An Evaluation of a Community Youth Befriending Programme for Young People with Cystic Fibrosis and their Carers in Lothian

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ACKNOWLEDGEMENTS

The authors would like to thank the following for their contribution to the research:

- The Queen’s Nursing Institute Scotland
- Research Steering Group: Julia Quickfall, Shona Cameron, Helen Macfarlane, Aileen Mallinson, Tracey Hamburgh, Jackie Smart
- Staff and volunteers: The Butterfly Trust
- Fiona O’May, Faculty Research Fellow
- All staff, parents and young people who participated in the research project.
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Published by: Subject Area Nursing
Queen Margaret University
Edinburgh
EH12 8TS

[http://www.qmu.ac.uk/hn/](http://www.qmu.ac.uk/hn/)

ISBN 978-1-902520-17-9
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EXECUTIVE SUMMARY

Introduction and background

Cystic Fibrosis (CF) is the UK’s most common genetically inherited life limiting condition, which currently affects around 700 people in Scotland (CF Trust 2002). The condition is caused by a gene defect and affects primarily the lungs and digestive system. Children with CF become aware that they are different from their peers, they can be small and thin as puberty usually comes late, there is often a chronic cough and lung function is substantially reduced causing restricted energy levels. Issues relating to cross infection make peer support problematic for this group. In addition, treatments and self care behaviours are substantial, time consuming and add to social isolation due to regular hospitalisation, and absences from school. Consequently this group often need practical and emotional support that would not normally be required in this age group, (Hodson et al 1993).

Rationale for the study

The Butterfly Trust was set up in 2002 to support sufferers and families with CF. In November 2004 the Trust was awarded funding to establish a befriending programme for children with CF in Lothian (aged 8-18) with the intention of mentoring and supporting, relieving stress and boredom, improving self confidence, and enhancing general well being. The existing programme was developed in partnership with the CF community nurses at the Royal Hospital for Sick Children (RHSC).

Aims and Methods

The purpose of our study was to evaluate the impact of The Butterfly Trust’s befriending programme (Cool Friends) on:

• Young people’s self esteem, empowerment and independence
• Issues such as boredom and social isolation when young people are at home and in hospital.
• Its function for raising issues of personal importance for young people and their carers.
• Support for carers; e.g. time out, networking
• Its potential for influencing concordance with treatment regimens.

Design and Sample

This longitudinal ‘cross over’ survey commenced February 2006. Six befriender / family partnerships (one cohort) were followed for a duration of 18 months. Ten people were interviewed face to face in their own homes six months into the befriending programme (first cross over period - young people n=5; parents n=5). Six were interviewed twice if their befriending experience had extended to the full year after the first interview (second cross over period - young people n= 4; parents n=2). From this one cohort, four of the families reflected a child-parent dyad, and in two families one child, and one parent were interviewed respectively.
Young people varied in their disease severity, (27-101% % predicted FEV$_1$). All but one of the young people was still at school.

Individual interviews were also conducted with four hospital and educational personnel, who had contact with the young people with cystic fibrosis (CF). Three befrienders were interviewed via a focus group.

Findings

The participant’s stories are told under two main themes.

Theme 1 – having CF and living with it

Young people and parents were experts of their own situation, the condition of CF and relevant treatments. For parents they were clear as to their caring role and what this entailed. Help and support was at hand from voluntary agencies, hospital and educational personnel. Parents were concerned about their child with CF, their future (short and long term), their education and also about the effect CF has on other members of the family. Their time was limited, and competing priorities were draining and exhausting. Personal sacrifices had to be made in order to manage the condition. The hardest job was dealing with the ‘big questions’ and they needed someone else to share this load. As the main care givers, their burden of responsibility (physically, psychologically, financially and emotionally) was enormous. Socially they were quite isolated, but the professional and familial networks they had were supportive and accessible.

Young people were, in the main, stoical about their condition. They saw themselves first and foremost as individuals typical of their peer group, but limited by the disease. This attitude was very much dependent upon friend’s attitudes, for example, their acceptance of the condition and the necessary equipment and treatments. In other words, their peers were significant in helping them to normalise the disease, boost their self image and nurture their self worth. Hospital admissions were dreaded and seen as an interruption to much needed socialisation – the isolation and boredom from being in hospital had negative psychological effects. Play therapists made a big difference. Young people were aware of the long term effects of the disease and needed to talk about this, but were aware of the distress this could cause to parents. Educational issues where not so much of a concern to the young people in this sample group as they identified their ability to catch up, especially through protracted hospitalised stays.

Young people’s negative attitudes to treatment regimes were not apparent from the young people themselves, but more apparent from the parents. This aspect of the research was difficult to explore with the young people for reasons which can only be surmised: young people may not have been comfortable discussing this with us; they were atypical of their age or peer group and so demonstrated concordance; or we did not ask the right questions.
Theme 2 – experiences of befriending

Befriending was seen as a good thing by all parties in the project. For young people it offers a fun distraction, impacts positively on their self esteem and helps them raise issues of personal importance. For the more mature young person it provided someone else for them to talk to, and they appreciated being able to take issues to someone outside their own family. For parents, befriending helps relieve the burden physically and emotionally and gives them some time out for themselves. They saw the befriender as helping with the ‘big questions’ and difficult issues about their child’s prognosis. Befrienders themselves saw that activities could broaden young people’s horizons, and the nature of their relationship with young people could help foster trust to discuss difficult subjects. The associated prognosis of CF makes befriending young people and children with this disease exacting. Ongoing support and training for the befrienders was seen as important, especially as the parents and young people themselves were perceived as experts of their own condition and situation. As yet, befriending has not widened the young peoples’ social networks beyond that of the befriender. Communication processes are at times unclear and exit strategies have not been addressed. Befrienders want more support both from the families they work with and from The Butterfly Trust. Referral processes can be slow and there is potential for the befriending role to develop further.

RECOMMENDATIONS

• A minimum of one year is given by the befriender to the project*
• The Butterfly Trust makes explicit what that commitment entails and the consequences of non-commitment, for each party in the relationship.
• Exit strategies are discussed with the young person, their family and the befriender at the outset of the project and managed throughout the duration of the relationship.
• Recognise that befrienders need extra support at the beginning of the relationship, which should include supported visits to families.
• Regular training updates for befrienders should include peer reflection, information giving and networking with other befriending agencies*.
• Examine ways of working which would allow the young person to expand their social circle to that other than the befriender (e.g. outings with users from other non CF befriending organisations)
• Encourage chains of communication in both directions between the Butterfly Trust, other organisations (e.g. hospital, school), the family and the befriender to increase awareness of the project and improve communication on ongoing personal, educational and social issues.
• Befrienders should have ongoing dialogue with The Butterfly Trust re costs of activities according to frequency of outings*.
• Explore ways of working between young people and befrienders which meets their continued mutual development within Child Protection legislation.
• Investigate ways of streamlining the referral, screening and matching processes to reduce delays.
• Facilitate processes to ensure more joined up working between befrienders and outside agencies; for example in assisting with educational review meetings or school projects.

FINAL CONSIDERATIONS

This was a pilot study and since its implementation the scope of the original befriending project has been extended outwith the Lothian area in response to demand. There have also been requests from older adults with CF and siblings of young people with CF to have a befriender. More research needs to be carried out to evaluate the effectiveness of the wider project.

*Indicates that these recommendations have been implemented during progression of the study, but have not been formally evaluated.
CHAPTER 1:

INTRODUCTION

Cystic Fibrosis (CF) is the UK’s most common genetically inherited life limiting condition, which currently affects around 750 people in Scotland, half of whom are under the age of fifteen (Scottish Executive 2003). This progressive condition is caused by a gene defect which results in abnormal thick sticky secretions in the lungs and digestive system, causing repeated chest infections and low weight (Hodson 2000). Median survival in the UK is 31 years (Dodge et al. 1997). Other problems include liver disease (Diwakar et al. 2001), CF-related diabetes (Laang et al. 1994) and infertility in males, (Sawyer 1996). Death for people with CF usually occurs as a result of respiratory failure (Madden 2000).

Children with CF become aware that they are different from their peers, they can be small and thin as puberty is often delayed (Aswani et al. 2003). There is often a chronic cough, and lung function is substantially reduced causing restricted energy levels. Malabsorption and chronic infection further limit growth and development necessitating a high energy diet. (UK Cystic Fibrosis Trust Nutrition Group 2002)

Issues relating to cross infection between people with CF make peer support problematic for this group, (Badlan 2006, Walters and Smith 1993). Face to face contact is discouraged.

