating Disorder

You can lead a horse to water ...

All parents described in detail their attempts to manage the eating disorder. For the parents of children with anorexia nervosa this generally centred on trying to encourage their children to gain weight through eating more, reducing exercise and/or preventing vomiting. The attempts of parents of children with selective eating focused on encouraging their children to try new foods outside of their restricted range. While the two sets of parents had different goals in mind, their general experience appeared to be the same. Fundamentally all parents reported that despite their very best efforts, they could not influence their child's behaviour. As one parent put it "you can lead a horse to water but you can't make it drink", this seemed to capture the feelings of most parents.

*"I tried like mad to say 'look darling you know you've got to try and make an effort to increase, to eat more, because you're losing weight on a weekly basis and if this carries on you're going to go to hospital'. And I mean I just couldn't make her eat a spoonful more, there was no way!" (11M).*

*"It's so frustrating, you can't force her to eat. You can put food in front of her, you can ask her what she wants but at the end of the day if she doesn't eat, she doesn't eat... I just have to accept that she's not going to eat but it's very, very difficult to watch your own child starve in front of you" (5M).*

*"I mean it comes down to at the end of the day what else can you say, what else can you try to do .. if he won't eat it you can't force them" (4M).*

Parents reported trying every possible tactic they could think of to get through to their child. Although parents tried incredibly hard, often they felt their child's lack

of motivation to change got in the way. Many parents of children with anorexia noted that the 'dreadful monster' appeared to recruit the child into sabotaging their every move.

The parents of children with selective eating often felt that their children were unmotivated to change, thus making their task almost impossible. Both sets of parents described this experience as extremely frustrating.

*"I think in the early stages it was very frustrating .....because I knew that he should be eating and trying other things. Even if he tried them and then said he didn't like them, he should have at least tried them" (2m).*

*"It's the sort of illness that try as hard as you want to make them co-operate, it's, ....as though I'm trying to get her better and some days she's not trying to get better and it's incredibly frustrating" (5M).*

However, for the parents of children with anorexia the experience was also incredibly frightening. Not being able to get their child to eat meant they were also faced with the risk of losing their child through starvation.

It was apparent that frustration gave way to a sense of desperation when the very best efforts of parents were unsuccessful. Many were left not knowing what else to try or do. This often prompted parents to seek the advice of others.

*"Basically it was not knowing how to reverse the situation that we were in" (9M).*

*"We really are at a loss as to, hence really why we want to come up here to talk to people who we figure might have more experience than ourselves" (1F).*

Many parents reported receiving advice from family, friends or non-specialist health care professionals on how to manage their child's behaviour. Often advice was conflicting and parents remained confused as to the best course of action.

*"If you go and ask a dozen people, what should I do? You'll have a dozen different answers, and I just wanted to have it in my head, right, from the outset" (11F).*

*"It's hard really, you've got a lot of other parents around ...and 'oh you just feed them you, show them, you do this and you do that'. Then you've got the other side going 'oh just leave it and it will sort itself out' and you don't really know who to listen to and who to take no notice of" (1M).*

Several parents of children with anorexia nervosa commented that if their child had been suffering from a physical illness, as opposed to a mental illness, they would have had a better sense of the best course of action. For many parents their child's eating disorder was their first encounter with a mental illness and thus, they did not feel confident in knowing what to do.

*" I think had it been a physical illness I could have forced her to take her anti-biotic or chemotherapy or whatever it was. I could have seen an end to it, or seen that we were trying." (5M).*

*"I mean any illness if you've got a child is awful, but this has been hard because, it's been more difficult for me to help her than if she'd had bronchitis or something. I could go to the doctor, antibiotics, wrap her up and give her nice hot drinks etc. You can do a lot of positive things but with this, you don't feel that you can help in the same way" (9M).*

The not knowing what else to do or try to help their child with the eating disorder often accelerated parents' efforts to approach specialist services. They hoped to gain advice from people who "know better".

### Adapting – Taking control

All parents of children with anorexia nervosa ‘adapted’ in an attempt to manage the eating disorder. Despite often feeling that they are not able to make a difference to their child’s battle, parents are clearly vital to the process of recovery. In order to help their children with their eating disorder, parents described investing a large amount of time and effort. Parents reported that commitment, perseverance and determination were also essential tools that they used in the fight against the eating disorder.

*“I think... it’s just the biggest battle of any battle that you’ve ever been in and you have to adjust your weapons against the battle according to the thing of the day ...it takes time, ...you just have to be supportive of your child throughout what is going to happen” (7m).*

*“You’ve just got to be very committed in supporting your child through it and in supplementing what you as the professionals are treating him or her with ... It does require a lot of attention, perseverance and determination on the parents part” (8F).*

*“What is helpful with her is patience, understanding and time” (11F).*

In a sense the frustration and recognition that they cannot solve the problem through ‘good’ parenting alone prompted parents to adopt and seek specialist advice. In this way parents gathered their resources from where ever they could and all turned to professionals for help.

*“I think you have to put all your resources into being stronger and bigger than the illness ... and you just gather your help from where ever you can get it be it the hospital, friends, family or strangers, accept help where it comes” (7M).*

Fundamentally, parents of children with anorexia nervosa felt the most important adaptation they made was to 'take control'. This involved taking back the control of their child's life from the eating disorder that had been ruling it. For many parents the importance of taking control was fully realised once they had made contact with specialist services. In fact, acquiring services appeared to be the first step in the process. Parents reported several key features to 'taking control'. Primarily they had to learn to be strong and stand firm against the eating disorder. 'Taking control' also required all the adults involved in the child's life to present a consistent united front. Whether this be both parents agreeing on a mealtime strategy, or parents agreeing with the approach of the medical team caring for their child, there needs to be agreement. Without this, parents felt the eating disorder was able to re-assert itself and take control again.

*"Every thing has been controlled by this person with the eating disorder .. and somehow I think you've got to maintain the power, you're got to be more powerful than the person with the eating disorder .. without being fierce with your power, it has to be a saintly power and the power must be used with care and consideration" (7M).*

*"Be together, stick together, support each other and be united in your approach on how you tackle it, you know before you sit down and have the meal with the child .. work out your game plan between yourselves ....so that you are united, because the moment the child or the anorexic voice sees a chink between the two of you, they will drive the wedge between you ...The anorexic voice and the child wants to split or get between the two of you because they can deal with you on a one to one, ... we have been that united and we weren't under any circumstances going to let that anorexic voice or [the child's] behaviour split us (11F).*

*"As a medic you are in some ways acting like parents, ...you need to be in co-hoots with the parents and know where you all stand ...If you couldn't agree then maybe there was something that you could do that would take you to some other place where you could agree .... because more than anything I think the child needs to feel that somebody is in control here, they're battling with this out of control thing and they need to feel there is control somewhere" (7M).*

Initially 'taking control' was not easy and the children put up a fight, particularly at mealtimes. Many children also resisted attempts to go for treatment, parents knew this was vital to their recovery and so 'took control' by taking them against their will.

*"On a weekly basis we used to go and see [the consultant psychologist] and drag [the child] kicking and screaming along the corridor ... I felt we had to continue with that because if we didn't take her then she was controlling every situation even more" (11M).*

However, once the initial resistance has passed some parents noticed that their children appeared to be relieved that the adults were now in control.

*"I think probably it was good for her to know that somebody else was in control and I think she found it easier once it was taken out of her hands" (8M).*

As part of 'taking control', many parents became highly organised and structured. They set meal times at which they used time limits and set amounts that needed to be eaten by the child. This appeared to help parents maintain in control.

*"Well we don't skip meals ever! ... Its quite difficult in the holidays as well so ...I think she responds well to routine so that for example over Christmas when the routine was broken that probably did cause more problems" (5M).*

Parents reported that 'taking control' is a delicate process, particularly if the child is an adolescent. Parents recognised that adolescence is a time when they should be giving their child more freedom and thus relinquish some of their responsibilities. It therefore felt incongruous to be taking more control of the child's life, so a balance had to be found. Several parents described feeling worried about how to negotiate

giving back control and responsibility to the child. Essentially parents felt they couldn't be in control forever, at some point the child would need to take charge.

*"I suppose she's got to take responsibility sometime hasn't she, she's got to say you know I know what will happen if I don't eat ... I can't always be there" (11M).*

Despite the difficulties that parents could encounter during the process of 'taking control', they felt they had no choice but to deal with it head on. After all to give up would mean to risk losing their child to an eating disorder that could destroy them.

*"There's no choice, it's the no choice thing really .... I think it's exactly about being a parent... You can never negate your responsibilities what ever age they are ... and that's the price you pay and the child has the right to expect it" (7M).*

*"Well you can't give in can you? It's your daughters health and livelihood. You know it's high stakes, I mean ...you'd do anything to get them back" (11M).*

'Taking control' is almost an inflection point in the whole 'battle' with the disease.

### **Adapting and accepting**

The parents of children with selective eating also 'adapted' to their child's problem. However, in contrast to the parents of children with anorexia nervosa acceptance of the problem seemed to be a central part of the process of adapting. Acceptance appears to develop out of the problem being so prolonged that it is seen as part of the child. Unlike the parents of children with anorexia, parents do not face the same pressure to challenge the eating disorder, as their child's life is not threatened.

*"I think it's gone on for so long that it's nothing new, you don't know what your family would be like without it really ...you just accept things" (4M).*

Many parents described going through 'phases' of adapting to and accepting the problem. Generally parents provided their children with the foods within their range and did not prompt them to try anything new. However, occasionally parents were spurred into feeling that something needed to be done about the eating problem. Parents would then begin to encourage their children to try new foods. Entry into this phase was usually triggered by a concern relating to the eating problem.

*"I went through phases and I thought well I'll ignore it, and then I thought well no I've got to do something and then we would sort of try and encourage him. I mean we've bribed him, we've done all sorts of things,.. he still wouldn't do it" (4M).*

Allowing the children to eat their preferred foods made life easier all round. Parents felt they had 'tried every trick in the book' to encourage their children to broaden their range but to no avail. Often when parents had stood firm and tried to get their child to try a new food it either ended in a battle that they lost, or the child became very distressed. As a result parents felt it was easier not to push the matter. This was the acceptance characterising the parents of children with selective eating.

*"I suppose we had more or less resigned ourselves to it's better not to have those emotional situations, therefore give up on expanding the diet" (3F).*

*"What is the point of getting cross with him because now if I got cross with him, now he'd just feel ten times worse ... you can't make him eat it so ..I would say just grin and bear it! You can't do much else!" (2F).*

*"I suppose we haven't made a big fuss about it because a) we knew it didn't help and b) I was always afraid of making things worse" (3F).*

Parents ensured that they always had their child's preferred food on hand at home. Outside of the home parents became highly organised to cope with the child's selective diet. This often meant planning in advance to ensure that they could purchase foods that the child would like, or where it was not possible, they took something with them.

*"When its good you just get on with it, you're organised, you get ready in the morning you take your can of pasta just in case you never know, and then on bad days you sit there thinking why do I have to do this, why can't we just be normal? ... More often than not when everything else is going along fine then you wash over it" (1M).*

Although the planning and organisation required some effort on the part of parents, mainly mothers, it was generally not regarded as personally demanding rather as an inconvenience they would rather not have.

### **Managing Personally**

Caring for a child with an eating disorder can be a personally demanding experience for parents. Several themes emerged that related to parents' attempts to manage personally throughout their child's illness. The theme 'sharing experiences' applied to both sets of parents.

### **Sharing experiences**

'Sharing experiences' refer to those experiences where parents had the chance to 'connect' with other parents who had a child with similar eating disorder. These typically included: being introduced by mutual friends to other parents and attending

a 'parents group' at a specialist eating disorder service. It also included reading books with illustrations of other parents' experiences which, seemed to serve as a kind of indirect contact with others in a similar situation. Not all parents had the opportunity to engage in 'sharing experiences' but those who had them generally found them invaluable.

*"I think that you know you get huge comfort from the fact that you know people who have been there, who have come through it and that there is light at the end of the tunnel. ... I've taken great comfort from knowing people that have been in a similar situation or you know who I could ring" (11M).*

*"When actually we went down hill we could say ... oh we met so and so's mum who survived that and she can smile about it now and talk about it, so that's a really positive thing, ... It's really nice to think well yeah she's been there they've survived it, they came out of it, they are still battling but there's hope for us, so I found that very, very helpful" (5M).*

Those parents who had not had the opportunity to talk to other parents in similar situations were generally eager to do so.

*"I think it certainly would be helpful .... knowing what's going to happen, knowing what to expect, and when it comes to meet us we know not to do this, or not to do that, or we should do such and such" (10F).*

*"I don't talk about it to anybody because ....I don't think anybody really understand unless they've had somebody go through this. It would be nice to talk to other parents and people that have experienced it and come through it" (6M).*

Parents described a variety of ways in which 'sharing experiences' were useful. On the whole the experiences of those who had talked to other parents in a similar situation tallied with the hopes and expectations of those who had not. This included viewing the encounters as an opportunity for understanding, support and reassurance from others 'who know what it's really like'. A chance to discover solutions, such as

ideas for how to deal with the eating problem, what to expect from the course of the illness, and seeing how other people come through it. For these experiences to be optimal parents suggested the need for contact with parents of a child with the same eating disorder. Furthermore, they felt that these encounters needed to offer hope rather than “stories of failure”. Parents generally assumed that ‘sharing experiences’ “would spur them on”.

There was some suggestion from parents that greater opportunities for parents to access ‘sharing experiences’ would be desirable. Several ideas were suggested including a national register which people could use to contact parents locally and/or access to a specialist ‘chat room’ via the Internet.

*“I know you read stories of examples in the book, ... it would be nice to I suppose be able to, I don’t know you could even have one of these chat rooms on the computer or something, where you could just sort of find out or to hear of somebody who is identical almost to [your child’s] problems and hear how they came through it” (4M).*

*“It’s a pity ... there’s no sort of network, local network where somebody who’s got a child with problem could contact you because I feel it’s such a wide national problem nowadays that a register would be actually quite useful...If you felt you were happy to talk to another parent about it, I mean we were fortunate in having [a friend] to talk to but there can’t be many people who share that good fortune and I feel it is such an enormous help to have somebody who has been through it and come out at the other end” (8F).*

Both sets of parents seemed to view opportunities to meet with other parents who had a child with similar eating disorder as experiences that helped them managing personally. For parents of children with anorexia nervosa two further themes emerged that related to parents’ attempts to manage personally throughout their child’s illness. Neither of these themes applied to the parents of children with selective eating.

### **Support and understanding**

Dealing with a child with anorexia nervosa is extremely demanding on parents personally. In order to survive the experience parents felt they needed ‘support and understanding’. Parents obtained this from a variety of different sources. On the whole, parents with partners found their partners a tremendous support. Often, although not always, parents felt that supporting each other drew them closer together. Parents also described receiving support from family and friends, while others cited services.

*“We had to support each other ...It would be awful I think doing it on your own, I feel sorry for a single parent having to battle away with this because you need the support of each other” (8M).*

*“I think if I wasn’t married then that would be very, very hard if you didn’t have a partner, because it’s quite good sometimes to say I’ve got to go out for an hour, or to have someone else to say what can we do? What do you think? Particularly when we had to admit her to hospital it was really, really awful and I think if I’d have been on my own and the responsibility had just been mine that would have been much harder” (5M).*

While all parents recognised the desirability of receiving ‘support’, some reported that it was not always easy to find. This particularly applied to single parents.

*“What I found at [the hospital] is people kept saying to me you need more support. Where? I’m a single parent, working full time, where am I going to find it, my family failed to come up with the goods, my friends failed to come up with the goods, and funnily enough it was people who I’d never met or hardly knew who came forward” (7M).*

The accounts of parents suggest that ‘support’ did not necessarily go hand in hand with ‘understanding’, although in an ideal world it would. Many parents reported

that while friends and family offered support, be it practical or emotional, they did not always 'understand'.

*"We had tremendous support from family and close friends but I don't think they could really comprehend what it was all about, I mean they couldn't understand it ...but I think it was the concern and support of friends and relations generally which gave one strength" (8F).*

*"My parents are quite close and I think they still don't really understand quite what's the matter with [the child]. Although they've been very supportive it's really difficult to say you know she has to have her meals and she has to have her snacks and they'll say 'oh let her go swimming', I'll say 'oh no, no she can't swim', 'oh poor thing'... my parents have been brilliant but they don't understand at all" (5M)*

There was a sense that if people understood more about the eating disorder, parents would feel even more supported.

### **Time out**

The majority of parents reported that when you are caring for a child with anorexia nervosa you have to "deal with it hour in and hour out". As a result, parents emphasised the importance of having 'time out' to take a break.

*"I used to go and play tennis .... You could just get away from it all and I think that's probably what you need ... You've got to ...divorce your self sometimes ... and I think maybe we should have got away more often maybe in retrospect ... but on the other hand I don't know, we couldn't have left [the child], so you know its a catch 22 situation really" (8M).*

*"It's very demanding. I feel if I hadn't been working and if I hadn't been able to get out of the house and get away from it I wouldn't have been able to gather strength enough to be able to come ....home and deal with the eating disorder .. and the feeling of achievement. I think if you're not getting anywhere and yet you've got to gather strength to fight this problem you need to find ways of feeling good. If you're not getting encouragement from those around you, the medical professionals, you're going to have to find it in some other way" (7M).*

Time away from the stresses of the eating disorder seemed vital to the well being of parents but was also invaluable in managing the problem. Several parents noted that ‘time out’ was necessary to have ‘thinking space’ and to gather the strength required to deal with the eating disorder. Despite recognising the merits of ‘time out’, practically it was not always easy to achieve. This was particularly the case as parents felt they need to be constantly available for their child. For single parents, who are caring for their child with little other support, it was even harder to arrange. Often the work place became the only possible refuge.

### **Experiences of Treatment and Services**

All parents described their experience of the services and treatments they received in relation to the eating problem.

### **Battling for services**

For many parents the process of acquiring specialist services for their children was not an easy one. In fact, many parents reported that they had to ‘battle’ to obtain services. ‘Battling’ often necessitated that parents stood firm with their general practitioner and ‘demanded’ the services they felt they needed. It frequently involved several visits to the GP in which parents had to demand a referral. Often they were encouraged to try local services first, or told they that no funding was available for specialist treatment. Parents often felt they had to really “push” and described how this was hard to do when you are up against the medical profession.

*“I think that if you are not a very demanding person, and fortunately I am, it can be tremendously difficult” (7M).*

*“It was only because we persisted that we got him in touch with [the specialist hospital] (2M).*

*“If you didn’t go back to the doctor and keep moaning he would never refer us any further, he would just assume that the problem had gone away” (1F).*

As the previous quote shows, many parents reported that without this persistence they may not have been referred to a specialist service and could well have been “fobbed off”. Those who did have to ‘battle’ felt it was their responsibility as a parent to “fight for their child’s corner”.

*“We went to see this doctor at [the child and family centre] and my husband came as well and he said we’re not satisfied we want a second opinion and he said he couldn’t refer us to anybody else because of the funding” (6M).*

*“We did have to fight really quite hard and it was then we started doing quite a lot of homework and said no we want to go to [a specialist hospital] and he said I’m not sure about that and we said well I’m sorry .... We were absolutely insistent ... You suddenly think this is our child and you know you’ve got to pull out all the stops here, well you do if it’s your own child” (8F).*

The next ‘battle’ that parents faced was getting their children treated quickly. The speed of service delivery was an area of great importance to parents.

### **Speed**

The majority of parents reported that ‘speed’ was of the utmost importance when it came to accessing specialist services. Ideally, eating problems would be recognised quickly by parents and then promptly confirmed by primary health care professionals. This would then facilitate a speedy referral to specialist services.

Unfortunately, this was not the experience of most parents. Often ‘slow recognition’ of the eating problem, followed by ‘battling for services’ slowed down the process. This was unfortunate as all parents saw ‘speed’ as advantageous.

*“I would say definitely get to an eating disorder unit as quickly as you could because I really don’t think that you can sort it out on your own, simple as that, don’t hang around...Don’t try and do it yourself, don’t ignore it and get to an eating disorder unit as quickly as you can because with all the best will of the world and all the love you’ve got .. It’s a very tricky one to sort out” (9M).*

*“P: We were glad to be seen so quickly because I just felt as if we couldn’t wait any longer  
I: So that was very important?”*

*P: It was extremely important because I think she’d lost over 2 stone in 2 months and to wait 3 months I just couldn’t bear to think what sort of state she would have been in. I don’t think she would have lasted that long so it was very critical that she saw somebody soon” (9M).*

The majority of parents felt that they could not afford to waste any time in getting their children help. In particular, this was related to most parents feeling unable to manage their child’s problem and/or feeling out of their depth. Therefore most wanted the advice of the specialists. For parents of children with anorexia nervosa reaching specialist services quickly was particularly vital due to the potential fatal consequences of the disease. The majority of parents also believed that the quicker their child began receiving treatment from specialist services, the better their prognosis.

*“Maybe if I could have got her in there when it very first started we might have been able to ..I don’t know, ... but if she’d have got the proper help that she needed at that particular time maybe she wouldn’t have been so bad, you know wouldn’t have gone on so long” (6M).*

*“We should have seen you really 5 years ago to try stopping it at an earlier age” (4F).*

*“ I also think that if it was picked up earlier on the problem can be alleviated a lot more easily with assistance ... bringing him earlier I think it would be less entrenched in his*

*mind, psychologically I don't think he would have had the same difficulties when you're 4 and 5 as he is now, ... Hopefully if it had been improved he wouldn't be facing the social consequences" (2F).*

Many parents reported that the shorter the duration of the eating disorder, the less entrenched it was likely to be. While this view applied to both sets of parents, the parents of children with selective eating also emphasised the younger the child, the easier it was to encourage change. Some parents also reported that the longer the child had the eating disorder the more problems they were likely to have as a result of it. Thus speed of access to specialist services was an obvious priority for parents.

### **Specialist understanding and knowledge**

Parents unanimously reported that it was essential for professionals to have 'specialist understanding and knowledge' of their child's eating problem. There was an overwhelming feeling that "amateurs" could not treat eating disorders. Fundamentally, parents' approached services because they wanted advice on how to cope with an illness they knew very little about. Thus they expected the professionals to have "expertise" that they did not possess.

*"Its helpful going up to [the specialist hospital]. It's good for us we don't think of it as a bind ... It's well worth, you know you need the people that understand and you need the reassurance that the problem is solvable" (9F).*

*"One felt a sense of relief I think that ...she was very much now in .. dare I say in more professional hands .. with a more enlightened .. professional approach, specifically focused on eating disorders....you felt confident that hopefully she would improve from there on in" (8F).*

*"I think [the specialist hospital] have been brilliant. I think [the psychologist] has been great and she's been fantastic especially when she had meetings where [our child] just sat on my lap and turned her head into my shoulder and flatly refused to speak and clearly*

*didn't like [the psychologist]. And [the psychologist] was so good and understanding and knowing that that's all part of the problem" (11F).*

To feel confident in a service, parents needed to know that the professionals had 'specialist understanding and knowledge' that would ensure they acted in the best interests of the child.

Many parents initially had contact with local services, which reinforced their opinion that 'specialist understanding and knowledge' in eating disorders was vital. This was in part because parents' often felt local services did not know enough about the illness. Therefore they lost confidence in their ability to help. Several parents recounted that seeing non-specialists wasted valuable time.

*"She went into the local general hospital ...and she was on complete bed rest for 6 weeks where they did give her high calorie in take ...They gave her the option to chose her food which wasn't ideal and a nurse sat there watching and there was such an assortment of nurses, I mean I was disgusted some nurses at the weekend the agency nurses used to put their feet on her bed while she was eating, read her magazines and call her demented, .... which isn't really the way you treat anorexics" (10M).*

*"I don't think they are experienced enough in that problem, they haven't got an eating disorder unit [locally] and I don't think they know enough about the problem quite honestly .. You know I used to find bits in the newspaper and sometimes cut out and take them with me and they'd say oh thank-you can I keep that. .. They didn't know enough about it, I think it is quite a specialised thing and you've got to really know, go into depth about it and I don't think they know enough" (6M).*

*"Our GP, who is excellent, wasn't specialised enough in eating disorders" (5M).*

Several parents felt they had received unhelpful advice from local, non-specialist services. Essentially when a parent is putting their child's life in the hands of professionals they need to be able to trust what they will do. Most parents felt they were only able to have this confidence when they reached specialist services. Here

they felt they had a better chance of gaining expert ‘advice’ and a ‘solution’ to their problem.

### Solutions and advice

Whilst there is no panacea for eating disorders it is clear parents need guidance and expert help.

*“We were still a bit mystified to be honest, as to what we were supposed to be doing, because you know what’s it’s like when you don’t know what to do, you want someone to say right put your left foot here or whatever!” (9M).*

*“You hope they know the answer, you hope you can listen to advice and get good advice” (7M).*

Parents were keen to be told what they should do to help their child. Often parents had ideas about what they might do but they wanted to check these out. In particular, parents were eager to learn the best way of handling ‘difficult situations’, as they were frequently concerned about making ‘situations worse’. Parents were willing to try what ever was suggested as long as it was in the best interests of the child.

*“Where the solution comes or how it comes I don’t know at the moment but we’ll do ...absolutely anything... I don’t mind where it is, what it is, how much it costs or anything I’ll do whatever’s necessary, you know as long as he feels good about it” (2F).*

*“I mean I wish somebody would come and say well you know if you do this, this, this and this [your child] will eat normally, you know I’d do it! I mean I’d do whatever was suggested if I thought he was going to eat because I know ...he feels very strongly, and it upsets him and I don’t like to think of [my child] ...getting upset about it” (2M).*

However, naturally not all parents received the ‘solutions and advice’ they hoped for. This was not necessarily related to their length of contact with services. Several parents mentioned that they would have preferred more opportunities to meet with professionals without their child present.

*“It was more helpful than anything when we had our meetings without the child because then actually we’d sit down and we’d have a conversation about the problem instead of skirting around, ‘what’s our plan of action this week what’s gone right, what’s gone wrong’ (7M).*

Nevertheless, the majority of parents reported receiving good advice.

*“When things were really bad [the professional] at [the specialist hospital] was wonderful. She was the person that I could ring and say “she’s missed 3 meals, what do you think I should do and that was very, very helpful ... It’s great to have someone else with more experience to ring and say you know what, even if you can’t do anything just for someone to say look you know lots of people have been there before” (5M).*

*“I several times come up against a brick wall and thought well where do we go from here, what do we do now because she’s simply not responding to what I would have thought was common sense... So therefore one needed the guidance from [the specialist hospital], from the experts who have been down this road before, ‘although it seems hard you must persevere because this would be the outcome’. One needed that constant reassurance I think so therefore as a parent you followed it through and then ‘yes they were absolutely right, yes it did work like that’ and then you went over to the next hurdle” (8F).*

The majority of parents felt that they could not have managed without professional help and that it was through this that they were “shown the way”.

### **Summary**

This chapter has presented the themes that emerged from the qualitative analysis of the interview data. It has described experiences of two sets of parents; those with children with anorexia nervosa and those with selective eating. The themes were

presented under three broad domains: understanding the eating disorder; the impact of the eating disorder; and finally, managing the eating disorder and its impact. This account has shown that while there are many similarities between the reports of parents with children with anorexia nervosa and selective eating, key differences also exist.

## **Chapter Four: Discussion**

### **Overview**

This study is based on the interviews of 19 parents of children with either anorexia nervosa or selective eating. The interviews aimed to describe the experience of parents who have a child with an eating disorder. The focal point of interest was parents' views on the impact of having a child with an eating disorder: how it affected them personally, how it affected their daily lives and how it impacted on the family as a whole. The study explored parents' understanding of their child's eating disorder, including their views on the possible causes of their child's illness. Furthermore, it described parents' experience of services and the help they thought they needed in relation to the eating disorder. The interview data were analysed using Interpretative Phenomenological Analysis (IPA; Smith, 1995) and a number of themes were identified. Then were described under three broad domains: understanding the eating disorder, the impact of the eating disorder and managing the eating disorder.

This chapter will summarise the findings of the study and discuss them in relation to the literature presented in the Introduction. Suggestions for further research will also be made. Methodological issues will then be addressed with particular attention given to the limitations of the research carried out and principles of good practice in qualitative research. Finally the potential implications for clinical practice will be explored.