Treatments such as intravenous and nebulised antibiotics (Ryan et al 2003) are substantial, time consuming and can add to social isolation due to regular hospitalisation, and absences from school. However the growth in self care and home treatments has helped to decrease the number of school absences, (Strawhacker and Wellendorf 2004, Zoritch et al 1996, Dyer 1996). These self care demands can however, put further strain on the individual and their carers to
manage increasingly complex treatments and as a consequence of this they become as Peterson (2006) states “the best experts” in their care and management. Lowton (2002) reports that “lay carers are routinely performing tasks that were once the remit of trained nurses” (p180).

This can however have a significant impact on quality of life (qol) for individuals with CF their carers and families.

Gee et al (2003) contend that although decreased qol in CF appears to correlate with increased disease severity, it is more complex than this; with variability between males and females. In addition, they contend that coping styles, locus of control, social support and optimism/pessimism may also impact on perceived qol. Staab et al (1998) suggest that other factors such as perceived health status rather than actual clinical severity may influence qol. They found noticeable differences between children with CF and their parents in terms of their reporting of health status in relation to qol and hypothesised that those parents who use adaptive coping strategies are enabled- even when the child is severely ill- to manage a reasonable qol, compared to those with relatively well children, who report a negative correlation with qol.

A recent study by Havermans et al (2007) compared child and parental concordance with qol in several domains. Disagreement was found in several of these domains: with children scoring significantly higher than parents: (higher scores = better qol). This is in line with other studies; (Britto et al 2004). Possible explanations include that children learn to live with these effects on an everyday level and rate the impact as less, whereas parents may report the impact of illness as more significant because they have more information regarding the illness, prognosis and development of the illness than their child. As the burden of care is often left to the parents (Lowton 2002) perhaps the results of these studies should not come as a surprise.
It can be seen then from the literature that effects of cystic fibrosis can lead to social isolation due to hospitalisation and time off school, decreased quality of life, (although parents and children rate this differently) and increased self care demands which place a burden on both patients and their carers and can further impact on quality of life.

BACKGROUND TO THE PROJECT

The Butterfly Trust was set up in 2002 to support young people with CF and their families in Scotland and is a registered charity.

In November 2004 the Trust was awarded funding to establish a befriending programme (Cool Friends) for children with CF in Lothian (aged 8-18) with the intention of mentoring and supporting, relieving stress and boredom, increasing self confidence, decreasing social isolation and enhancing general well being.

The programme was developed in partnership with the CF Nurse Specialists and Social Work Department at the Royal Hospital for Sick Children (RHSC), who recognised that additional support was required for some particularly vulnerable families and young people for the reasons highlighted in the literature. The programme endeavours to work collaboratively across medical and social disciplines to provide holistic support for this hidden and marginalised group.

Funding was secured in 2005 from the Queen’s Nursing Institute Scotland, to evaluate this programme and to inform The Butterfly Trust’s quality assurance processes.
Aims of the research:

To evaluate the impact of the befriending programme on

- Young people’s self esteem, empowerment and independence
- Issues such as boredom and social isolation when young people are at home and in hospital.
- Its significance for raising issues of personal importance for young people and their carers.
- Support for carers; e.g. time out, networking
- Its potential for influencing concordance with treatment regimens.

Achievement of these aims will be addressed in Chapter 4.
CHAPTER 2:

LITERATURE REVIEW:

Befriending has been found to be highly valued by the people who are befriended and offers the opportunity for social activities and new experiences (Heslop (2005). In addition, befriending would appear to impact positively on self confidence and self esteem (Dean and Goodlad 1998).

There is, according to the Befriending Network Scotland (2005) a great variability in the nature and practices of befriending projects. Furthermore, they suggest that projects exist along a spectrum from “companionship” to “mentorship” with befriending somewhere in between. The former focuses on the development of social relationships whilst the latter focuses on specific objectives. (See Appendix 1 for definitions; Befriending Network Scotland 2005).

Further confusion exists in the interchange of the terms befriending and mentoring. The United States of America (USA) typically refers to “mentoring” whereas UK studies use both terms.

Whilst government policy supports a commitment to befriending, it is reported that few schemes collect evidence to demonstrate the effectiveness of these services, (Armstrong and Hill 2001).

A literature review by Hall (2003) reports that most of the evidence on the impact of befriending (or mentoring as it is referred to in this report), comes from the USA. However several papers in Scotland have been published since then giving a more up to date picture of the situation here (Befriending Network Scotland 2005, INtegr8 2006).
Dubois et al (2002) conducted a meta analysis of 55 evaluations of the effect of mentoring schemes in the USA. They concluded that mentoring does have a measurable effect on the people who are mentored, but that the effects are somewhat modest. Positive outcomes include effects on high risk behaviours, and educational and employment outcomes. These effects are apparent across variations in age, race, and family structure. However greatest benefits are gained from those considered “high risk” - (socio-economically or environmentally disadvantaged).

Hall (2003) reports that there is a poor evidence base in the UK on the outcomes of mentoring programmes. Much of the research is focused on perceptions of either mentors or mentees and unlike the USA, studies have not used control groups for comparative purposes. Additionally, according to Hall (2003) the UK research does not attempt to quantify the impact of mentoring/befriending.

One study by St James Roberts and Singh (2001) evaluating the impact of mentoring on high risk primary school pupils found similar gains in the control and experimental groups in the development of confidence, self control and social awareness after one year. The authors concluded that perhaps longer would be required to achieve significant gains in the mentored group.

Heslop’s (2005) study which was conducted after the literature review by Hall, evaluated seven befriending schemes throughout England. A sample of 132 befrienders, befrienees, and their carers from across the seven schemes were interviewed on various aspects of the service. Findings revealed that fewer than a fifth of participants experienced an increase in social inclusion as few activities included interaction with wider groups.

Other issues raised were those of risk assessment, resourcing activities and managing exit strategies. Heslop also reported that few schemes collected any evidence on the effectiveness of their service in relation to the needs of their
clients or their service providers. This is in keeping with Hall’s (2003) conclusions. She recommends the provision of good practice guidelines which include evaluation strategies.

The Befriending Network Scotland (2005) received information on 277 projects in Scotland through a postal survey. Projects were classified as either Companionship/befriending (46%), Befriending/Mentoring (25%), Mentoring (18%) or unclassified (11%). The report gives demographic data on the nature of support offered, duration of relationship (<3 to >18 months), frequency and location of meetings, gender and ethnicity of service users and befrienders, and networks with other agencies. Low self esteem, isolation and loneliness and the need for positive role models were the main issues faced by those referred.

In terms of outcome measures, improved self esteem, reduced isolation and improved quality of life were reported in 90% of projects. No information was given on how this was measured or evidenced although the report includes quotes from the project providers:

“although not easy to measure we have evidenced more positive relationships between adults and young people” (Befriending Network Scotland 2005, p36.)

Rhodes (2002), a researcher in one of the largest befriending American studies; the Big Brothers/Big Sisters of America (BBBSA), suggests that mentoring can do more harm than good if mentors fail to deliver consistent support. She suggests that some mentoring programmes adopt a cavalier approach substituting one for another, suggesting that the protégés are interchangeable.

Rhodes (2002) cites Sipe’s (1998) work which suggests that successful mentoring is dependent on screening, training and support and supervision of mentors. Hall ‘s (2003) findings support this and contends that good mentoring is dependent on screening of prospective mentors, length and frequency of
relationship, on going training and support for mentors, parental support and involvement and suitable matching of mentees with mentors. Grossman and Rhodes (2002) also found that mentoring relationships which lasted for a year or more were the most successful.

Successful mentoring should also, according to the UK literature, establish links with other agencies affording wider opportunities for social inclusion of the mentee.

Service redesign in Scotland focuses on locating services within community settings and cross agency partnership working (NHS Scotland 2003), with emphasis increasingly being placed on self care strategies for those with chronic illness (Department of Health 2005).

However, there is a dearth of information available as to what is occurring in the community and the extent to which these services are effective, in particular with regard to how vulnerable individuals with chronic illness are supported, (Department of Health 2001). A review of the literature using CINAHL, Cochrane, BNI, and Medline databases, incorporating keywords such as befriending, chronic illness and cystic fibrosis revealed nothing of note specific to this group. Thus it would seem that this is the first project of its kind in this particular group of young people.

This research seeks to go some way to address the criticisms made in the literature about the lack of evaluation of befriending services, and add to the body of knowledge in this area.
CHAPTER 3:

METHODOLOGY

A challenge for researchers is presenting a clear explanation of the processes (methods) involved, as this has a direct bearing on the credibility of the evidence or findings. How believable these findings are is dependent on the sample selected, methods of recruitment and ways in which information is collected, analysed and ultimately reported on. This chapter will illustrate our research processes so that the quality of our evidence about befriending can be judged accordingly. In this chapter we will explain i) who we included in the study and why ii) what we asked of them iii) how we asked it and iv) how we analysed the information they gave us.

Overview

Overall, our research intention was to explore the impact of befriending for:

a) young people, in terms of their self perception, independence, education and socialisation. We also wanted to know if befriending helped them adjust to changes in their physical condition, and also to capture what they thought was important in a befriending relationship (what worked well, what didn’t work so well, and what would make things better);

b) parents, and how they perceived befriending as it affected them, and other family members, which of course included their child with CF

To achieve these aims, our study needed to include a variety of people. For example, young people with CF who had a befriender (between the ages of 8-18) and their parents, the befrienders themselves and other people who worked in community and hospital settings who had direct contact with children with CF (and their families). All these people's perspectives provided us with
comprehensive evidence about befriending. Their views, experiences and expertise identified important features about befriending in terms of what made it successful, what needs to be in place for befriending to work, what the benefits to having a befriender are and the skills and knowledge befrienders need to have to do the task well. Deliberately capturing all these differing perspectives about befriending and the befriender’s role, revealed to us what was common amongst everyone as well as what was unique to each individual ‘case’ scenario. So, although the child’s and parent’s view points were of primary importance in this research, the expertise of others added to the emerging picture of ‘befriending’. In this way, we were able to capture a rich and colourful account of the nature of befriending as it emerged, as well as identify the complexities the Butterfly Trust has to face in rolling out a service which is tailored to meet the needs of individual children with CF and their families.

**Planning, preparation and governance.**

In December 2005 the Queen’s Nursing Institute Scotland provided financial backing for the study which ensured the research was adequately resourced and supported. In January 2006 we approached Lothian Research Ethics Committee who provided a favourable ethical opinion on our intended research processes and procedures. Having already secured a steering group, (a panel of individual academics and experts in the field) to monitor and provide advice for us as researchers as the study progressed, we were finally ready to embark on the research in February 2006.

**Sample and sampling procedures.**

(i) Accessing children and families

The characteristics which made individuals relevant for the study in terms of their experiences of befriending were that:
(for the children / young people):
- they had CF
- had been allocated a befriender for a minimum of six months

(for the parents)
- they were the main care giver for their child
- their child had been in the Butterfly Trust befriending programme for a minimum of six months

Identifying relevant children and families who had experience of befriending was done through the Butterfly Trust.

We had targeted the start of the research to coincide with the first allocation of befriender / family partnerships. This partnership would have been in existence for six months, an ideal time for methods of befriending to become established, and rapport to be made between the befriender, the child and their main care giving parent. It was our intention to feed back to the Butterfly Trust concerns and accomplishments at this early stage of the programme so that appropriate changes could be made to processes such as recruiting and training befrienders or planning and allocating of befrienders to subsequent families. These same families would be interviewed 18 months into the programme to map their journey and evaluate the outcomes of the befriending programme at this established point in time.

Originally we had intended to interview a second cohort of befriender/family partnerships at their respective six month stage, so that we could evaluate the previous changes made to the befriending programme based on the experiences of the first family cohort. However, staffing issues specific to the Butterfly Trust incurred delays in recruiting more befrienders to the programme. This had implications for the timing of the research which meant this element of the study had to be dropped.
(ii) Consent procedures

The Butterfly Trust, on our behalf, approached families within the befriending programme and sought their permission for us to make contact. With the parents’ full knowledge, we were able to speak to children individually by phone, in order for us to ascertain their willingness to participate. Parents consented for themselves and the involvement of their child but children also gave their consent. We left contact numbers for the children and parents should they change their mind or had any follow up questions. We also checked out their continued consent before we started our interviews. Using this process, one child and one parent felt able to withdraw from the study.

(iii) Profile of the sample group

In total, six befriender/family partnerships (x 1 cohort) were followed and interviewed twice, if their befriending experience had extended to the full year after the first interview. From this one cohort, four of the families reflected a child-parent dyad, and in two families one child, and one parent was interviewed respectively.

These children varied in their disease severity, (27–101% % predicted FEV₁). All but one of the young people were still at school.

As can be seen from Table 1, 10 people in total were interviewed, only half of these were interviewed on two separate occasions. This was due either to participants withdrawing voluntarily from the study, or no longer complying with selection criteria – in other words, their experience of befriending was no longer relevant at the 12 month stage.
Table 1: Children and parents sample profile

<table>
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<tr>
<th>Time of interview</th>
<th>Family dyad 1</th>
<th>Family dyad 2</th>
<th>Family dyad 3</th>
<th>Family dyad 4</th>
<th>Family 5</th>
<th>Family 6</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>6 months</td>
<td>Father / child (age 15)</td>
<td>Mother / child (age 8)</td>
<td>Mother / young person (age 16)</td>
<td>Mother / child (age 10)</td>
<td>Mother / young person (age 18)</td>
<td>10</td>
<td></td>
</tr>
<tr>
<td>18 months</td>
<td>Mother / child (age 9)</td>
<td>Young Person (age 17)</td>
<td>Mother / Child (age 11)</td>
<td>Young person (age 19)</td>
<td>6</td>
<td></td>
<td></td>
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The Butterfly Trust supported our endeavours to recruit other people who had;
- relevant experience of the befriending programme (such as the befrienders themselves)
  and / or
- close working associations with CF children and their families (for example hospital personnel or individuals who had a hospital or community/educational link)

Table 2: Other personnel sample profile

<table>
<thead>
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<th>Play specialists</th>
<th>Befrienders</th>
<th>Educational liaison (hosp / community)</th>
<th>Total</th>
</tr>
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<tbody>
<tr>
<td>2</td>
<td>3</td>
<td>2</td>
<td>7</td>
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The befrienders were interviewed as a group, and the two play specialists were interviewed together. The other health care and community worker were interviewed individually.
Methods of collecting the data

Each of the participant’s knowledge and experiences of CF (either suffering from it, managing it, coping with it, monitoring and supporting children / young people through it) meant perspectives about befriending would be unique, depending on the context in which they experienced the disease – directly or indirectly.

What we wanted therefore was to capture subjective impressions with all of the 17 participants and describe fully their individual opinions and perspectives. This could best be achieved by face to face interviews. For the young people and parents, these interviews were ‘semi-structured’. This meant we followed a schedule of questions, which framed the information around what we wanted to find out. Semi structured interviews are highly efficient in terms of time (which suited the parents) and for people whose attention span is limited (which was good for some of the children). The semi-structured format was kept fairly consistent between each family dyad but we did allow for flexibility in our line of enquiry, depending on the preferred topic areas indicated by either the parent or child. In some cases, the child and the parent were interviewed together to aid the process and make the child feel at ease. For the befrienders and the play specialists, because of convenience, the interviews were conducted in their respective groups. An unstructured interview format was applied for the Educational personnel. This was because their level of expertise with either the befriending programme or knowledge of children with CF required maximum flexibility in the line of enquiry.

Each interview was conducted by either one of us, in the participant’s own setting (home or place of work). Each interview was tape recorded and we kept a record of our own thoughts and feelings and about what influenced the interview process while we were ‘in the field’. We did our own transcriptions verbatim, and then forwarded these typescripts to each other (with the tapes), to check for accuracy of what we recorded at each interview. For the families who we
interviewed twice, the information from the first interview was shared with them and used to structure a line of questioning in their subsequent interview.

Data analysis

To help with the analysis stage we used Ritchie and Lewis's (2003) ‘Framework’ model to build a matrix of themes and codes from the data. This helped to organise information so that an all inclusive picture could emerge from individual accounts. There were four stages in the construction of our thematic framework;

1. identifying themes and categories
2. constructing a coding tree to index and link these themes,
3. creating thematic charts
4. concept mapping.