### **Discussion of Findings**

A number of similarities and differences were found between the accounts of parents of children of anorexia nervosa and those with selective eating. Themes relating to 'understanding the eating disorder' were strikingly similar between the two sets of parents. For example, all parents reported 'slow recognition' of the eating problem and described how primary health care professionals often exacerbated this process. These themes will be discussed in relation to media coverage of eating disorders and general practitioners' knowledge about early onset eating disorders. The issues of whether parents could receive better service in the early stages of their child's illness will also be discussed.

Pronounced differences were observed between the groups of parents in their accounts of 'the impact of the eating disorder'. The central issue that arose was the concept of severity. While both types of eating disorders did have an impact on parents and families, they did so with a different intensity. Parents experienced anorexia nervosa as pervading and overwhelming: it was 'a living nightmare'. Conversely, the parents of children with selective eating regarded the problem as a frustrating addition to the hassles of everyday life. A further difference that will be discussed relates to the concerns that the two sets of parents emphasised in relation to their child's health. Parents of children with selective eating focused primarily on the possible long-term consequences for their child's health. In contrast, this issue was not emphasised by the parents of children with anorexia nervosa.

Further variation emerged in terms of the ways in which parents attempted to manage their child's eating problem. Parents of children with selective eating seemed to go through phases of 'adapting to' and 'accepting' the eating problem. Notably, life was easier for these families when they allowed their child to eat what they liked. Conversely, the parents of children with anorexia nervosa felt the most important adaptation they made was to 'take control' of the child's life. The difference in the approach of the two sets of parents will be discussed in relation to the concept of severity.

In spite of the differences that emerged in the accounts of the two sets of parents, the expressed needs of all parents appeared to be very similar. Of paramount importance was the need for 'solutions and advice' from 'specialist' services.

A further consideration rarely covered in previous literature is the experience of fathers. Previous research that has sought to understand the experience of parents has tended to focus solely on the experience of mothers. This has often arisen unintentionally due to difficulties in recruiting fathers into studies. In this study both mothers and fathers were successfully recruited. On close inspection, the accounts of mothers and fathers did not appear to be markedly different. In fact, the experiences they reported appeared very similar. This suggests that the experience of mothers and fathers with children with eating disorders greatly overlap.

### Understanding the eating disorder

'Slow recognition' captured parents' descriptions of realising that their child had a clinical eating disorder. In general, parents linked this 'slow recognition' to their lack of knowledge about eating problems. While it is clear that parents had their child's best interests at heart and were keen to get to the bottom of the changes witnessed in their child, this was difficult to do due to their lack of knowledge about the disorder. This suggests that despite increased media attention focusing on eating disorders, there is no consistent message filtering through to parents. While parents are likely to have been exposed to a variety of features on eating disorders within the media, much of the information presented may not have been perceived as directly applicable to their situation. This may be due to the tendency for features on eating disorders to focus on adults or older adolescent sufferers. Several parents in the study noted that children with eating disorders generally receive less coverage and that the more "peripheral" eating disorders such as selective eating rarely get a mention.

How can parents with little or no knowledge of childhood eating disorders hope to identify the early signs at this stage? Parents generally took their concerns about their child to a primary health care professional (most often their general practitioner). They generally hoped that they would then receive some help or guidance in relation to their child. Unfortunately these professionals often missed the early warning signs too. In fact many parents reported that 'slow recognition' was often exacerbated by the professionals not attributing the child's presentation to

an eating disorder. This was particularly worrying because for some parents the lack of recognition resulted in a delay in receiving appropriate treatment.

Parents' experience of primary health care professionals brings into question whether these professionals are adequately trained in identifying childhood onset eating disorders such as anorexia nervosa and selective eating. Unfortunately, the experience of many parents in this study suggests that they were not. The findings of this study are disappointingly consistent with previous reports that suggest primary health care professionals frequently overlook eating disorders in this younger age group (Bryant-Waugh, 1992; Bryant-Waugh, Lask, Shafron and Fosson, 1992). The current study shows that whilst many parents found that their general practitioner was helpful, their knowledge did not go far enough. In fact, some of the best general practitioners knew they did not have the necessary expertise and quickly referred the child to specialist services.

These findings reiterate the call for better education of primary health care professionals as to the early signs of childhood eating disorders. This is vital because misdiagnosis inevitably leads to a delay in the initiation of appropriate treatment for this group. The study suggests that many primary health care professionals also require fuller information on the availability of specialist services for eating disorders. General practitioners will generally have several options in terms of where to refer a child with an eating disorder (e.g., local Child and Family Psychology/ Psychiatry Services or Specialist/Tier Three services). The expertise of services will vary between trusts and as a result of this some children will need to be referred outside of their region to obtain the most appropriate service. A difficulty

may arise if general practitioners are not aware of the specialist services available outside of their region. This was highlighted in the current study as some parents felt it was only their own initiative, i.e. informing their general practitioner about the specialist service, that precipitated the referral. This suggests there would be great value in producing a document that outlines the availability of specialist eating disorder services across all regions in the country.

Parents in the current study seem to have spent significant amounts of time 'analysing' the eating problem, speculating on the possible reasons why and from where it arose. This process of 'analysing it' is consistent with research suggesting that people tend to search for causal explanations in an attempt to attribute a cause to an illness (Brewin, 1988). This activity seemed particularly important for parents as they hoped it would generate ideas about what to do to help their child.

In the process of 'analysing it', parents viewed their child's eating problem as 'complex' and 'puzzling'. They were not sure about the precise nature of the causes of the illness but generally believed it was the result of a multitude of factors coming together. This viewpoint fits with previous research into the aetiology of eating disorders. Such research has underlined the fact that only multi-factorial accounts can adequately explain the complexity of eating disorders. In line with the views of parents, these models also attempt to integrate a number of factors that may impact on the predisposing, precipitating and perpetuating elements in eating disorders (Wren and Lask, 1993).

The findings from the study complement research that has investigated lay beliefs about eating disorders. An informal survey of mothers (MacDonald, 2000) and investigations into the beliefs of young men and women (Furnham et al 1992, 1997) have found that when considering causes of eating disorders people tend to report a variety of contributory factors that encompass an extensive range. This suggests that both parents and the general public do not hold simplistic views about eating disorders. What remains less clear is how parents form this picture. It is likely that this is achieved through the combination of observing their child and the events in his or her life, consulting professionals in the field and referring to the literature on eating disorders.

The 'complex' and 'puzzling' picture that parents held about their child's eating disorder appeared to leave them feeling somewhat helpless as to what they could do to help. Most parents solved this dilemma by approaching specialist services for advice.

### **The impact of the eating disorder**

#### **The impact on the child**

The two sets of parents gave contrasting accounts about the impact of the eating disorder on their child. These highlight the variance in the severity of the respective eating disorders. The parents of children with anorexia nervosa described dramatic negative changes that appeared to turn their child into a 'dreadful monster'. In contrast, the parents of children with selective eating primarily described their

children as generally 'normal apart from their eating'. Both these accounts echoed descriptions given in prior research.

For example, the concept of 'dreadful monster', reported by the parents of children with anorexia nervosa, parallels descriptions that have been outlined by other authors (Bryant-Waugh & Lask, 1995; Lask, 2000). The accounts of parents clearly demonstrate that the changes they witnessed in their child were extremely distressing. Fundamentally this was because parents felt that they had completely lost their child to the eating disorder. This suggests that it may be helpful for clinicians to reassure parents that these changes are typical in children with anorexia nervosa. They could be made aware that the child is unlikely to be permanently altered, as most children do eventually return to their pre-morbid personality on recovery from the illness.

Parents of children with anorexia nervosa are likely to feel distressed as a result of a number of negative changes witnessed in their child from the onset of its illness through to recovery. Bryant-Waugh and Lask (1995) describe one stage that they highlight as particularly difficult for parents. The authors explain that many children with anorexia nervosa go through a phase of intense negativism, characterised by rudeness, assertiveness, oppositional behaviour and sullenness. These changes typically occur along side the relinquishment of the anorexia nervosa, i.e. the child starts to accept a more normal diet and begins to gain weight. They suggest that the parents typically find this stage of the disease difficult as the negativism is most often be directed at them (Bryant-Waugh & Lask, 1995; Lask, 2000). Whilst

appreciating this, Bryant-Waugh and Lask welcome this phase as children who successfully pass through this stage seem to have the best chance of recovery.

The findings of this study seem to support those of Bryant-Waugh and Lask in terms of the behavioural patterns that are observed in children with anorexia nervosa and the distress experienced by parents at this stage. This suggests that it may be helpful for clinicians to reassure parents that while this stage can be emotionally draining and horrific for them, it is thought to be vital to their child's recovery. Clinicians could further remind parents that it is a 'stage' that children with anorexia pass through. Bryant-Waugh and Lask note that the phase passes as children begin to get better and move on to find more acceptable ways of expressing their feelings. Parents in this study also reported that thankfully, their child's premorbid personality eventually surfaced again as they improved.

Both sets of parents expressed concern about the extent to which their children appeared to be 'missing out' due to the eating disorder. Parents were keen to prevent their children from being disadvantaged in any way by the illness. Concerns about the impact of the eating disorder on the child's health were particularly prevalent amongst parents. Interestingly, parents of children with anorexia nervosa rarely mentioned the long-term health issues or concerns that can be associated with anorexia such as osteoporosis, infertility and delayed growth (Nichols, de Bruyn and Gordon, 2000). In contrast, the possible long-term effects of selective eating on health were highly debated by parents of children with selective eating. The reason for this difference is unclear. One possibility is that the parents of children with anorexia nervosa were more focused on the issue of immediate survival. It could be

that this concern overshadowed the long-term risks or somehow made them pale into insignificance when facing the prospect of losing the child.

Similar reactions have been observed in other areas. For example, clinical experience suggests that some parents of children with life threatening illnesses, such as cancer, tend not to worry about the long-term complications of either the cancer and/or the treatments that the child needs to save its life. These complications tend to be contemplated once the child has recovered or is out of immediate danger. It is possible that a similar process could be at play in the parents of children with anorexia nervosa. This difference between the accounts of the two sets of parents appears to give support to the notion that the severity of an eating disorder is highly influential in the extent to which it impacts on the lives of parents. It clearly affected how parents thought about their child's illness; furthermore, it determined the degree to which it impacted on their everyday life.

#### The impact on everyday life

The impact of the eating disorder on everyday life varied significantly between the two sets of parents. Once again this difference seemed to be the result of anorexia nervosa representing a more severe and all encompassing illness in comparison to selective eating.

The lives of parents of children with anorexia nervosa were severely disrupted. Everyone in the family was affected as normal family 'life stopped'. Parents were forced to make many changes to their lives in order to cope with the eating problem.

This experience seemed akin to the effects seen when a child has a major physical illness (Eiser, 1993; Sabbeth, 1984). In addition there appeared to be some unique aspects that were related to the illness being a psychological problem. In particular, parents felt they faced the stigma that is often associated with mental illness. There was a sense that if their child had been suffering from a major physical illness people would have been more sympathetic to their plight.

Conversely, the descriptions of daily life for the parents of children with selective eating generally indicated that 'life goes on' despite the problem. While the parents reported that the eating disorder did have an impact on their lives, they emphasised that it was not a significant one. In general, life was easy if parents could provide their child with the foods that were in their preferred range; they sometimes ran into difficulties when eating outside of the home.

#### The impact on the parent

The personal impact of having a child with an eating disorder also varied significantly between the two sets of parents. This difference seemed to relate to the following points. Firstly, anorexia nervosa can be life threatening and rates of mortality are relatively high, whereas selective eating is rarely associated with immediate health risks. The two sets of parents were therefore faced with very different situations. Secondly, while both types of eating disorder impacted on the everyday lives of parents, they did so with a different intensity. Parents experienced anorexia nervosa as pervading and overwhelming, like 'a living nightmare'. This

experience echoes the little previous research available on the experience of parents (Macdonald, 2000).

In contrast to the experience of parents of children with anorexia nervosa, the parents of children with selective eating regarded the problem as a frustrating addition to the hassles of everyday life. There is very little research on the experience of these parents and previous reports have tended to be case note reviews. These have highlighted that mothers' report feeling anxious about their child's eating problem (Nicholls, et al 2001; Timimi et al 1997). While the current study supports this, it reveals that despite their concerns parents do manage to carry on with normal life.

The difference in severity between the eating problems has resounding implications for the support that parents need. In particular, it highlights that parents of children with anorexia nervosa often need additional support to cope with caring for their child. This will be discussed in greater detail under the section 'managing personally'. The effect of the differences in the severity of the two eating disorders also reverberates through the attempts parents made to manage their child's eating problem.

## Managing the eating disorder and its impact

### Attempts to manage the eating disorder

All parents described in detail their attempts to manage the eating disorder. Unsurprisingly, despite their very best efforts all parents found it very difficult to influence their child's behaviour. This was extremely frustrating for parents and left them not knowing what else to do.

The measures that parents took in their attempts to manage the eating disorder varied, depending on the type of eating disorder. Parents of children with selective eating generally 'accepted' the problem and 'adapted' accordingly. In contrast, the parents of children with anorexia nervosa felt the most important adaptation they made was to 'take control'. This involved taking back the control of their child's life from the eating disorder that had been ruling it. This observed difference is likely to have been influenced by several factors. First and foremost of these is the severity of the respective eating disorders: anorexia nervosa is a serious illness that can be life threatening.

Thus the parents of children with anorexia nervosa were left with little choice but to try to 'take control' of their child's illness. The alternative was to risk losing their child. In contrast, while selective eating did impact upon the psychosocial functioning of the child it was not life threatening. This allowed parents a greater degree of choice. This is highlighted in the parents' descriptions of going through 'phases' of attempts to manage the problem. Sometimes allowing the child to be

selective in their eating and then feeling compelled to encourage the child to confront their eating problem. This was not a realistic choice open to the parents of children with anorexia nervosa.

A further factor that is likely to have influenced parents' management strategies is the available professional advice on treatments for childhood eating disorders. Prior research in the area has underlined the fact that 'taking control' is often the key to success in treating childhood onset anorexia nervosa. It is, therefore, the approach that is recommended to parents of children with anorexia nervosa. Indeed, Lask (2000) emphasises that the focus of work with parents should be helping them 'take charge'. He highlights that this is not easy to do and that parents will often need help to reach agreement on how to manage this. Parents in this study did in fact report that 'taking control' was difficult and that they valued professional advice to assist them in this process. Interestingly, parents also reported struggling with how to give control back to their child. This suggests a further area where parents would welcome professional guidance.