A brief account of these stages will indicate this analysis process.

(i) Identifying themes / categories

By referring back to the aims of our research, we were able to review each interview transcript to select relevant categories of data according to the important themes or concepts which were emerging from what people had told us. For example, ‘child’s perceptions’, ‘parents’ perceptions’, ‘support’, ‘befriending’ etc. This process was continual – in other words, as each interview was transcribed and checked, they were individually scrutinised and cross checked to extract new and existing themes. A separate list of themes and categories was constructed for each participant group. Not only did this process help inform our lines of enquiry for each subsequent interview, but it also ensured that all new categories were included on relevant lists as they emerged.
(ii) Constructing a coding tree (or index)

Links between these categories needed to be made so that we could describe a composite, inclusive and holistic picture of what people had told us. Data was therefore labelled or coded according to each theme. For example under the theme of ‘befriending’ data was labelled and clustered into smaller unit codes such as:

<table>
<thead>
<tr>
<th>Befriending (theme):</th>
</tr>
</thead>
<tbody>
<tr>
<td>Expectations (code)</td>
</tr>
<tr>
<td>someone else for the child to talk to</td>
</tr>
<tr>
<td>support for self</td>
</tr>
<tr>
<td>knowledge of CF</td>
</tr>
</tbody>
</table>

This coding tree provided a structure to the data which could be easily indexed. For example, although overall 110 codes were used to label relevant data sets in all parents’ interviews, these codes could be indexed under just 12 headings (Appendix 2). Each participant group had their own coding tree.

(iii) Creating thematic charts

The next step entailed the construction of a matrix to refine themes and summarise key points according to each piece of coded data, whilst at the same time, making sure we reflected the context and the language of each individual participant. One matrix was constructed per theme. Each theme was therefore charted separately and headed using the codes from the coding tree allotted to that theme, and plotted against participants who were all allocated a row in the matrix. Plotting codes against all participants revealed significant areas with respect to; number of times they were mentioned, differences in opinions, gaps in participant’s responses (which indicated limited or no significance to associated codes). The matrix allowed comparisons to be made between all participants.
within each participating group (to reveal areas of consensus and individual differences), and across each grouping to identify where themes reoccurred or overlapped. It also provided opportunities to document our own process notes from the interviews. Because of the size and scale of thematic charts it is possible to only provide a section, which is hopefully illustrative of the process (Appendix 3)

(iv) Concept mapping.

Thematic charting provided a narrative to emerge around each theme. We could use the thematic charts to develop concept maps outlining participants' experiences. These concepts maps enabled us to link logically key elements of the experiences of CF and befriending, while keeping true, the detail and idiosyncrasy of each case. An example of the parent's concept map (Appendix 4) indicates how key themes were mapped to provide a composite picture of inter-linking themes. We used the concepts maps as the basic outline to the findings chapter. Both concept mapping and thematic charting facilitated a process of back-tracking to relevant quotations which are included to support and illustrate the following research findings.
CHAPTER 4:

FINDINGS AND DISCUSSION

The participants’ stories will be told under two main themes. Theme one describes having CF and living with it, whilst theme two describes experiences of befriendering. Within the two themes, stories are told from firstly the young people’s point of view, followed by the parents, the befrienders and finally the hospital and education personnel. Occasionally these stories overlap, and are therefore not always in that order, but in our view, this was the best way of reflecting the whole story.

Quotations have been used to illustrate emerging issues. For consistency all children irrespective of age have been referred to as ‘young people’ – YP, but remain connected to their family dyad (FD) as illustrated in Table 1 (Chapter 3). For example, where a young person’s quote has been used this has been coded as FD (number) YP, and for parents quotes, FD (number) P. Hospital and community personnel have been coded according to their professional role (Education Liaison – EL 1 or 2; Play Therapist PT 1 or 2; Befriender B 1-3).

Theme 1 - Having CF and living with it

Young people as experts of their condition

Young people with CF are knowledgeable about their disease and the effects CF has on them, with physical effects usually being described first. Older children showed more knowledge about the origins and progression of the disease:
“What do you know about CF?
“I get a bug, makes me cough, sick, breathless” FD2 YP (aged 8)

“Well I ken what it is and how I got it … I was born with it, it effects your lungs and digestion … I get thick mucus, I go to hospital every 3 months for 2 weeks for IV antibiotics” FD3 YP (aged 16)”

Metaphors were also used to describe the condition:

“… you use a ‘shield’ everyone else has got a shield, ours are like … weakened” FD4 YP

Indepth knowledge about their condition is not surprising as most of these young people have been living with their disease since infancy and managing self care treatments such as physiotherapy from an early age.

Young people were aware of their routines and, with encouragement from parents, got on with treatments;

“Well its a lot easier now cause she can dae her ain physio and take her ain nebuliser” FD3 P

Despite the age of the young people, the language they used which described the condition and treatments were sophisticated and medicalised, for example IVs, ‘Cepacia’, DNase, antibiotic names (Ceftazadime / Meropenem) ‘Pegs’ ‘buttons’ ‘nebs’ and ‘Ports’.

This level of expertise was seen by the befrienders as a real challenge. They recognised that the young people (and parents) used unfamiliar terminology and talked about people (e.g. hospital personnel), thinking that the befrienders knew who they all were. This is in keeping with Peterson’s (2006) notion of experts who are said to value technical information. The befrienders felt challenged by this and recognised that they were not at all expert and had to quickly get up to speed with the technical jargon. This befriender had been in a relationship with the young person for 2 years, but obviously had still not come to know the medicalised jargon.
“I would like more training about CF, the parents talk to you in jargon you don’t understand - what’s IV’s?” B3

Befrienders felt that perhaps parents and young people had high expectations of their knowledge base which made them feel uncomfortable and which made them want to pursue further training in CF. The importance of CF specific knowledge does not become apparent to befriender until they are in the field, although information about CF is available on an ongoing basis from the organisation. Perhaps befrienders feel they can never know enough about CF.

It would appear that the experience of coping with CF is so embedded in the daily routines of young people (and their parents), that they do not notice how specialised their language and terminology is. How they use these terms is matter of fact but never the less indicative of their expert knowledge and skill.

**Young people’s self perception and CF**

What was apparent in the conversations with more mature young people was their awareness of their own mortality. When asking them about their disease, they were forthright about its progressive nature and the fact that it can’t be cured.

“*You can die quite young with it, but the more you do your physio’ the fitter you’ll be*” FD1 YP (aged 15)

This knowledge of personal mortality is unusual for young people, and indicative of coping with the condition. However, far from this having an overwhelming negative impact on their lives, they demonstrated a resilience and matter-of-factness about getting on with the condition to make the most out of life. When asking one young person about how they thought CF affected them on a daily basis:

“*It doesn’t affect me at all … just parts of my daily routine and that, I just live with it*” FD6 YP
Despite physical limitations, parents also see their children attempting to normalise their disease, living in the moment, and to some extent ignoring their illness. This is in keeping with other studies (Staab et al 1998, Gee et al 2003). One father noted how his son, who is usually upbeat, tries to be like a 'normal child' in the sense that he ‘\textit{disnae let his illness sort of rule his life}’ \textit{FD1 P}

But on the other hand they do have periods where it gets to them. It makes them ‘angry' and ‘fed up', 'sad' and in general 'gets them down'.

\textit{“I cannae run aboot, I just feel crap and low” FD3 YP}

Young people are aware of their physical limitations compared to their peers and this inability to keep up can lead to feelings of frustration, low self esteem and embarrassment.

\textit{“My friends are all better than me, well not at everything, but I'm different compared to them........I'm sitting out huffing and puffing away all the time and they're all having fun running around” FD 1 YP (aged 15).}

In an attempt to be normal, parents indicated that their children often needed a great deal of encouragement to take their medication and do their physio regularly. Parents would talk about their children ‘rebelling right now’ or relying on the hospital to ‘sort it out’ or ‘put them back on the mend rather than do it themselves'.

As researchers we were anticipating negative attitudes to concordance with treatment regimes (Bernard et al 2004), but throughout our interviews with the young people, we did not pick this up. The reasons can only be surmised, but maybe a combination of two factors influenced the dynamic and made this aspect of the research difficult to explore with the young people themselves. One factor was who we were as researchers. Both being health care professionals (and one an expert in CF), young people may not have felt able to share with us the extent to which they refused to comply with treatments, for fear of reprisals
from health care professionals who were monitoring their progress. The other factor could have been the young people themselves. The fact that we had a group of young people participating in the research voluntarily, and sharing their experiences willingly about CF could be evidence that this group was not typical of their age or peer group. Or perhaps we just did not ask the right questions.

Parents themselves did not know whether maverick and negative attitudes their children displayed towards treatments was due to "a phase", or whether it was something more insidious - a genuine change in attitude that was indicative of a steady decline in their frame of mind.

The importance of friends

As would be expected in this group, peers are important, both in terms of providing support in helping to manage the condition, but also to act as a benchmark for how young people perceive themselves in comparison to their peers.

“I can’t do sports very well, I can’t go out every single day cos I’m not well. I can’t go pheww play with ma pals because I’m always in hospital. I get a bit jealous at others that aren’t like me – they get to do everything and I can’t”

FD4 YP

In terms of support, their friends visited when young people were in hospital and nagged them about being diligent with their treatments when bouts of ‘poorliness’ kicked in. Friends made allowances for what the young people had to cope with in terms of managing treatments, and did not discriminate on this basis.

“How do you feel about taking medicines when your pals are around? OK cos they all ken. Not embarrassed”. FD3 YP

For this young person, even sleepovers were not perceived as a problem. Feeding pumps where just accepted as part and parcel of the paraphernalia which accompanied the young person on their overnight stay. Likewise, dietary requirements were taken into consideration:
“I always get a wee wee portion cause they all ken” (about my condition) FD3 YP

However, taking treatments in front of others was difficult. When asked about how they managed their nebulisers in school one young person remarked;

“But I keep one in my bag in case I go outside and then take it in my coat and if I get puffed outside then I just take it when no one’s looking … it’s just I don’t like my friends seeing me …. When I’m on holiday I wear a T shirt when I’m swimming, coz like you know I’ve got a tube, a gastrostomy, the balloon one. Basically I put on a top they would ask me why and I’d just say … I just make up an excuse … I can’t tell them the real truth” FD4 YP

This quote indicates the difficulty young people face in trying to join in activities which are seen as fun and social. It reinforces why positive attitudes by peers help young people normalise their condition, which in turn, helps with their self esteem. For this sample of young people we interviewed, friends were fundamental in helping them see CF as an inconvenience, rather than a label which defined them. Their friends’ attitudes made a significant difference to a young person’s quality of life- being seen as an individual first and foremost helped these young people with CF not to consider themselves as primarily ‘CF sufferers’.

Disruptions to young people’s lives:

Education

Despite the growth in self care and home treatments enabling shorter stays in hospital, absences from school and social isolation continues to be a problem in CF in this sample.

Symptoms such as chest infections and uncontrollable coughing, sore joints and swollen knees, digestive problems, tiredness and feeling down generally, mitigated against regular school attendance. Even when they manage to make it
into school turning up at class could be a bit hit and miss, mainly because of the strict routine of their treatments. For example, a typical daily physio regimen for one young person during school hours was a 40 minute session, in two twenty minute bouts. Physiotherapy was only part of it. She still had to take inhalers creon and calogen. The school nurse was available for help with all this, and in one school, the headmistress had been known to assist with physiotherapy for pupils with CF.

While parents were concerned about the disruption to schooling, young people themselves weren’t. In some instances, young people used CF as an excuse for not going to school but in the main, young people had an optimistic view about their ability to ‘keep up’. To a large extent this ability was facilitated by multigency working, which included the young person’s school, the CF team, voluntary agencies and educational liaison specialists. Contact with these individuals could be daily;

“… because (he) was doing very well at school and his illness sort of set him back … we cannae fault the school they have done as much as they can … been quite sympathetic … I mean I know that even whatever situations arise that we’ve always got (The Butterfly Trust), we’ve got the CF team, the school and there’s loads of professionals there we can contact, the social worker etc. So we know with anything, we just contact them”. FD1 P

Other young people felt that they had plenty of time and opportunity to catch up with their school work, especially during protracted hospital admissions. When hospitalisation was required, access to outreach teachers helped enormously, so although absences from school could be significant, catching up on school work was possible with the assistance of multi-agency working and supervised education while in hospital.
**Socialisation and hospitalisation**

Young people manage their own care while at home, but never the less, hospitalisation was a regular part of life for these young people. On average, young people were admitted to hospital for a minimum of 2-4 weeks every 3 months.

This necessary period of hospitalisation (for IV antibiotics, intensive physio, treatment of chest infections) impacted on young people’s social and emotional well being. Boredom and a perceived lack of control was frequently mentioned.

“*What’s the worst thing about having CF? All the hospital visits. It just kills me, coz your just sitting doing nothing all day, it’s so boring*” FD6 YP (aged 18)

“I cant go and play with my pals cos I’m always in hospital” FD4 YP (aged 10)

Young people often spoke about the ‘play ladies’ who were a significant figure for them when in hospital, bored and isolated from other children. Time with the play therapists was looked forward to, as it provided a focus for the day. The individual attention was also welcomed. The play therapists themselves recognised that boredom for these young people with CF was a problem and found CF children a challenge to keep entertained;

“*If they are in for two weeks it’s hard and it’s hard for us you know to provide activities for a two week stint*” PT 1

Patterns of hospital stay have altered, and when possible children are allowed home even though treatments continue. But this is not always the case, especially if complications arise or the necessary expertise is not readily available at home.
For some though, hospital is not something to dread. Because of the routine and individual attention which can be provided by the play therapists hospital can be seen as ‘a second home’.

“When in hospital … “He’s brilliant. I mean all the nurses have got to know him that well. (Nurse) she’s just a life saver, yeah, he just loves it he has no hassle … the only thing he hates is having to go back and get his IVs. He’d rather be out playing. It’s worse in the summer when all his friends are out” FD2 P

Because of the nature of the condition, young people with CF are prohibited from mixing with peers and friends with CF even when admissions coincide. The enforced segregation exacerbates isolation and levels of boredom and negatively impacts on their emotional well being. Young people and parents themselves find this frustrating and the emotional support that was once gained from mixing with other young people with CF is now lost;

“You know there should be some sort of set up, I mean obviously they wont have the CFs together, they used to have the CFs together, that was so beneficial for (kids like him) … he watched the kids that were doing their treatment … you know they learn more about the illness from each other” FD4 P

“It’s no good when the nurses say ‘he’s got a different bug and I cannae mix with them coz I’ll get infections and the illness will get worse’ so I don’t get to see them as much” FD1 YP

Parents attempt to minimise disruption to their children’s routines during hospitalisation by using various strategies, such as bringing them home for a few hours from hospital in between treatments, and being with them in hospital last thing at night and first thing in the morning. However, this impacts on the parents themselves, causing fatigue, feelings of guilt and being pulled in different directions.
Parents as care givers:

Parents as experts

The burden of care usually falls on parents, who are taking on more and more advanced technical roles such as administration of nebulisers and intravenous antibiotics. The literature recognises that these roles were once the remit of trained nurses (Lowton 2002), and further reinforces the parents as experts of their child’s condition.

Although clearly technically competent when administrating IVs, providing physiotherapy, setting up nebulisers and feeding pumps their expertise could only be assumed when treatments where administered at home, but when in hospital this expertise needed to be relinquished. This opinion was not universal, what was however, was the non recognition by medical staff of the parent as expert of their own child at the time of diagnosis. Despite the fact that for some diagnosis was 15 years ago, parents still felt the need to vent their frustrations about not being listened to during the interview.

“That was the biggest nightmare ever….diagnosed from a baby……we were sent to (hospital)! for every test imaginable and they kept saying there’s nothing wrong with him, he had asthma….i used to carry pots of his poo everywhere I went and they said I was feeding him too many dairy products…. And I was like- it’s not normal…..you know yourself there’s something wrong” FD2 P

In the intervening years since diagnosis, parent’s knowledge about CF has grown and become embedded so that now, they are attuned to subtle changes in their child’s mental and physical condition. Recognition of these changes acts as a cue for them to seek help, support and treatment;

“… I know what’s going to happen … I know when he’s going to get ill” FD5 P

“… and sometimes in the morning you could tell that (he’s) just no, he’s not gonnae have a good day today – just not in the frame of mind. He’d be feeling really down” FD1 P
Being so close makes it hard for parents. When it is their own offspring, the burden of ‘expertise’ can be overwhelming:

“… not sure if I could manage it (IVs) I approached them and I said I’d like to do home IVs and then they started saying ‘Oh well, you’ll need to do this and do … and I was thinking maybe I’m not ready for it yet … I deal with handicapped kids at my work and I just felt Oh no, what if something …. It’s your own eh?”