While 'taking control' is clearly advised in the treatment of children with anorexia nervosa, it does not appear to be recommended in cases of selective eating. Research that outlines interventions for children with selective eating does not detail the role of the parent in any great detail (e.g. Nicholls et al, 2001; Christie, 2000). The recommended focus of treatment is individual therapy, utilising cognitive-behavioural techniques to help children develop their own plan for change. Thus it appears to encourage the child to 'take control' in comparison to treatments for anorexia nervosa where it is recommended that parents take charge. However, it is

likely that few clinicians would recommend treating a child without some form of parental involvement. Certainly the parents of children with selective eating in this study were keen to be involved. In particular, they wanted the professionals treating their child to offer them guidance and advice on how they could best support their child through the process.

### Managing personally

Caring for a child with an eating disorder can be a personally demanding experience for parents. In the current study, parents were frequently trying to juggle their everyday responsibilities with their child's eating problem. On top of this many parents, particularly those with children with anorexia nervosa, also had to deal with their own emotional responses to their child's illness. Several themes emerged that relate to parents' attempts to manage personally throughout their child's illness.

One central theme, 'sharing experiences', applied to both sets of parents. Parents' clearly valued opportunities to 'connect' with other parents who had a child with a similar eating disorder. This seemed very important in helping parents to manage personally: such experiences provided understanding, ideas for managing and, most importantly, hope. The question that remains is how can services help foster these experiences for parents? Clearly offering parental support groups is one strategy. Parents in this study made it clear that such provision would be welcome, particularly on a local level. This might include services compiling a database of local support groups or parents who would be happy to be contacted or consulted.

In recent years much more information has become available for parents, which should serve as a further support. For example, the Eating Disorders Association (EDA) is a particularly good resource. It offers a telephone help-line, produces leaflets and provides information on self-help networks. There is also an ever-growing literature on eating disorders. In fact, a book has now been published that is written specifically for parents of children with eating disorders (Bryant-Waugh and Lask, 1999). Finally, this year marks the hosting of the 'second international conference for carers of people with eating disorders', which is being held in London. While it seems the message has got through to professionals that parents want more information and support, the challenge remains: how can we ensure that this filters through and parents have access to these resources? Often these resources are easily accessed once parents have made contact with specialist services. However, it is often before this point that parents may feel most in need of it. In an ideal world, organisations like the EDA would gain greater coverage within the media and be as well known as AA or Childline.

For parents of children with anorexia nervosa, two further themes emerged that relate to parents' attempts to manage personally throughout their child's illness. Parents of children with anorexia nervosa described the importance of 'support and understanding' and opportunities for 'time out' from caring for their child. (It should be noted that neither of these themes applied to the parents of children with selective eating; again this is probably due to the less severe nature of selective eating).

Parents were clear that these were personally helpful to them in their efforts to care for their child. Whilst there is little doubt these were invaluable to parents, they were

not always available or easy to achieve. As professionals we surely have a duty to assist parents in accessing resources that will help them feel more able to support their child. How we can best achieve this within the constraints of the current health care system remains a challenge. Services may not have the facilities or resources to provide everything parents need. The best we may be able to do is recommend other agencies or organisations that might be able to offer further help to parents, for example, social services for extra practical help, or voluntary organisations such as the EDA that parents could utilise to explore other avenues.

### Experiences of treatment and services

Parents viewed ‘specialist knowledge and understanding’ in professionals as vital to a successful outcome in the treatment of their child’s eating problem. The accounts of all participants in this study sent the clear message that parents need access to this kind of help as quickly as possible. There can be little doubt that we must endeavour to speed up access to specialist professional help and support parents in ways that they find most helpful. Parents should not have to ‘battle’ for the services their child needs. Neither should they have to wait unnecessarily for this, particularly as it is clear that ‘speed’ is of essence when it comes to accessing services. Sadly, many parents in this study reported that getting to specialist services did feel like a battle that took too long. This echoes the views of parents in an informal survey conducted a decade ago (Bryant-Waugh, 1992) which suggests that things have not moved on significantly since then. The question that must be asked is why? It is unclear whether this is a reflection of inadequate training amongst primary health care professionals, or information not filtering through to the grass roots level, or over

stretched services. Certainly, this longstanding issue requires further investigation if we are to ensure that children with eating disorders receive appropriate services.

The accounts of parents highlight their eagerness to be involved in their child's treatment with specialist services. All parents felt responsible for their child's well being and as a result were keen to be 'shown the way' when it came to managing their child's eating problem. This fits with current research that suggests a positive outcome associated with involving parents in treatment. In fact, it calls for a strong focus on helping parents manage their child's symptomatic behaviour, with the clinician helping to mobilise the family's resources to help themselves. Within the literature it remains unclear as to what format parental involvement should take. Le Grange et al (1992) suggest that parental involvement is indeed essential in interventions with early onset anorexia nervosa, but that intervening with the whole family present may not always be necessary. In fact, this does fit with the feelings of many parents who reported they would prefer to have some time alone with clinicians without their child present. They hoped this would provide an opportunity for them to explore not only their own feelings, but also provide a forum for discussing in detail how they could best help and manage their child's eating problem.

## **Methodological Issues**

### **Methodological limitations**

The findings of this study should be considered in the context of a number of methodological limitations.

#### **The representativeness of the sample**

The provision of basic descriptive data about the participants of a study allows the reader to evaluate the representativeness of the sample, that is, the range of persons and situations that the findings might be relevant to. It is particularly important to consider this when addressing the meaning, and the clinical implications, of the findings.

One strength of the study is that the sample consisted of both mothers and fathers of children with either anorexia nervosa or selective eating. The children represented a range in terms of the duration of their eating disorder and the length of their contact with specialist services. All children were outpatients at the time of study, although several parents of children with anorexia nervosa reported their child had in the past been hospitalised due to the eating disorder. This range of contact with services, along with the broad nature of the questions asked in the interviews, resulted in a very global picture of the experience of parents with a child with an eating disorder. The interviews varied in depth and content, which suggests that a range of

perspectives was included. However, despite this, the issue of sampling bias needs to be considered.

Sampling bias may have occurred due to the sample being self-selected. Only half of the total number of the parents contacted agreed to take part in the study. It is likely that those parents who agreed to participate may have differed in some way from those parents who did not take part. There is very little information available on the non-participants, so one can only speculate on the possible biases in the sample. Those that did participate were likely to have felt more able to explore their experience of being the parent of a child with an eating disorder in a research interview context. Those parents who declined to participate may have been less satisfied or less well functioning, and therefore may have perceived the study as more threatening. They may also have been less committed to their child's treatment programme, or may have been feeling more stressed or distressed.

The parents who participated in the study were all Caucasian and were predominantly in professional/semi-skilled occupations. This is despite indications that children with eating disorders come from a range of social and cultural backgrounds. It is not clear whether parents of different ethnic or social backgrounds might have different experiences to those reported by the parents in this study.

Finally all parents in this study were in contact with a specialist service, in particular a London teaching hospital. These parents may have children with more severe problems, or the parents themselves may have been more persistent in gaining access to a specialist service. The sample therefore may not be representative of the

broader population of parents, some of whom are not in contact with services. Additionally, the findings of the study may not be generalisable to parents of children with eating disorders other than anorexia nervosa or selective eating. It is clear that further research is needed on the experience of parents who have children with other eating disorders.

### Social desirability

A second issue to consider is that of social desirability, or the tendency for participants to produce accounts that they think are expected of them. Several attempts were made to reduce the effect of social desirability in this study. First and foremost, at the start of all interviews the researcher stressed to parents that the focus of the study was to hear their own story, therefore there were no 'right' or 'wrong' answers. It was made clear to participants that the research was separate from 'treatment' and that the researcher was not part of the clinical team. Intentionally, the aim was to relieve any pressure participants might have felt to produce positive views. Parents were also reassured that their accounts would remain anonymous and confidential. Participants did give a range of different accounts, suggesting that they felt able to freely express their views. However, it is difficult to entirely rule out the possible effect of social desirability.

### Design

The small sample size of this study did not allow for the investigation of some potentially interesting variables. For example, it would have been interesting to

compare the experience of parents at different stages in their child's eating disorder. The accounts of parents did suggest that their experience was to a degree mediated by the severity of their child's symptoms. Thus further investigation this area may give us a clearer indication of how we can best meet their needs at these various points of treatment. A larger sample and, ideally, longitudinal research would be needed to specifically address these questions.

### **Principles of good practice in qualitative research**

There are now a number of recently published guidelines that provide a description of 'good practice' in qualitative research (see Smith, 1996; Turpin, et al, 1997; Elliott et al, 1999; Reicher, 2000). These recommendations mark an important development in the field by encouraging qualitative research to be evaluated against pertinent criteria rather than "make the mistake of evaluating qualitative research using the standards of quantitative" (Elliott et al, 1999, p. 215).

Elliott et al (1999) presents a detailed set of guidelines that are particularly pertinent to evaluating the 'analysis and interpretation of qualitative data' in a study. The recommendations most relevant to this study are discussed in turn.

Several authors, including Elliott et al (1999) recommend that qualitative researchers provide a description of their personal perspective (Elliott et al, 1999). This is a practice that is also encouraged in research using IPA, the approach used to analyse the interview data in this study. In describing IPA, Smith (1995) suggests that any themes that emerge from the interview data will be a reflection of the dynamic process between the researcher and the participants. An explicit statement

of the researcher's values and assumptions therefore serves to assist the reader in evaluating the interpretations of the data. It also encourages the reader to consider possible alternatives to the researcher's interpretations. In the present study, the researcher's theoretical and clinical background were made explicit in the method chapter, in order to adhere to this guideline for good practice.

'Grounding' the study in examples of the data is highly recommended as a principle of good practice in qualitative research (Elliott et al, 1999). In this study the themes were labelled using the participants' own language rather than abstract categories; they were described and illustrated using specific examples from the interviews. The quotes provide the reader with an illustration of how themes were derived and provide a vital opportunity to evaluate the fit between the data and the researchers understanding of it. Moreover, it allows the reader to speculate on alternative meanings and understandings

There are many other aspects of IPA procedures with Elliott et al's guidelines. For example, both emphasise the need for organising extracted themes into a coherent, integrated structure. In the current study, the themes were organised into three broad organisational domains in an effort to provide a coherent structure. Similarities and differences between the accounts of the two groups of parents were also highlighted throughout the presentation of the results. Efforts were made to present a coherent account but also to preserve the nuances and variations that existed within the data.

In an attempt to check both the credibility of the themes and address researcher bias, several procedures were implemented, as recommended by Elliott et al (1999) and

Smith (1996). Firstly, another experienced qualitative researcher was enlisted to independently examine a number of the transcripts. The researcher was asked to identify themes, and these themes were then compared with those identified by the first researcher. The second researcher's comments were then used to modify the themes. In addition, two other researchers conducted an audit of the "paper trail" (Smith, 1996). This involved checking that a coherent chain of argument ran from the initial raw data to the final list of themes. The aim of this audit was not to reach a consensus between the researchers but to validate one particular interpretation of the data. These procedures were used to safeguard the validity and reliability of the final themes by checking that the themes were a good reflection of the verbatim accounts.

Several attempts have been made to ensure that the reader can also engage in this process of checking credibility. Firstly, in the Results Chapter each theme is illustrated with verbatim quotes from participants. Secondly, a transcript with examples of the associated themes is included in Appendix I. These steps aim to ensure that the method used is transparent (Yardley, 2000). To a degree they allow the reader to follow the route by which the data was processed from the initial stages to the final write up.

An additional credibility check that might have improved the analysis would have been to check the final themes with the participants themselves. This is referred to as testimonial validity (Barker et al, 1998). It aims to check on the interpretation of the researcher by asking participants whether the analysis is an accurate reflection of their experiences. This is a process that is recommended in qualitative research despite the acknowledgement that it is not problem free (Stiles, 1993). Unfortunately

due to the time constraints of this study it was not possible to achieve. However, each participant was sent a summary of the findings of the study. It is hoped that the themes will 'resonate with the reader'(Elliott et al, 1999) and will clarify or expand the reader's understanding of the topic

### **Conclusions and Clinical Implications**

In view of the limitations outlined above, a degree of caution should be exercised in attempting to generalise the findings of this study. This study has described the experience of parents in relation to having a child with an eating disorder. It focuses on the experience of the parents themselves, in contrast to the focus in most of the existing literature, which tends to reflect the perspectives of clinicians and researchers. The qualitative method of the study aimed to provide an open forum for parents to describe their experiences. While many similarities existed between the reports of parents with children with anorexia nervosa and selective eating, key differences also emerged. This variability indicates that some caution should be exercised in making broad conclusions about experiences and needs. However, key themes did appear to emerge which may serve as useful pointers for professionals working with these families. Based on these themes, several recommendations can be made. These have been noted earlier in the discussion of the study's findings, but are summarised below.

Ideally, parents want their child's eating disorder diagnosed promptly by primary health care professionals. Following this a speedy referral to specialist services should then be made. Parents felt these two factors would help ensure that their child

had the best chance of recovering from their eating problem. It seems this ideal would be best met if primary health care professionals were, firstly, better educated as to the early signs of childhood onset eater disorders and, secondly, made aware of the specialist services that can best meet the child's needs.

It was evident from the accounts of parents that information about their child's eating disorder was essential. It is clear that parents do not always know how to access the information that is available. Access to information is frequently facilitated by specialist services that can recommend, guide or hand out to parents what they need. However, accessing such information is more difficult outside of specialist services. Since primary health care services are likely to be the first port of call for parents it would seem sensible for professionals in these services to be able to recommend or have information available. In an ideal world, organisations that might be helpful to parents such as the Eating Disorders Association (EDA) would receive greater coverage in the media. If the EDA was as well known as Childline or AA, many parents might find it easier to access information on eating disorders.

Over and above the need for information, parents want clear guidance and advice from professionals as to how they can best manage and support their child through to recovery. Most parents felt they received this once they reached specialist services. However, many parents reported that regular opportunities to meet with clinicians without their child present would further aid this process.