FD2 P

Parents see their role as monitor, assessor and deliver of care. This has physical, social and emotional effects on the parents. Physical effects include lack of sleep deprivation and so exhaustion, and general fatigue due to the daily care routines or endless rounds of appointments and hospital visits. A great deal of parents’ time was invested in physical caring to try and keep their children out of hospital;

“I would rather that I did everything than take him in and let the nurses deal with it, cos he’s such a handful” FD2 P

“You’ve got to monitor him, so you can’t go to bed or anything, just to make sure he doesn’t have a reaction” FD4 P

Although caring for a child with CF is physically and technically demanding, this aspect of the role eventually becomes routine albeit with input and support from specialist practitioners. As the child develops and matures, this aspect of care is entrusted to the child, and the responsibility for the parent shifts from one of physical carer to one of encourager and mentor. Relying on their (often) rebellious teenager to be responsible and take their health seriously was viewed as a far more challenging aspect to the caring role than being ‘merely’ technically competent.
Parents as encouragers

Within their sphere as carers, one of parents’ major roles would appear to be that of encourager/supporter to their child. Parents described how they spent their time nagging children about treatments. This constant “nagging” by parents leaves them feeling drained and emotional. The language of the battlefield is used frequently in quotes from parents who in describing this role as encourager used terms like “constant battle”, “rebellion” and “fight”.

In keeping with recent literature (Havermans et al. 2007), parents noted discrepancies in their child’s perceptions of the impact and burden of treatments compared to that of their own;

“To (son) it’s an hour a day (laughs), he doesn’t see nebulisers
........it’s half an hour of physio morning and night” FD4 P

This parent could be spending up to six hours per day on treatments yet her son reported treatment demands as an hour per day. Perhaps treatment has become so embedded into some of the children’s lives that they don’t view it as a separate issue. Alternatively, parents generally have more information regarding, illness and prognosis of the disease and this may impact on their perception of the reality.

Despite the fact that interviews with young people did not indicate any problems in terms of concordance with treatments, the picture from the parents told a different story.

“Aw, (sighs) she’s just at that age, that everything’s a fight, it was easier when she was younger, she would sit and she would eat and take her capsules nae bother. She’s a typical teenager, it can be stressful at times right enough’ FD3 P

“It can be quite tiring and stressful coz (son) isnae the best of cooperative kids and you’ve got to persuade him and it’s just one battle
after another trying to get him to do his medicines and his nebulisers” FD2 P

“… he’s rebelling a lot just now. His physio … he has to have physio twice a day. And he’s lucky … I’m lucky if I can get once a day. He’s not takin his medication. He’s thrown that away” FD5 P.

Although the physical element of care giving had all but been relinquished to the child, for most of these family dyads the weight of responsibility and accountability for adherence to prescribed regimes was still lying heavily with the parent. Locus of control had shifted to empower the child, but it was clear from interview data that the burden of care was still all-encompassing for the parent.

**The cost of caring on parents**

**Physical, social financial and emotional**

Because administering treatments and monitoring their child according to a prescribed regimen, is a twenty four hour, seven day a week responsibility, social activities can be few and far between, and for some parents it was easy to lose touch with friends. There were also stresses and strains within partnerships. Activities with other parents of children with CF could work in the parents’ favour, but not if they wanted to escape from CF for a while, especially if other parents needed to offload. Parents were physically tired as often sleep was disturbed, but in general, they displayed a stoical attitude towards their role, presumably because they knew how much their child was suffering with this debilitating condition.

However, the burden of caring has meant much personal sacrifice for parents financially and emotionally, with several of the parents giving up their jobs or only working part-time in order to care for their child. This was the case whether the child was perceived as “well” or at the “unwell” end of the CF spectrum, as there is great variation in the extent and effects of the disease.
One parent had to sacrifice her studies in order to provide continuing care with treatments;

“I was doing IVs at home, I was trying to study for my Highers, then he was in hospital I was trying to study in the hospital, that’s hopeless”

FD4 P

while another mother had to reduce her hours dramatically in order to fit in with her son’s treatment regimen;

“… he was in hospital that often to start with that I couldnae get the time off and it was just you know … it was just getting really bad and I thought nut, time to give up. I just do one night a week now and it’s not as stressful”

FD2 P

This disruption to working life and planning a career is one way in which financial stressors add to the burden of caring but on a more pragmatic level, costs incurred while travelling to and from hospital can be onerous. Financial costs are apparent to the parent, but not necessarily to others outside the situation;

“… well if we’re going in to see her, it’s a train - £4 – taxi up, taxi back, then take her out for something to eat – a tenner – its well 35 quid. Well I’m on income support and I asked them and I kept all my train tickets, filled in the forms and they said I wasn’t entitled. I said ‘Christ Almighty’

‘FD3 P

The fact that CF is a genetic condition meant that for some parents, guilt was overwhelming and added to the weight of their caring load. This made dealing with ‘the big questions’ almost impossible to cope with. Understandably, parents didn’t want to look too far ahead, preferring to stay in the present:

“I feel very guilty and emotionally drained. It’s constant all the time … because I know what’s going to happen … I go day by day cause if I looked too far ahead, I would just be a mess probably. Cause I’ve had a few friends with CF that I have met through (son) and they died quite young and it’s just – god! … So I just do (son) day by day”

FD4 P

or when necessary, asking someone else to take on the big issues:

“… sometimes you’re optimistic and you think things are working out no too bad, and then you look at the other side of things … maybe no
work out too good. (His son) spoke several times tae me about ‘could he die o his illness’ … if he’s got any fears like that, that hopefully he’ll speak tae the befriender” FD1 P

For parents, the emotional cost of helping their child come to terms with an early death was significant. The more mature young people recognised this, and so deliberately took this elsewhere (usually to the befriender). For the parents themselves, their support came from other family members (partners, grandparents) friends, The Butterfly Trust and in particular the CF Nurse Specialists:

“I mean I just feel you can phone them at any time and they’re there … we’ve got a lot of family who’ll help if they need to” FD2 P.

**Being pulled in different directions**

“We get stressed by it ah mean, (brother) gets everything he wants under the sun and more, you try through the social work, you try and give him extra time. When (son) in hospital … do something special. We’ve done all that and it just doesnae make any difference. … and of course we end up fighting cos his dad loses the head and I say look he cannae help it and then I lose the head, and it’s just a big vicious circle” FD2 P

This quotation reflects the different directions parents can be pulled in when caring for a child with CF. Siblings can react negatively to having a brother or sister with CF and this further impacts on family functioning and parental stress. Jealousy was underpinning the behaviour in the above case, as the brother saw attention being diverted away.

Examples were cited of how CF dominated the household activities - giving medications, hospital visits, appointments with the school – and consumed the mother’s / father’s time which took them away from other children.
This diverted attention can take its toll. Jealousy can break out into violent outbursts – verbally and physically which is upsetting for parents to witness, and the effects on the sibling rivalry can be long lasting:

(Brother and sister) they’re like cat and dug, just don’t get on at all and eh ‘he’s jealous’. Jealous of whit? He says all the attention she gets. I said, well, I cannae help it, she’s got to get her medicines, she’s in the hospital I’ve got to go and see her. Christ he’s 18, he’s no wain. I says well (2 years ago) he’s nothing to be jealous of. He never missed oot, she never got anything that they never got, so I dunno what he’s jealous o’” FD3 P

Jealousy is not the only emotion parents have to deal with. In some families, parents have to cope with younger brother’s and sister’s heightened anxiety, as their level of concern for their sibling reaches tipping point;

“L (the wee one – sister) is like, oh I’ll give (brother) his tablets, but J (wee brother) is starting to soil himself again. He worries very much about (his brother) and it’s him that comes and tells me that his feeds been taken off. He worries a great deal. I think as well, because they’re all at different stages and all my attention is basically on (child with CF) the wee ones (L&J) are feeling so left out” FD5 P

However, the picture was less bleak for some families as life, busy as it was, just continued uninterrupted – CF was just absorbed by the comings and goings of family life.