The majority of parents felt opportunities to meet other parents who have or have had a child with an eating disorder would be invaluable in terms of offering support,

advice and a chance to meet with others who really understand. Facilitating such opportunities, whether this be organising a parents support group or providing a telephone list of parents willing to exchange numbers, could be a simple but vital adjunct to treatment. Helping parents find support for themselves will help them fulfil their responsibility to their child. Moreover, in the most severe cases it can provide parents with hope that there is light at the end of the tunnel. This is particularly pertinent if parents are just beginning to 'battle' the disease.

It is clear that the parents in this study tried to do all they could for their children. It is now up to us as professionals to try to instigate improvements that will help minimise the suffering of such parents and their children.

While the current study has several limitations, the findings add to the existing literature in several ways. Firstly, the findings of this study help to demonstrate the potential contribution of qualitative approaches to the literature on eating disorders. Secondly, they give a voice to the parents themselves, who have often been neglected in eating disorders research. The findings also highlight the similarities and differences that exist in the experience of being the parent of a child with either anorexia nervosa or selective eating. Finally, it is hoped that studies such as this will ultimately contribute to improving services and making the experience of having a child with an eating disorder easier for parents to manage.

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**Appendix A: Ethical Approval**

Great Ormond Street Hospital  
for Children NHS Trust  
and the Institute of Child Health  
(University College London)



14 August 2000

Ms DC Cottee  
Clinical Psychologist in Training  
BSU  
ICH

30 Guilford Street  
London WC1N 1EH  
Telephone: 020 7242 9789  
Direct Fax: 020 7813 8234

Dear Ms Cottee,

**99BS17** Children with eating disorders: parent's perspectives and experiences.

Notification of ethical approval

The above research has been given ethical approval after review by the Great Ormond Street Hospital for Children NHS Trust / Institute of Child Health Research Ethics Committee subject to the following conditions.

1. Your research must commence within twelve months of the date of this letter and ethical approval is given for a period of 13 months from the commencement of the project. If you wish to start the research more than twelve months from the date of this letter or extend the duration of your approval you should seek Chairman's approval.
2. You must seek Chairman's approval for proposed amendments to the research for which this approval has been given. Ethical approval is specific to this project and must not be treated as applicable to research of a similar nature, eg. using the same procedure(s) or medicinal product(s). Each research project is reviewed separately and if there are significant changes to the research protocol, for example in response to a grant giving body's requirements you should seek confirmation of continued ethical approval.
3. Researchers are reminded that REC approval does not imply approval by the GOS Trust. Researchers should confirm with the R&D office that all necessary permissions have been obtained before proceeding.

Research and Development Office

4. It is your responsibility to notify the Committee immediately of any information which would raise questions about the safety and continued conduct of the research.
5. On completion of the research, you must submit a report of your findings to the Research Ethics Committee.
6. Specific conditions pertaining to the approval of this project are:
  - The use of the enclosed standard consent forms for the research. A copy of the signed consent form must be placed in the patient's clinical records and a copy must be kept by you with the research records.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Orlagh Sheils'.

Orlagh Sheils  
Secretary to the Research Ethics Committee

cc: Dr R Bryant-Waugh, Ethics Supervisor

**Appendix B: Letter, Information Sheet and Consent Forms**

**Letter to Parents**

DEPARTMENT OF PSYCHOLOGICAL MEDICINE  
TEL: 020 7829 8679  
FAX: 020 7829 8657

Dear .....

**Re: Children with Eating Disorders: Parents' Perspectives and Experiences.**

The Eating disorders research team at Great Ormond Street Hospital for Children, NHS Trust, is currently conducting research into the understandings and experiences of parents of children with eating disorders. Very little research has been carried out in this area, and it is important that we listen to parents' views and experiences in order to form ideas about how to best support them.

The research we are currently conducting involves two-parts. The first part of the study will require you to each separately complete several short questionnaires. These aim to look at your thoughts about your child, the possible causes of your child's eating disorder and the impact of your child's eating disorder on your relationship with your partner/spouse.

If you also decide to participate in the second part of the study this will involve meeting both of you individually for an interview. During this interview you will be asked to talk about your understanding of your child's eating disorder and your thoughts on the possible causes. We will also ask you about your experience of the impact of having a child with an eating disorder. In essence the interview will be a realisation of your responses on the questionnaires.

The interview will be tape-recorded so that the information can be looked at in more detail afterwards. However, all material will be held in confidence and will only be used for research purposes. The results may be published in a scientific journal, but no individual's identity will be revealed.

You are under no obligation to participate in this research. The research is entirely separate from treatment and refusing to participate will not affect any treatment that your child may

be having now or in the future. Should you agree to participate and then change your mind, you are free to withdraw your consent at any time.

If you have any complaints about the way in which this research has been, or is being conducted, please, in the first instance, discuss them with the researcher. If the problems are not resolved, or you wish to comment in any other way, please contact the Chairman of the Research Ethics Committee, by post via the Research and Development Office, Institute of Child Health, 30 Guilford Street, London, WC1N 1EH, or if urgent, by telephone on 020 242 9789 ext 2620, and the Committee administration will put you in contact with him.

If you are interested in participating in either Part I (Questionnaires) or Part II (Interview) of this study, please complete the enclosed form and return it in the stamped addressed envelope provided. We would like the consent of both parents. If you agree to participate in Part II (Interview) we will then contact you to make an appointment time.

With many thanks,

Yours sincerely,

**Danielle Cottee**  
**Clinical Psychologist in Training**

**Dr Rachel Bryant-Waugh**  
**Consultant Clinical Psychologist**

**Dr Dasha Nicholls**  
**Clinical Lecturer**

## **Information Sheet**

### **'Children with eating disorders: Parents perspectives and experiences'**

#### **Information Sheet for Parents**

##### **The aim of the study?**

The aim of this study is to gain a greater understanding about the perspectives and experiences of parents who have a child with an eating disorder.

##### **Why is this study being done?**

There has been lots of research into eating disorders, but very little research has involved talking directly to the parents of children with eating disorders. We feel that talking to the parents of children with eating disorders is the best way of finding out about their views and experiences. This information is important for helping us think about ways of supporting families who are affected by eating disorders.

##### **How is the study to be done?**

The study we are currently conducting involves two-parts. Participation in the **Part I** of the study would involve both the parents of a child with an eating disorder. It would require you to each separately complete several questionnaires during one of your visits to the Eating Disorders Clinic in the Department of Psychological Medicine, GOSH. These questionnaires aim to look at your thoughts about your child, the possible causes of your child's eating disorder and the impact of having a child with an eating disorder on your relationship with your partner/spouse.

Participation in **Part II** of the study would involve meeting both the parents of a child with an eating disorder for an interview. We would contact you to arrange a convenient time to interview you both individually. During your interview you will be asked to talk about your understanding of your child's eating disorder and your thoughts on the possible causes. We will also ask you about your experience of the impact of having a child with an eating disorder. In essence the interview will be a realisation of your responses on the questionnaires.

The interview will be tape-recorded so that the information can be looked at in more detail afterwards. However, all material will be held in confidence and will only be used for

research purposes. The results may be published in a scientific journal, but no individual's identity will be revealed.

The interview will take place in the Department of Psychological Medicine, Great Ormond Street Hospital for Children, NHS Trust, and would last 1-1 ½ hour/s.

**Are there risks and discomforts?**

There are no particular risks attached to this study, however, we appreciate that thinking about the issues the study will focus on may in itself cause some distress.

**What are the potential benefits?**

While the study will have no immediate benefit to you, there is a strong need to understand the perspectives of parents of children with eating disorders. We do hope that this information will help us inform future interventions with families effected by eating disorders.

**Who will have access to the case/research records?**

Only the researchers and a representative of the Research Ethics Committee will have access to the data collected during this study.

**What are the arrangements for compensation?**

This project has been approved by an independent research ethics committee who believe that it is of minimal risk to you. However, research can carry unforeseen risks and we want you to be informed of your rights in the unlikely event that any harm should occur as a result of taking part in the study.

No special compensation arrangements have been made for this project but you have the right to claim damages in a court of law. This would require you to prove fault on the part of the Hospital and/or any manufacturer involved.

**Do I have to take part in this study?**

You are under no obligation to participate in either part of this study. If you decide, now or at a later stage, that you do not wish to participate in this research project, that is entirely your right, and will not in any way prejudice any present or future treatment at this hospital.

**Who do I speak to if problems arise?**

If you have any complaints about the way in which this research has been, or is being conducted, please, in the first instance, discuss them with the researcher. If the problems are not resolved, or you wish to comment in any other way, please contact the Chairman of the Research Ethics Committee, by post via the Research and Development Office, Institute of Child Health, 30 Guilford Street, London, WC1N 1EH, or if urgent, by telephone on 020 7905 2620, and the Committee administration will put you in contact with him.

**The researcher who will have contact with you is ;** Ms Danielle Cottee. You are welcome to contact her, or alternatively Dr Rachel Bryant-Waugh, Dr Dasha Nicholls or Dr Nancy Pistrang who are all involved in the research, to discuss the study further.

**Details of how to contact the researchers**

You can contact us by ringing the Department of Psychological Medicine on 020 7829 8679, and asking them to put you through to Ms Danielle Cottee, Dr Rachel Bryant- Waugh and Dr Nicholls. Alternatively you can leave a message on extension 5823. If you want to write with your concerns or for further information, please write to Ms Danielle Cottee, Honorary Researcher, Eating Disorders Team, Department of Psychological Medicine, Great Ormond Street Hospital for Children NHS Trust, London WC1N 3JH. Dr Nancy Pistrang can be contacted at the Sub Department of Clinical Health Psychology, University College London, Torrington Place, London WC1E 6BT, telephone number 020 7504 5962.

# Great Ormond Street Hospital for Children NHS Trust and Institute of Child Health Research Ethics Committee

## Consent Form for PARTICIPANTS in Research Studies

**Title:** Children with eating disorders: parent's perspectives and experiences.

### NOTES FOR PARTICIPANTS

1. You have been asked to take part in some research. The person organising that study must explain the project to you before you agree to take part.
2. Please ask the researcher any questions you like about this project, before you decide whether to join in.
3. If you decide, now or at any other time, that you do not wish to be involved in the research project, just tell us and we will stop the research. If you are a patient your treatment will carry on as normal.
4. You will be given an information sheet which describes the research. This information is for you to keep and refer to at any time. *Please read it carefully.*
5. If you have any complaints about the research project, discuss them with the researcher. If the problems are not resolved, or you wish to comment in any other way, please contact the Chairman of the Research Ethics Committee, by post via The Research and Development Office, Institute of Child Health, 30 Guilford Street, London, WC1N 1EH or if urgent, by telephone on 020 7905 2620 and the committee administration will put you in contact with him.

### CONSENT

I \_\_\_\_\_ agree that the Research Project named above has been explained to me to my satisfaction, and I agree to take part in this study.

I have read both the notes written above and the Information Sheet about the project, and understand what the research study involves.

SIGNED

DATE

-----

-----

SIGNED (Researcher)

DATE

-----

-----

**Consent to Release Recordings**

**'Children with eating disorders: parents perspectives and experiences'**

**Consent to release recordings**

The reason we tape record your ideas during our interview is so that we can carefully listen to these in more detail afterwards. When we publish our findings, it is often useful if we can include verbatim extracts of your ideas (with names and other identifying information removed). We will not do this without your consent, which you may withdraw at any time in the future.

We give consent for all or part of the transcript of our interview to be published in scientific journals or books. Yes / No

If you have any questions about anything on this form please ask one of us.

Name of child in treatment: .....

Date of birth of child:.....

Name of parent: .....

Signed: ..... Date: .....

Name of parent: .....

Signed: ..... Date: .....

Danielle Cottee, Clinical Psychologist in Training  
Dr Rachel Bryant-Waugh, Consultant Clinical Psychologist  
Dr Dasha Nicholls, Clinical Lecturer  
Tel: 020 7829 8679

Dr Nancy Pistrang, Senior Lecturer in Clinical Psychology  
Tel: 020 7504 5962

**Appendix C: Letter to GP**

DEPARTMENT OF PSYCHOLOGICAL MEDICINE  
TEL: 020 7829 8679  
FAX: 020 7829 8657

Dear .....

**Re: A study examining ‘Children with Eating Disorders: Parents’ perspectives and experiences’.**

(Child’s Name .....)

(Child’s Date of Birth.....)

(Child’s Address.....)

We are writing to inform you that (name of participants) have agreed to take part in the above study currently being conducted by the Eating Disorders Research Team at Great Ormond Street Hospital for Children, NHS Trust.

This study will involve participants either completing questionnaires or participating in an in-depth interview. These aim to examine parents’ understanding of their child’s eating disorder, their thoughts on its possible causes and the impact of having a child with an eating disorder.

Should you require any further information please do not hesitate to contact us.

Yours sincerely,

**Danielle Cottee**  
**Clinical Psychologist in Training**

**Dr Rachel Bryant-Waugh**  
**Consultant Clinical Psychologist**

**Dr Dasha Nicholls**  
**Clinical Lecturer**

**Appendix D: Locke-Wallis Marital Adjustment Scale**

I.D .....

DATE:.....

**Parental Relationship Index**

1. Tick the box on the scale below which best describes the degree of happiness, everything considered, of your present relationship/marriage. The middle point, 'happy', represents the degree of happiness which most people get from their relationship/marriage and the scale gradually ranges on one side to those few who are very unhappy in their relationship/marriage, and on the other side, to those few who experience extreme joy in their relationship/marriage.

<b>Very Unhappy</b>			<b>Happy</b>			<b>Perfectly Happy</b>

State the approximate extent of agreement or disagreement between you and your partner/spouse on the following items. Please put a tick in one box for each item.

<b><u>ITEM</u></b>	Always Agree	Almost Always Agree	Occasion-ally Agree	Frequently Disagree	Almost Always Disagree	Always Disagree
2. Handling family finances						
3. Matters of recreation						
4. Demonstration of affection						
5. Friends						
6. Sex relations						
7. Conventional-ity (right, good, proper conduct)						
8. Philosophy of life						
9. Ways of dealing with in-laws						

Please tick one answer for each of the following questions.