Either way, the picture that emerged for the parents was one of pressure. Time and space for themselves was practically non existent, as attention had to be divided according to competing priorities. Even when CF was not predominant, the general mêlée of family life was very much in existence as we were able to witness first hand. Interruptions were constant with phones and door bells ringing, pets barking or scratching, brothers, sisters, girlfriends and relations (curiosity getting the better of them) surreptitiously observing the interview process. In many ways this was an advantage for it gave us an inside and unique perspective on ‘normal’ family life, and provided a peek into what a typical day looked like for some of these parents.
SUMMARY OF THEME 1

Young people and parents were experts of their own situation, the condition of CF and relevant treatments.

Although stresses, strains and fears for the future were apparent, parents were clear as to their caring role and what this entailed. Help and support was at hand from voluntary agencies, hospital and educational personnel. Parents were concerned about their child with CF, their future (short and long term) and also about the effect CF has on other members of the family. Their time was limited, and competing priorities were draining and exhausting. Personal sacrifices had to be made in order to manage the condition. The hardest job was dealing with the 'big questions' and they needed someone else to share this load. As the main care givers, their burden of responsibility (physically, psychologically, financially and emotionally) was enormous. Socially they were quite isolated, but the professional and familial networks they had were supportive and accessible.

Young people were in the main, stoical about their condition. They saw themselves first and foremost as individuals typical of their peer group, but limited by the disease. This attitude was very much dependent upon friend's attitudes, for example their acceptance of the condition and the necessary equipment and treatments. In other words, their peers were significant in helping them to normalise the disease, boost their self image and nurture their self worth. Hospital admissions were dreaded and seen as an interruption to much needed socialisation – the isolation and boredom from being in hospital had negative psychological effects. Play therapists made a big difference. Young people were aware of the long term effects of the disease and needed to talk about this, but were aware of the distress this could cause to parents.
The next theme indicates how significant the befriender is for young people with respect to these issues although this is only one facet of the benefits to befriending for both the young person and their parent.

**Theme 2: Experiences of befriending**

**Profile of befriending**

Table 3 gives information regarding the number of befrienders, duration of relationship and frequency of meetings of the six young people in the first cohort who were befriended.

**Table 3: Numbers of befrienders and duration of befriending relationship**

<table>
<thead>
<tr>
<th>Family</th>
<th>No of befrienders</th>
<th>Duration of relationship</th>
<th>Frequency of meetings</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>FD 1</td>
<td>1 (male)</td>
<td>2 yrs</td>
<td>weekly</td>
<td>Now finished</td>
</tr>
<tr>
<td>FD 2</td>
<td>2 (male)</td>
<td>2 months, 5 months</td>
<td>monthly</td>
<td>Going well</td>
</tr>
<tr>
<td>FD 3</td>
<td>3 (female)</td>
<td>1 months, 2 months, 1-2 months</td>
<td>2 weekly</td>
<td>just started with new one</td>
</tr>
<tr>
<td>FD 4</td>
<td>1 (female)</td>
<td>19 months</td>
<td>2 weekly initially, now 6 weekly</td>
<td>ongoing</td>
</tr>
<tr>
<td>FD 5</td>
<td>1 (female)</td>
<td>1 month</td>
<td>once</td>
<td>1 outing only</td>
</tr>
<tr>
<td>FD 6</td>
<td>2 (female)</td>
<td>7 months, 1 month</td>
<td>monthly</td>
<td>Just started with new one</td>
</tr>
</tbody>
</table>

From Table 3 it can be seen that young people have had between one and three befrienders over the duration of the project (18 months). It was envisaged that
each family would have had just one befriender which indicates the difficulty of retaining befrienders. Explanations for this might be because life events for the befrienders impacted on the length of the relationship. Befrienders are busy people who have other commitments and sometimes found it difficult to sustain the befriending relationship. For example, several of the befrienders were young people in their 20’s who were in transition between education and employment;

“They’d be better if the lassies were a wee bit older, ken they’re away on holiday, I dunno what age, she can only be in her 20s, changing jobs, its months since we’ve seen her”. FD3 P

However, while age may have been important in terms of the way in which befriendning worked in some cases, this was not true in all situations. Rather, because of the nature of befriending children with CF and the potential burden this carries, the characteristics and attributes of the befriender would appear to be more significant for a sustainable relationship. In relation to the role of the befriender;

“I think it has to be quite specialised and that the people who are the befrienders need to know about the condition … I suppose some people would have an anxiety about that, it’s a life threatening illness …. There’s an added dimension to that in that the kids future … unlike other kids who don’t have to think about their future … So it’s companionship as well. Someone that has a lot of energy because it can be tough being with young people. All the demands”. EL 2

Befriending children and young people is a challenge for any adult, but when this is exacerbated by a debilitating, progressive and life threatening disease, the potential burden on the befriender necessitates a maturity and steadiness of attitude in order to sustain a supportive and empathic relationship.

By the time of the second interviews, befriending relationships had lasted from between one month to two years indicating that the pattern of befriending was still not well established in all cases.
Where possible, befriending were matched to young people by gender, although one boy specifically requested a female befriender. This was not always possible given the low availability of male volunteer befrienders.

Frequency of meetings depended largely on the individual relationship (range 1-6 weekly). Length of meetings were usually between one and four hours depending on the planned activities. Meetings were usually focused around an activity such as bowling or going to the pictures or going to a coffee bar. Meetings were always on a one to one basis, and did not involve integration with other agencies. The nature of the activities very much depended on the preferences of the young person which was attributable to their age. Funding for these activities was provided by The Butterfly Trust.

Initiating meetings was done in a variety of ways: through befrienders contacting parents, or befrienders contacting the young people directly - only occasionally did young persons initiate contact.

**Befriending – what’s good about it?**

Young people see befriending as fun, they enjoy going places, and see it as a distraction away from everyday things.

The more mature young people appeared happy to spend time chatting (e.g. in a coffee bar) and used their befrienders more as confidantes, compared to the less mature young people who were more focused on doing things or going places.

“it’s what I expected, going out having a wee bit of a laugh and when I come back my dad says I’m always happier than when I left home”

*FD1 YP aged 15*

“ It’s good, he took me to his laboratory…. I got to make smoke!”

*FD2 aged 9*
Physical activities that befriencers and young people chose to do, were different from those that perhaps parents would undertake, such as rock climbing and Go-Karting. The young people we interviewed were energetic and enjoyed physical activities. Coffee bars and ice creams were pleasurable enough, but the young people needed to explore the boundaries to their physicality and have adventures – do things that they wouldn’t normally do with their mums and dads. Befrienders provided this opportunity. Befrienders themselves saw their role as providing a sense of fun, providing a safe place physically and emotionally, offering mentorship and widening young peoples’ horizons, as well as creating space for parents. They felt that they could provide new experiences for the young people which they might not otherwise have.

“I said let’s give it a try and he enjoyed it. If you don’t push them to do something different they’ll never expand their small worlds” B3

Parents expressed a general view that befriending is great for their young people when it works well. Working well for these families meant that the befrienders were present, accessible and were making a difference to their child’s life. There was an acknowledgement from parents that it gave their children a sense of purpose, something to look forward to, and was helpful in building confidence:

“she mopes about and it drives me nuts, then (befriender) phoned …..she was out of that bed, in the shower and dressed before 10am” FD3 P

This is in keeping with the literature (Befriending Network Scotland 2005) which states that improved self esteem was reported as a positive outcome in 90% of projects surveyed.

Young people recognised that having a befriender took the pressure off parents. Mature young people were aware of the stress CF can incur for parents with regards to the long term view of prognosis:

“when they first asked me if I wanted a befriender, I just wanted to go through it myself, saves my mum and dad having to do all that stuff” FD6 YP
This young person was referring to her need to protect her parents from the difficult issues regarding poor prognosis and an uncertain future. Being able to offload on another individual who was separate from the family felt safer for all concerned. For this young person the befriender was also there for ‘something really personal you don’t want to talk to family about’. This was echoed by one of the Education Liaison Personnel

“What could you see as the benefits of befriending? Having another person to talk to …because sometimes the young people are quite protective of their parents feelings and don't tell what they’re worried about” EL 1

Parents also recognise that their children may not always want to share the big questions with them and that having someone outside the family would be beneficial and would relieve the emotional burden somewhat.