10. When disagreements arise, they usually result in:

Husband/partner giving in \_\_\_\_\_  
Wife/Partner giving in \_\_\_\_\_  
Agreement by mutual give and take \_\_\_\_\_

11. Do you and your partner/spouse engage in outside interests together:

All of them \_\_\_\_\_  
Some of them \_\_\_\_\_  
Very few of them \_\_\_\_\_  
None of them \_\_\_\_\_

12. In leisure time do you generally prefer:

To be 'on the go' \_\_\_\_\_  
Stay at home \_\_\_\_\_

Does your partner/spouse generally prefer:

To be 'on the go' \_\_\_\_\_  
Stay at home \_\_\_\_\_

Both stay \_\_\_\_\_  
Both go \_\_\_\_\_  
Disagree \_\_\_\_\_

13. Do you ever wish you had not married/got together:

Frequently \_\_\_\_\_  
Occasionally \_\_\_\_\_  
Rarely \_\_\_\_\_  
Not at all \_\_\_\_\_

14. If you had your life to live over, do you think you would:

Marry the same person \_\_\_\_\_  
Marry a different person \_\_\_\_\_  
Not marry at all \_\_\_\_\_

15. Do you confide in your partner/spouse:

Almost never \_\_\_\_\_  
Rarely \_\_\_\_\_  
In most things \_\_\_\_\_  
In everything \_\_\_\_\_

**Appendix E: Strengths and Difficulties Questionnaire**

I.D. ....

Date:.....

**Strengths and Difficulties Questionnaire**

For each item, please mark the box for Not True, Somewhat True or Certainly True. It would help us if you answered all items as best you can even if you are not absolutely certain or the item seems daft! Please give your answers on the basis of the child's behaviour over the last six months or this school year.

Child's Age .....

Male / Female

	Not True	Somewhat True	Certainly True
Considerate of other people's feelings	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Restless, overactive, cannot stay still for long	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often complains of headaches, stomach-aches or sickness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Shares readily with other children (treats, toys, pencils etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often has temper tantrums or hot tempers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Rather solitary, tends to play alone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Generally obedient, usually does what adults request	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Many worries, often seems worried	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Helpful if someone is hurt, upset or feeling ill	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Constantly fidgeting or squirming	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Has at least one good friend	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often fights with other children or bullies them	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often unhappy, down-hearted or tearful	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Generally liked by other children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Easily distracted, concentration wanders	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nervous or clingy in new situations, easily loses confidence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Kind to younger children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often lies and cheats	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Picked on or bullied by other children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often volunteers to help others (parents, teachers, other children)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Thinks things out before acting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Steals from home, school or elsewhere	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Gets on better with adults than with other children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Many fears, easily scared	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sees tasks through to the end, good attention span	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Thank you very much for your help**

**Appendix F: Causal Dimension Scale**

I.D. ....

Date:.....

**Causes of Eating Problems.**

We are interested in finding out how parents understand their child's eating problem, that is what they think are the possible causes of the eating problem. There are no right or wrong answers we are interested in your views.

1. Briefly describe your child's eating problem as you see it.

2. What do you think are the main causes of your child's eating problem.

3. If you have mentioned more than one cause above, what do you think is the most **important** cause.

I.D. ....

Date:.....

4. Now think about the most **important** cause you have written above. The items below concern your opinions of this cause. Please circle **one** number for each of the following items.

**Is the cause something that .....**

a)	Reflects an aspect of the situation	1	2	3	4	5	6	7	8	9	Reflects an aspect of your child
b)	Is uncontrollable by your child or other people	1	2	3	4	5	6	7	8	9	Is controllable by your child or other people
c)	Is temporary	1	2	3	4	5	6	7	8	9	Is permanent
d)	Is unintended by your child or other people	1	2	3	4	5	6	7	8	9	Is intended by your child or other people
e)	Is outside your child	1	2	3	4	5	6	7	8	9	Is inside of your child
f)	Is variable over time	1	2	3	4	5	6	7	8	9	Is stable over time
g)	Is something about others	1	2	3	4	5	6	7	8	9	Is something about your child
h)	Is changeable	1	2	3	4	5	6	7	8	9	Is unchangeable
i)	No one is responsible for	1	2	3	4	5	6	7	8	9	Some one is responsible for

## **Appendix G: Interview Schedule**

### **Initial statements to parents:**

- *Thank you very much for agreeing to participate in this interview.*
- *The interview will cover a number of areas about your experience of having a child with an eating disorder.*
- *There are no right or wrong answers, I simply want to hear your views and your experience.*
- *The interview is confidential and will not be shared with the clinical team.*
- *You do not have to talk about anything that you do not feel that you want to, so let me know if there are any questions that you do not want to answer or that are upsetting in any way.*
- *You can stop the interview at any time you wish, or take a break at any point.*
- *I will be sending a summary of my findings to all parents that participated in the study over the summer.*

### **Outline of potential interview questions:**

#### **1) Background information:**

- I'd like to start by getting a little bit of background information and I wonder if ...

You can you tell me about .....’s eating problem?

*Prompts:* How long has ..... been unwell/ had this problem?  
Can you remember when this problem started?

Could you tell me a bit about ...

Before you came to Great Ormond Street, did you see any other professionals about ....’s problem?

What was your experience of the professionals who were involved?

Did you meet any other professionals in the past that have given .....a diagnosis for her/his problem?

Can you tell me what that term meant to you?

*Prompt:* Did you understand what the term meant when you heard it?

#### **2) The Impact of having a child with an eating disorder**

- I'd like to spend some time now thinking about the impact .....’s illness has had on you?

Could you tell me what has life been like for you having a child with an eating disorder?

*Prompts:* How does it (having a child with an eating disorder) affect your everyday life?

Can you tell me how it affects you practically?

Can you tell me how it affects you emotionally?

Miracle Question? What would life be like for you without the eating disorder?

(Do you have a partner?)

What kind of affect does .....’s eating disorder have on your relationship with your partner/spouse?

What are the consequences/affect for your relationship with your wife/husband/partner?

(The child with the eating disorder)

What kind of affect has .....’s eating disorder had on your relationship with her/him?

What affect / what are the consequences for your relationship with .....?

Could you tell me whether you have had any difficulties parenting .....?

Have you had any difficulties parenting ..... as a result of the eating disorder?

(Do you have any other children?)

Do you think that .....’s eating disorder has affected your relationship with your other child/ren?

On a day to day basis how do you cope with having a child with an eating disorder?

*Prompt:* What resources help you cope with your child’s illness?

What things do you do to help you cope?

What do you find helpful / unhelpful?

### **3) Understandings of causes:**

- I’d be interested to hear about your understanding of the development / cause of .....’s eating disorder?

Can you begin by telling me what you personally think may have caused .....’s eating disorder?

*Prompts:* What (else) may have contributed to the development of .....’s eating disorder?

Was there anything that could have made ..... susceptible to getting an eating disorder?

Did anything happen just before .....became unwell which you think may have triggered her/his eating disorder?

Is there (was there) anything going on at the moment that you think may be affecting your child?

Or that may be maintaining your child’s eating disorder? (kept it going/acted as a life support)

Are there any other causes you have considered?

Can you tell me what kinds of things have informed/influenced your ideas about what may have caused .....’s eating disorder?

*Prompts:* Have you read anything; seen any programmes on TV or spoke to anyone, about eating disorders? Did any of this fit for .....

Have any of the professionals you have seen told you what may be the cause/ influential in the development of .....’s eating disorder?

Did this (the professionals opinion) make any sense to you?

Were any of their ideas similar or different to your own thoughts about the problem?

Have any members of your family or friends told you what they think may have caused .....’s eating disorder?

Did this make any sense to you?

Were any of their ideas similar or different to your own thoughts about the problem?

#### **4) Treatments**

What do you think .....(might) need(ed) to help her/him with the eating disorder?

Have any professionals told you what ..... needs to help her/him with the eating disorder? Did this fit for you or for .....

What do you think you (might) need to help her/him with the eating disorder?

What do you need to help you?

#### **Before we finish ...**

- What, if anything, would you want to convey to other parents who may have a child with an eating disorder?
- Is there anything else you would like to tell me about your experience which you feel is important, or we have not covered?
- Are there any questions you would like to ask me?
- Thank you very much for participating

**Appendix H: Transcript****Transcript 11M***(With some examples of associated working).***Key****I= Interviewer****P= participant****...= pause****() = could not hear**

I: So I wonder if you could start by telling me a bit about [child] eating problem as you see it?

P: um when it started? I would say it was about .. we'd just been to [country] for my mother's [age] birthday and it was soon after that a friend of mine picked it up when we went skiing she said you know she's handing her chocolate to somebody else or she's .. I'd just noticed that she had started to cut out the things that normally she'd have eaten without batting an eyelid before, she had done a project at school on food and she came back and I remember the day she came back and she said you know crisps are bad for you mummy you know this is what it says in the science thing and chocolate and I said you know well if you lived on it would be bad but in moderation it's fine but .. I think she wasn't particularly happy at school and I think that she was finding it difficult to make new friendships and girls aged 9 or 10 can be quite bitchy and I think she lacked a best mate at that time and the one that she did have was off with another one and another couple of friends were the best mates and I think she felt quite alone and then going on the kind of easter and summer of that year [confidential] ... I thought you have lost weight and a lot of people had commented saying and I think she picked up on that and I think you know she knew that she was slimmer ... and over the summer she started almost to be completely obsessive about [confidential].... I'd taken her to be weighed in june because I you know suspected that something was wrong and we've got a local GP and he said oh just bring her down and we'll just say it's all part of you going on to your next school and it's just part of your standard procedure and she then weighed 37 kilos and that was in the june and over the summer it was very much .. exercising, cutting down, losing weight and but you know she was still eating with her sisters then and you know fine, and then started her new school and that's when I suppose it really went down, you know obviously she wasn't eating lunch at all ... and you know she became to be more and more difficult and I remember very clearly she went to a birthday party at a friends house in the October of that half term and the mother rung me up after wards and she said is [child] alright, you know I think she'd become quite withdrawn, she didn't want to mix socially and the next day I'd arranged to take her up to london and she had a very late night and a sleep over and we were going to , oh were was it .. and we were going to madame tausaud place to meet some friends and she said I don't want to go! And she was very adamant and I said look I'm sorry you know you're tired you've had a late night but it's booked and your sisters are looking forward to it and I

Lots of different reasons for illness - complex

Analysing it

Recognition

dragged her along and we then went for a pizza and I mean she could hardly two mouthful's which is when I then took her back to see [GP] again and he ... said that she'd lost 6 kilos since the june which was when we got referred and .. then do you want me to carry on? So I think then it got very bad towards the end of the autumn term [date], [GP] came round, she ran away, locked her self in the loo, ... and he signed her off school for the last two or three weeks of term and by then meal times were taking an hour and a half she was very very uptight about any body seeing her eat .... If anybody came to the door she'd run away, if they saw her eating I think she, she wouldn't let her sisters in the room while she ate she was so controlling and .. we saw [consultant psychologist] at the beginning of December I was extremely worried that she'd be admitted, I thought you know we're not going to have her around for christmas, she's going to be in hospital and I think we fought like mad at that time to sit there until we thought she had eaten but scenes at meal times were absolutely horrific, you know I suppose it took anything from one and a half hours every meal time basically with horrendous scenes and the only time we could get her to eat was by .. I don't know how we ... but we managed we struggled through, I suppose at that time actually she was quite interested in the thought of going up to get [confidential] so january went on and she was getting better she was putting on weight and we had I suppose it was in about February that we started to eat to, to introduce [sibling 1] eating with the meal to start with and then [sibling 2] and it was you know slow progress but little by little she started to eat with her sisters again ... and the weight continued to increase weekly ... I think it must have been about the end of march that she suddenly realised that she had put on a lot of weight and I think that she started to worry incredibly about her change of shape and panic set in and ..... she was I haven't said that she has actually gone back to school in January, and the only difference was that I used to collect her every lunchtime and bring her home, feed her a meal and then take her back, which took less than an hour really and we're very fortunate that the school was 5 minutes away, so we managed and we struggled through that term and her eating lunch at home and it was fine, eating with [siblings] I don't think she then ate with [nanny] .. april [husband] took the other two skiing and I stayed at home with [child] and we had a very nice time riding, and ... although I think she was starting to fight more about what she ate and her portions again, she went back to school at the end of april and similar thing that we picked her up every lunch time and I went away and met my sister in [country] for 10 days and I think she was definitely going down hill again then but I think that probably was ... a crunch factor actually in her downfall ... because by the time I got back she was very much more .. angry and the exercising was getting out of control, her sleep patterns were worse, she was waking up in the night, she was exercising, jogging and she used to run everywhere she couldn't go down [confidential]without running, run to get her [confidential] and .... She then .. her weight was dropping, dropping, dropping and I tried like mad to say look darling you know you've got to try and make an effort to increase, to eat more because you're losing weight on a weekly basis and if this carries on you're going to go to hospital and I mean I just couldn't make her eat a spoonful more there was

Impact –  
disrupting

Impact –  
on parent

Managing  
- can lead  
a horse ...

no way you know! And finally in July she went in, she was very very, you know there was definitely this dreadful monster, it's just unbelievable when I think back to how she was I mean you couldn't reason with her you couldn't, she was just a different person .... And they did wonders you know, I think actually when I look back .. I think that when she came out she was still quite angry, you know it was going back to school, she was going to eat lunch at school and the first step was getting her school uniform ready and I remember her being very angry about how it didn't fit like it used to and oh, so we went and bought her a new skirt and she hated wearing jodpers and the jodpers that she wore you know before she'd been into hospital you know she hated them, ... but actually now she seems much more accepting of the fact that she gets bigger clothes and I bought her some bigger jodpers and she's different child.... And finally, .. oh I haven't told you how, the final straw was when she was out one of her weekends towards the end in [hospital] she still hadn't eaten with anybody else other than [nanny] and the family and I think she might have eaten with my sister but it was still a huge issue to her to .. you know not to eat with anybody else and finally towards the end of her stay at [hospital] she was so I'll do anything what do I have to do, and I said well you've got to learn to eat with other people and we had some people called the [name of family] for supper on the Saturday night and she said ... you know what do I do and I said just be normal just come and sit down and eat with everybody and she did and since then she's eaten with all her mates at school she's now eating in the school dining room, she's been out to a restaurant to eat with a friend for a birthday party .. where she ate a [food] which nearly knocked me over with a feather but she's still quite controlling about what she eats, you know it's still pasta or ham or cheese or toast or back beans or [other foods] she doesn't want to eat meat very much the only thing I can get her to eat is ham, .... and cereal .. but anyway other than that she's very very happy, things have changed she's always wants spends forever on the phone, always wants her mates over and seems to be , you know I don't think this puberty bit is so much of a problem then it obviously was, you know I think she definitely went through a time when she was frightened to grow or didn't want to change and now .. I still don't think she wants to be a kind of you know big strong person but I think she's happy that she is going to start, well she already is developing but .... I just don't think she doesn't want to really rush it , but she's happy that it's happening (...)

Impact on child - monster

I: (..) I wonder if I could just take you back to think about some of the professionals you've met along the way, you've mentioned that the first port of call was the GP and I just wondered what your experience was of your GP?

P: he's a very close friend actually I mean we've known him and his wife for ages ..and I've always found his advice fantastic and you know I can't fault him at all really .. he I think he didn't believe she was going to be anorexic I think he just thought she was going through a stage you know I don't think he for saw what was going to happen but in October you know he referred us and then towards the end of the term when things were getting extremely difficult I

Recognition - slow

think he came round one day and she ran off and that was when he signed her off school and said you know the most important thing is .. to get her eating again and to be happy and if she finds school a pressure then it's better to be remove that pressure and for her to stay at home and hopefully get back into the pattern of eating again ...

I: and did that advice make sense to you at the time?

Uncert  
-ainty

P: I mean I was so desperate at that time, yes ... she obviously wasn't happy at school, she was very very thin, she obviously, I mean she wasn't eating lunch at school anyway and the most important thing was to get her weight up and so she missed the end of that term and ..you know meal times were extremely stressful but she did then start to creep upwards by then we were just starting to see [consultant psychologist]

Impact

I: so your GP referred you straight to [london hospital]

P: yeah, .... So .. and actually she seemed a bit brighter then because Christmas was on the cards and .. she was off school, she was helping me do the Christmas shopping and wrapping up presents, meal times were still ghastly but in between meal times she was chirpier

I: you mentioned anorexia and I was just wondering when that was first mentioned?

P: ..... when did I first think that she might be anorexic? ... I don't know .. I mean obviously during the summer I thought, you know why are you doing this, you know its just, you know you're so obsessional about your [confidential] being so, but I didn't think that was really a side of , you know I didn't click the two together I suppose it must have been about the October time that I realised that she was anorexic but obviously the down ward trend had started before that the slide, but actually .. when my friend mentioned it on the skiing holiday she said just watch her you know she's cutting out food, you know and I think [friend] even then said she was at school with two or three other anorexics girls said just keep your eye on it because it's dreadful you know, so I suppose the word was in my head then if you see what I mean but I didn't put the two together, I mean I obviously knew she wasn't well because she was losing weight and took her in June and you know

Recognition  
-slow

I: but hadn't associated the obsessional side with

Lack  
of  
know-  
ledge

P: yeah I didn't know enough about the illness at the time to put the two together I knew that she was losing weight and wasn't well and was behaving oddly but it's ... you know .... I suppose I was praying that it wasn't really anorexia I suppose that you know you don't believe until you're actually diagnosed, well yes she has got this illness

Recognition  
-slow

I: and was that a message that you got when you went to [London hospital]?

P: yeah, yeah ... December I think it was (..) and I remember going to see [consultant psychologist] and I remember [child] had to go and see somebody else and she refused to co-operate completely I mean many a time we took her to [London hospital] and she refused to talk and I remember working out and I think it might have been [social worker] said your daughter is very very ill .. and I wanted to burst in to tears actually, I just thought god her mind is a complete mess and I look at it now and I think I mean she's fun and she's laughing I mean she still has, she can still be quite stropey but you know I think a lot of it's probably teenager, she said something very very interesting to the other day, (..) she said mummy do you know actually if I think about things I've always found new situations quite difficult she said .. you know when ever you wanted me to do something and it was something completely new she said I've always felt oh dear I hope I don't make a fool of myself when I do it, which I found quite interesting, didn't want to do it unless, she do it if she knew it was going to be alright and she wasn't going to make a fool of herself but quite worried about doing it and doing it badly, or wrong and making a fool of herself

High  
stakes

I: (...) I wonder if we could move on to think about the impact and how you feel it affected you as her mum, so what has life been life for you having daughter with an eating problem?

P: um ... are we going to go back to then (..) so we'll start when she was at her worst .. absolutely ghastly because you had no time at all for the other two, .. and you know you just, because she was the one that was ill you had to give her all the attention that she needed which deprived every one else in the family of any really and thankfully [nanny] who was fantastic during that time and my husband, I mean without him especially during those times that she was so difficult to feed and I always said the wrong things because I was so up tight and so nervous and the things that would really get her angry would be .. you're doing really well if she was eating and I said you're doing really well, she would just freak and what was the other thing, well done, you couldn't praise her at all if she had a mouthful I mean that would just finish her and I ... through nerves probably always ended up saying something wrong and I think [husband] was the one who really showed me the way to say the right things, and [nanny] was brilliant with the other two, thankfully she kept them happy while our attention so full on with [child] ... I think that the sisters, I think [sibling1] suffered more than [sibling 2] but I think that [sibling1] was going through a pretty rough time herself at school and because of the problems at home she just felt a bit kind of flat and there was a lot of bitching at her school and her best mate had gone off with somebody else and probably she didn't have the time to talk to me about it and bottled it all up actually

Impact –  
disruption,  
nightmare

Guidance

I: so a clear impact on her sisters as well

P: definitely on the middle one (..) not her youngest but I think [nanny] did a great job in keeping them happy but [sibling1] at the end of her spring term [date] was very kind of funny about her friendships and didn't really want to get on the phone and ring her

mates or just a bit sad and I think she was unhappy at school and her friendships had gone a bit haywire and she wanted to try a new school so we took her down to [school] and had a day there and said I just love it I want to move and so we moved and I think that was a great decision and they've gone there and they're both very happy, and I think ... I don't know, I don't think that they, I mean they obviously do remember how it was but things are quite normal really now ... so yeah I don't think that they have any lasting affects of you know damage to them

I: so at the time it was you were saying it was about having much less time for them and having to focus you attention on [child]

P: yeah yeah

I: and feeling lucky that you had [nanny] around to

P: to look after the other two and to play games with them and do their homework and cards and just keep them happy thankfully, I mean she was absolutely brilliant and I think she's been great for [child] too I mean her confidence has soared [child] confidence has soared you know she was never interested in music she was never interested in fashion, she would never wear the colour pink, and it's all she loves music now, she loves speaking to her mates on the phone and seems much more like a normal 13 / 12 year old

Support

I: (*.. not relevant ..*) well you mentioned that at the time [child] was unwell, you said it was ghastly and I wonder if we could think about we could think about breaking your experience down into two parts and I wonder if we could think about the emotional impact ... do you feel [child] eating disorder had any impact on you emotionally?

P: ..... I think that ..... I mean obviously it's completely and utterly draining but I think you know, I am a person that just carries on and I don't give up and you know you just do your best don't you, and you know it's the most important thing in your life really isn't it, for all of us and the trouble is is that mental illness is a millions times worse than somebody breaking their leg isn't it because you know you can't see the disability really .. but you just muddle through, you just do your best really, .. I mean I'm sure it put a tremendous strain on everyone because as the mother you know you are .. you try to be their to listen to your husbands problems and your children's and sometime that takes up so much time that you get no space at all and you end up feeling totally drained, exhausted and want to kind of just go and lock yourself in the bath and think just leave me alone! ... but there wasn't much time for that and you know you just did your best and muddled on really

Impact - nightmare

Adapting

I: so practically, time wise you had very little time

P: yep

I: and were there any changes practically that you noticed to your day to day life

P: well I mean you had no time do anything other than, if you think back to the early part of [year] it was just drop the kids off at school, drop [child], and then you know do what you could manage to fit in the morning before you had to be there at ten to one to pick her up and then by the time you got her back to school it was two, and then rush around trying to get everything else done before you collected them at four ... so there was no time I mean it makes you laugh actually because it takes you back to when you had three kids and there was never any time then really, it was always washing, ironing, shopping, cleaning, looking after babies where as you don't appreciate what time you have while they're at school now from kind of nine o'clock in the morning until four .. that's seven hours! (...not relevant..)

Impact-disruption

I: so (..) having no time and having to put her first and muddle through

P: yes yes

I: I mean you said you are a strong person who does kind of get on with things, and I just wondered how you feel you coped .. whether you feel there were any particular resources you used or anything that was particularly helpful?

P: ... I think I'm extremely lucky that I had the support of my husband and [nanny] .. if I didn't have that back up I think that I would have found it incredibly difficult you know you just .. and also I had terrific faith in [consultant psychologist] ... I have always thought that she would get us through really, it's a great asset to have somebody that you have huge confidence in isn't it

Support

Specialist's

I: so having confidence in a professional got you through and also having the support of people at home

P: yeah ... yeah not to give in, well you can't give in can you it's your daughters health and livelihood you know it's high stakes I mean you'd you know you'd do anything to get them back ..so ... .... There we go .....

High stakes

I: (...) I wonder if you feel [childs] eating problem had an impact on your relationship with your husband in any way?

P: I think, you know I'm sure it did because I had less time for him but I think he's quite grown up enough to understand that you know there was a reason behind it, it wasn't that I didn't love him any less or ... I think he understood why I just didn't have as much time for him, I mean yeah there we go

I: so time again

P: yeah time again .. I think we both just muddled through you know, it's always time though isn't it even no you know we're both busy rushing around and you know ..... roll on retirement !!

I: and again thinking about relationships, if you think about your relationship with [child] I wonder if you feel the eating disorder had any impact on your relationship with her?

P: I always remember, one dreadful scene where I was so angry and frustrated and she'd, I said don't go down the [confidential], you are , you know you have to stay in side and .. she didn't listen and we had a dreadful scene I think I pushed her I mean I don't think I've hardly ever smacked her or physically got angry with her and this time I just went bolistic and she was coming towards me to run away and I just kind of pushed her backwards and she fell over against some of the feed bins and it hurt her, and for months afterwards she would refer to this fact and say well you were so horrible to me look at what you did to me! And I said well you know darling that was because ... well I don't know if I've actually had a conversation with her since I feel she's herself again what I would like to say was well that wasn't really you then it was this dreadful illness that you had because I do think that ... she was not, you know there was this anorexia controlling her and anorexia would do everything possible to avoid being beaten or you know she had to exercise, she had to avoid eating she had and there was such a kind of fight in her .. do I think it's had any lasting damage, no I think we've got a great relationship, I think that we do argue, like I do think , she came back the other day having fallen out with her best mate at school and she was clearly very upset and I said what's the matter and she said oh [friend] you know she's talking to [friend 2] and [friend 2] has told [friend] that I don't like her and I don't want to be her friend any more, and so I sat her down and I said well darling what would be a really good idea is if you just rung them up and said you do want to be [friend] friend and what ever [friend 2] said you know it wasn't what you intended and you know it's best to be best mates with everybody .. you don't understand! ... and it's very odd, I think she does listen to what I say but you know but she doesn't accept you know when she's actually talking to me it's quite different .. but in fact in the end [nanny] had a word and said you know your mum's right , it would be better if you rung them both up and just talked through what went wrong and she did ... but I wonder if [nanny] hadn't been there to support me or what I'd said whether she would have done it, but any way she's best mates and very happy again and I'm sure this little drama's arise all the time during 12, 13, 14, 15, 16 year olds... but I think she ... is much more logical, I remember a situation when she wanted to go and get [friend] a present on a Friday night and we hadn't got round to it, I'd promised her everyday that week after school that I'd take her to [town] and buy [friend] a present and then she came to back and said oh I'm in a hockey match tonight, oh I'm in a net ball match tonight, and so Friday came the day of [friends] party and we still hadn't got a present and we got home and she said oh mum I've sorted it out, you can collect me from school and then I can [confidential] ..and then you can take me and I can buy a present for [friend] and then you can take me along to the party and you're invited to [restaurant]

Dreadful monster
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as well and I said well I'm sorry darling, I haven't got time, basically yes you can [confidential] ...but .. and I've got you a present that you can give [friend] anyway but [siblings] get home at 5 and I'm not going to just disappear off to [town] with you because they don't get much time with me and I'm going to be with them and help them with their homework and I will take you into [town] at 7 and I said you must realise that actually you are not the only .. one and I don't run around you 24 hours a day and you've got two sisters and they have long day at school and when they get home it's only fair that I give some time to them .. and you know she listened actually you know she wasn't angry so I do think she's, where as obviously when the time that she was ill you know she never ever thought about any body other than herself you know or the effect that it was having on her sisters or ...

Impact -  
disruption

I: so that conversation may have been very different then

P: well you know it wouldn't have happened would it! I mean she's much more logical now, she is prepared to listen more .....

I: and do you feel that has an impact on your parenting, does it feel easier?

P: well it is easier isn't it ..... Yeah I mean it's much easier when you can talk logically to your child and you think that they hear what they say I mean a year ago you'd bash your head against a brick wall and think doesn't make any difference you know you've got to eat .... You know, you've got to stop running everywhere and nothing you could do or say or whatever would make any difference

Can lead a  
horse ...

I: so what ever you attempted didn't seem to make a difference

P: yeah she was in control completely

I: and does that feel like its shifted?

Taking  
control

P: oh yeah completely .. the only thing that I would say is that I think she is quite controlling about what she eats but as long as she's you know putting on weight ... and I look at it like well you know there are loads of kids that are vegetarian so providing she accepts that she has to eat .. then it's not much different from having a vegetarian child ... ..

I: I wonder if we could move on to think about what you think may have been influential in [child] eating problem and I know you also mentioned some things at the beginning and I wonder if we could think through those again in more detail

P: yeah

I: what do you feel are the things that may have been important in [child] developing the eating problem?

P: going back to that time in school I think she was going back over her unhappiness at school, doing this project on eating, I think lack of self confidence with her peers and I remember time and time again saying to her when she came back and was unhappy about her friendships and I said well you know darling you've got to make an effort and I can remember her being very angry saying I do make an effort! You don't understand I do make an effort! And I don't think she did actually, I don't think she understood what you have to communicate with people and I think she rather .... Became a loner and I don't really understand why, I think she possibly found that it was easier to love [confidential] ..than handle tricky relationships at school... and she became more kind of into [sport] [confidential] because it was easier to run away then to make the effort to ... face up to having relationships with her mates at school, I don't think she really liked going to people's houses that much then, definitely when she was 9 or 10 she never really wanted to go she'd much prefer to stay here, but on the other hand she's got a beautiful home [confidential] and ... so .... But even when she had her friends here they always kind of had to fit in with what she wanted to do, so it was always easier if they enjoyed [sport] more or something like that but I think she did really find it difficult having .. being friends with people her own age I think she felt inferior and I think that it was quite tough the fact that she had never been that capable at school academically, I think she is quite capable but I think that you know there were some very clever kids at her school who were all in the A stream for this and the A stream for that , A stream for the other and she was in the bottom and she'd always been in the bottom right from year 3, year 4 year 5 and I think although she was fantastic sports wise and she won every single cup ever, you know the swimming cup, the netball cup the running cup, that that didn't make up for the fact that she just felt inferior to all these people because she wasn't clever academically and I think she always felt that her middle sister was in the A group for every thing and she wasn't ... but I think mainly her inability to mix or feel comfortable with her peers at that time was a major influence ..

Analysing it

Complex and puzzling

I: you mentioned some other things too

P: [confidential] ... at that time it was but definitely throughout the summer she was just terrified of one day being too big or too heavy ... yeah ....

I: and during that time (..) were there any other possible causes or influences that you considered?

P: um inability to mix with her peers, she cut out food .. causes.. [confidential] ... I think she didn't really want to change shape I think she was slightly .. and I don't think she wanted to change this look that she felt she had, you not a lot of them suddenly start to get broader and taller and much more chunky and I think that she felt she didn't want to look like that so that's why she you know got into the habit of cutting out everything, you know she didn't want to change ... ..

I: during that time whether also friends and family offered any ideas about the eating problem and what they thought was important?

P: did any advice us on the eating problem or what was

I: I guess both really (..)

P: not really I can't think of anybody offering any help or advice, I mean obviously my friend said you know you've got to go and see a doctor and say what was going to happen, what was obviously on the cards but I can't think that anybody said that this was the cause or might have contributed I suppose that my sister said do you think it had any thing to do with the fact that my husband is slightly over weight and do you think that she's terrified that one day she might end up looking like him but I don't think that really was the reason ... I think you know [child] understands that .. you know if you don't take much exercise and you do overeat then you are likely to be other weight, I think it's much more logical now, but I don't think that was a cause but I think my sister might have suggested that that might have been a reason but I didn't really think that it was

I: so that suggestion didn't make sense to you?

P: no I don't think it was one of the main, I don't think that it was one of the reasons I think that the ones that I've given you and I can't really think of any others, I suppose that the other thing that somebody might have suggested was the fact that she'd moved schools because of obviously she moved schools at 11 and a half and the other thing that I thought was we had moved here in the (...) so you know also we'd moved house and in fact actually it's quite funny because then when she was very ill she used to say I hate this house, I loath this house, I've never been happy in this house! And I think she probably made reference to the fact that she'd like to move back to where she was, where as if you ask her now today and said do you love this house, she would say I love this house I just love it! so that's very odd isn't it I think that she reflected when she was at her worst the fact that she lived in this house and since she'd lived in this house she hadn't been well and you know her memories of living in this house had always been unhappy ones you know she'd always been completely manic, running or exercising, not eating, scenes with us .. going and locking herself in the loo, all the memories were unhappy where as now .. she's very happy to be here so I don't think that the move caused her illness and I don't think that her new school, I think it might have made, you know accentuated it because but she was unwell before she moved schools but it can't have helped because you know she was faced with a new situation she had to make new friendships and I think she chose to run away from it all or not face up to it, so she chose not to eat and instead of going out in the school playground after lunch she used to just go and send her cousin email rather than go and make an effort and talk to her mates she walked away from it

Analysing  
it

Complex  
and  
puzzling

I: feeling that rather than being influential in triggering the eating disorder it was some how maybe exacerbated .. something that was already around

P: absolutely ... ..

I: I wonder if we can move on to (...) thinking about treatment and what you feel helps [child] (..) I wonder if you could tell me what you think has been helpful for her and what you think she still needs?

P: ..... There's no doubt that when she was in [london hospital] that she saw another side of life that she'd never ever seen before and I think that she definitely felt that when she was there how very sick the other people were in there .. and you know, ... I think she thought that they were completely mad some of them and you know as she became stronger mentally she became more logical and she wanted to get back to normal life again, she wanted to go back to school, she wanted to play sport again and she wanted to ride again, she wanted to do all those things the illness was taking away .. you know it took away her parents and everything during the time she was there and I think she just hated it so much there and I mean she made some reference about a month ago she said mummy, how on earth I could ever ever have you know, god I never ever want to go back there again and give [confidential]... again but I mean I used that argument in June when she was very ill saying unless you eat you won't be able [confidential] ... you'll be in hospital, but then it didn't make any difference at all ... I do think she's very ... close to me although we do have a typical mother daughter relationship ... she said something else quite interesting recently we were talking about camp which is in august this year, I said what do you feel about it, she said oh I want to go I want to go, [confidential] ... and it'll be really great, so I said right because obviously that will be seven days away you know, I know you can go and stay the night with [friend] and you can eat pasta and but how do you feel about actually going away for that length of time ... and she said well as long as you come and see me and pop in because you know I think if I was there for seven days with out seeing you I might find that quite hard but if you were able to come and see me during that time that, I think I would be alright, so I suppose that made me feel you know I'm quite worried about her, you know I do feel terrifically responsible you know I do feel I don't want her to go back so much because I know that at the end of the day it falls on me to be there when she is that ill you know, [husband] was a tremendous support but you know he still had to go to [place] he still had to do this, he still had to go to work and where as my life did change hugely and I do worry about the fact that if ever we went away as a couple whether she might go back and I suppose I'd feel ... god I'd rather not go than risk her going backwards and in fact I'm faced with this situation at the moment because my sister and my mother are going out somewhere to [country] and they said oh why don't you just come away for a few days and I do worry about the fact that she might go back, you know she's done so well that and I feel as though I've got my daughter back I don't want

Concern  
responsi-  
-bility

Impact-  
disruption,  
nightmare

that monster back again, oh god I'd do anything to avoid having that one back again!

Dreadful  
monster

I: so it's a real worry that hangs around?

Giving  
back  
control

P: well you just you know but ... I suppose she's got to take responsibility some time hasn't she, she's got to say you know I know what will happen if I don't eat ... so you know I can't always be there you know it's going to come that you know she will be going off and staying with friends or staying longer or being invited somewhere to go and stay with people for 4,5,6,7,8 days you know and later probably go to university, get a flat what ever, I can't be there then but those are kind off a bit more distant and as long as we kind of talk about what is going to happen when she goes on this [camp] thing, you know the fact that she can actually talk about you know her worries and her fears, you know the fact that she communicates is half the battle isn't it?

Control

I: talking through and thinking about what might be helpful feels

P: yeah, I mean it was a huge thing for her the other day because it was the first time she'd eaten in a restaurant at [friends] party, and you know I talked to her, actually I went and picked up a menu plan, I'd been in [town] and I picked up a menu and so I said oh you know I just picked it up because I thought it might be easier for you to find out what you might want to eat when you are there .. and it wasn't a big deal for her I thought it would be actually .. and the fact that she ate something that she hadn't eaten ever you know I say she's still controlling about what she eats here (..) the fact that she can do it, can't she, the fact that she can walk in there and eat a [food] you know she could sit down and eat a bloming roast chicken dinner but she won't! and you know she always has this [juice] stuff, apple and orange or ... and I said you know there not going to have [particular juice] in these places darling you know they just don't, I said so what are you going to have to drink, she said I'll just have a fanta! And she had some coke and apparently she said to [nanny] the next day, oh yeah actually I quite like coke ... she didn't say that to me though, .. but you know it wasn't a big deal .. so ..... I forgotten what the question now!

I: we were thinking about what was helpful and you were saying that now she can communicate, and that she can obviously now cope with new situations perhaps better than she used to

P: yep

I: but I wonder what you think was helpful for her mum (..) what you feel was helpful along the way ....

P: ..... we there's no doubt that once she'd gone into [london hospital] and come out that she was a different child, you know before she went in on a weekly basis we used to go and see [consultant psychologist] and drag her kicking and screaming along the corridor, and I mean I felt we had to continue with that because if we didn't take her then she was controlling every situation even

Taking  
control

more wasn't she, so ... and since she's been there or come out ... we can communicate with her so much more so .... I mean they definitely showed us the way of how, I mean you just had to believe that it's an illness you know nothing about until you're in there, you know you have to just listen and do your best really and you know that the way forward is to get her eating again and since she's been eating again she's much more rational and this kind of stubborn wall that was there is not so obvious .... Does that make sense?

Solutions and advice

I: yes it does .... So having some from professionals to help her get eating again

P: yep

I: helped to move that stuck, stubborn part

P: I mean it was definitely the time in [london hospital] that made the difference you know by taking every thing away and her knowing that the only way she was going to get back to everything that she loved was to eat and the more she ate, as her weight went up you know her determination to get back to playing sport, to normal life became more of an issue to her, that's what she wanted and the fact that you know about eating another spoonful wasn't really an issue anymore, there were other battles .....

I: (...) imagine, that you (..) have a regular day as usual and during the night while you are asleep a miracle happens and the miracle is that anything, any remnants of the eating disorder that are still around vanish through the night and obviously you don't know this because you are fast asleep so the (..) next day or week you would notice any difference to your life?

P: what if [child] just woke up the next morning came downstairs and said I want bacon and eggs!

I: perhaps

P: and would it make a huge difference? (...) yeah because it is a pain in the neck as I cook a normal Sunday lunch for everybody else then I have to think well you're not going to eat that and actually I've got to put backed beans on toast for you, and I suppose yes I do worry about the future and thinking you know if we do go on holiday in the summer, you know it's fine that .... She can eat what she eats here but obviously when you are on holiday you do tend to eat out much more ... so you know it's not always going to be that easy for her to have what she's used to, if we go to a restaurant but having said that I know that on one occasion she can eat a [food]! So yes it's a bit of pain that if we go out for Sunday lunch, you know we just can't walk into somebody else's house and say I right we've having roast beef and yorkshire pudding and roast potatoes I would automatically think oh my god well [child] is going to be very happy to eat with everybody but you know she's going to want backed beans on toast or pasta but it's no different to having a vegetarian is it, but yes I would , I mean it's it would be

Impact - disruption

nice that she ate what everybody else ate I mean there's no getting away from it

I: so practically it would be easier, a sense that not having the worries that if we go on holiday or if we go to somebody's house

P: yeah, I mean at least she can eat in front of everybody, we went to see her grandparents the other day down in [county] and she was fine but she wouldn't eat, what did we have roast pork that day, but you know she wouldn't eat that she had backed beans on toast with cheese on, but at least she picks up that knife and just starts eating and finishes it up .. but there's no denying the fact that god I would love her to eat what everybody else eats or just to say , or just to kind of, one thing she does say is mum can you get my lunch on because I am hungry and that is a lovely thing to hear actually, the fact that before I am sure she knew what hunger pains were like but yet she denied eating and she'll say oh I'm really hungry but I just wish oh I'd just love to see her not frightened of the bar of chocolate, there's something in her head that says no I don't like that, and I say you know there's no, I'm sure it's rubbish it's just you know .. I can't believe she doesn't like crisps she doesn't like chocolate, she doesn't like vegetables, she doesn't like chicken, you know there's something still controlling saying ... I'm not going to eat it! but you know she is varying her diet a bit which is you know since she's been home she is eating more things then she did do I mean not hugely but it's a step in the right direction so and I hope as ... she kind of comes across different situations like goes to somebody's house and all her mates are eating pizza she will think yeah I will have it, she came back the other day and said can I have pizza tonight and I said yeah fine, great, and she said if I had pizza how much would I have to eat so I said well the equivalent of say two pieces of toast with x on it, so I said you have to eat at least half, I said that would probably be about the same and she said oh no I think I'll just have my two pieces of toast with whatever she was having on it ... but the fact that she mentioned it ... so in other words she would eat pizza .. so um and I'm sure she will and I think because I hope she will actually get bored, I think she does get bored of what she eats actually but ....

I: the final question I have is what if anything would you want to convey to other parents who may have a child with an eating problem?

P: I've got two of my friends that have got .. that are right in it at the moment actually ..... god ..... it's very difficult I mean you know you can be ... I saw this friend who's right in the middle of it at the moment, I mean she's got a worse problem than I had actually because her daughter was a boarding school and now she's not a school at all so for the last three months she's been around [friend] 24 hours a day ... and I suppose at least I got two and half hours in the morning and an hour and a half in the afternoon when [child] was coming home for lunch everyday ... what would I say? I mean I think that every case is different isn't it and you know children who ... I mean [name] has just come out of the [private hospital] and you know she obviously can eat everything now

although obviously not masses but she doesn't have so much of a problem with food although other things are still more of a problem .. what would I say ? ... I mean just be ... I mean there is no real advise other than just go, take professional advice ... try and get them to put on weight .... And you know just well I'd be, you know I've always tried to help two friends of mine because I felt like I was there before them, I felt like kind of you know the anorexia help line here ... and I got a lot of comfort when I rang somebody before, actually [child] went in, somebody had given me this persons number and I rang up and they said you know .. by that time I knew she was going to have go into hospital and she said you know actually for my child it was the best thing, that had happened, .. and I think that you know you get huge comfort from the fact that you know people who have been there who have come through it and that there is light at the end of the tunnel ... that it's not, well sadly, it seems to be more and more on the up and up and effecting so many children that it isn't such a kind of you know illness that only effects one in a million it's not like that any more, it's horrific it's like ... it's terrible, I mean I don't know what the statistics are but ... it seems to me since .. you know just out of the circle of friends we have how many people are affected by eating disorders or anorexia ... and I've taken great comfort from knowing people that have been in a similar situation or you know who I could ring ... and you know I've hopefully been helpful to people that have been in touch with me .. but you know I think you've just got to ... and I think because of where we are now I think that you know looking back and thinking well .. you know it has worked so it is possible so you know there is ... you know it can be .. you can get through it hopefully ... touch wood .....

Specialist, advice

Sharing exp.

I: well (...) I wonder if there is anything else you feel would be useful for me to know about your experience?

P: ..... I can't really think of anything ..... I've gone blank! ..... No, gone blank at the moment

I: may be that means we've covered everything?

P: I hope so, I hope it will be helpful anyway .....

End of interview