“… this is one of the reasons that the befriender … plays a role in it … that builds up a sort of friendship with (son) … that if he’s got any fears like that, hopefully he’ll speak tae the befriender” FD1 P

This parent was not alone in feeling relieved that there was someone else for their child to share their fears with. Parents recognised that the befriender could reduce their own emotional burden if their child shared the big issues with their befriender.

However, the biggest benefit to parents themselves is time out from the young person, and was seen as a good thing by all parents.

“Peace! (laughs) 2 hours of peace!” FD2 P

If their child was happy, they could relax. If it was working well for the young person, it worked for them too on many levels; befriending a child with CF provides the parent as care giver with a few precious hours to themselves. Physically and psychologically this is a relief from the burden of caring, and something which was very much looked forward to.

“Aye, sit here, get the old black and white film on, cup of tea, that’ll dae me! (rubs her hands)” FD3 P
Play therapists knew very little about the project apart from occasionally coming into contact with befrienders visiting the young person in hospital or hearing about it positively from parents. Both they and the Education Liaison Officer recognised that it was a good thing, as evidenced by the apparent difference in one of the young people who had been befriended.

“Yes, definitely an excitement, suddenly he was able to access things he wasn’t doing before….” EL 2

What could be better?

We identified six key areas worthy of consideration which relate to the organisation of and processes incurred in befriending, (including ongoing support and training). We have discussed these under the following heading:

**Working with the barriers:**

**Getting started**

In some cases there seemed to be a delay in getting the programme going, with one parent and one professional commenting on the slowness of the referral system and the delay in getting started;

“She explained what it was and I thought well great…but I think it took something like six months to get off the ground after that” FD1 P

The referral system is currently tri-partite, between the CF Nurse Specialists, the Social Work Department and The Butterfly Trust. Suggestions from participants that families could self-refer and that other personnel involved with the young people could refer directly to The Butterfly Trust may help speed up this process. However it is recognised that matching and screening are important in successful mentoring schemes (Hall 2003), therefore perhaps this needs to be balanced with a streamlined referral process.
Improving social networks

Some young people (usually the younger ones) expressed a wish to have other young people along rather than always a one to one with the befriender:

“I want to go to the base (where there’s other young people) and I would like it if we could make cakes” FD 2 YP (aged 8)

Some befriending organisations have a ‘base’ where young people can be together playing pool, baking, doing art work etc. This was recognised by one of the young people and was a source of frustration for him in not being able to go and meet other children. There are practical difficulties: as highlighted in the introduction, young people with CF are not encouraged to mix together because of cross infection, therefore group activities would not be permitted unless the CF young person was in a group of non CF young people such as ‘the base’.

Mixing with other (non CF) young people would however address one of the fundamental criticisms in the literature of existing befriending programmes; that of increasing social inclusion and interaction with wider groups (Heslop 2005). Social inclusion is fundamentally linked to the role of the befriender as they act as gate keepers to a wider network to allow sustainable socialisation. Once the befriender steps back, this network should continue. Befriending therefore is only one step in increasing a child’s socialisation.

Understanding legislation

In terms of other ways of socialisation for the young person with CF, one young person was keen to foster a relationship with the befriender’s child. Both parties were frustrated by missed opportunities they could do nothing about.

“He doesn’t understand why he can’t come to my house or I can’t bring my child along. And neither do I.” B3

Current Child Protection Legislation results in organisations being very cautious about boundaries and would require a heavy administrative burden, for example,
disclosure checks on all family members, should a befriender want to take a young person into their home.

Befriending children with CF poses specific challenges. The nature of the disease dictates that widening social networks can only occur with other children without CF. However, as described Child Protection issues may limit these opportunities which can leave the befriender as the main point of social contact. Linking with non CF befriending agencies might therefore be a way to enable social inclusion for the child.

**Safely pushing boundaries**

In terms of those young people and befrienders who had been in longer term relationships, there was a desire from all parties in the relationship (young people, parents and befrienders) to push the boundaries a bit further, to move on, as illustrated by the following quotes:

“It’s a bit weird, when you’re friends with someone, they’re involved with your life, you’re involved with their life and you get to know each other….she can’t do that” (e.g. take him to her house) FD4 P

“It’s difficult to know how far the relationship will progress if we’re just going places all the time and can’t take it further than that. I would like him to meet my family” B2

Befrienders wanted to have more autonomy in decisions about how much they do with the young person. One young person was not sure about what they were allowed to do with their befriender, or how to negotiate this.

“I thought we would just be allowed to do the high street cafes, cinema and I dunno if I can ask to go go-karting… and then he says we can’t do that and that would put me quite down” FD1 YP

However, when unsure, they would usually turn to The Butterfly Trust for advice.

Processes of negotiation were usually unproblematic in terms of physical activities, as common sense usually prevailed. But for more complex
circumstances, such as social situations, the Butterfly Trust was required to take responsibility for decision making processes. This did not always please all parties involved. Perhaps this comes back to the point of understanding the legislation and should be made explicit to all parties at the start of the relationship.

**Exit strategies**

When young people were asked about how long they thought they might have a befriender they were generally unclear about the answer. One young person expected to have the same befriender for the next five years, whilst others were less clear, but expressed desires for the relationship to continue for a while. This uncertainty about exit strategies was shared by the parents and the befrienders, who had not discussed this issue with their young people or the organisation, but hoped that those relationships that were working well would continue.

“Say you decide to give it a go for 6 months, then at the end of that time you should sit down and evaluate what’s happened” B3

This quote demonstrates that endings have not been made explicit. There appears to be no understanding of the length of commitment that needs to be given, or any indication about settling in and winding down. The decision about how long to ‘give it a go’ appears to be arbitrary.

When relationships did end without warning, young people felt confused about the processes for maintaining contact, and sometimes were sad, angry, felt a lack of control, or felt to blame

“Don’t know what happened to the first one……I thought it was me…. I could never get in touch with her” FD3 YP

Parents expressed similar emotions to their young people when relationships were terminated without notice.

“I feel let down, and (son) has been let down because he was getting close to her” FD5 P
Young people and parents want to know what is going on in terms of communication processes between themselves and their befrienders. Befrienders usually took the initiative in setting up meetings although sometimes communication processes were two way with the young people initiating contact. Young people and parents appreciate that befrienders are busy people but are concerned when communication processes break down. Young people expressed a wish to stay with the same befriender:

“It’s horrible changing persons every so often, so stick with one”

FD6 YP

This echoes Rhodes (2002) sentiments that a cavalier approach to befriending can be damaging to young people and support should be consistent in its nature.

Support and training

Befrienders recognised that there were challenges to befriending, such as building relationships and maintaining boundaries. Those who were in longer term relationships recognised that it took a while to build a rapport.

“…It can take a while to get to that stage, I’m now totally comfortable with (child), we can talk about anything….” B3

Befrienders require more support at the early stage of the relationship especially at the initial meeting with the family.

“I had to initiate the first visit and first contact myself and that was a hard call to make, I would have really liked someone from the organisation to be there” B1

Normal practice within The Butterfly Trust is for the befriending co-ordinator to accompany the befriender to the first meeting at the young person’s home to introduce all parties and make people feel comfortable. This befriender’s experience was not therefore the norm, but nevertheless, this quote illustrates the importance of this practice.
When asked about their training and support needs in general, befrienders classified this in two ways; support from the organisation and support from the parents.

In terms of family support, befrienders want to be kept informed when the young person is hospitalised so that they can visit and offer support. They also want to know that they’re doing a good job:

“I want feedback from the kids and the parents, are they happy with what you’re doing?” B2

From the organisation

“I would like more formal evaluation about how it’s going …
“It would be great if I could even be given something to read about the routines or treatment” B3

This reflects the befrienders' anxiety about their own lack of knowledge of the disease compared to the perceived expertise of the family. Befrienders want to be given information about CF. When asked what skills they thought befrienders should have, both young people and parents expected their befrienders to have a degree of knowledge about CF.

This point is also echoed by one of the Education liaison personnel who suggests that befriending this group of young people requires an insight into the disease and its deteriorating nature, in order that the befrienders know the potential risks of getting involved with a young person whose life might end prematurely.

Other support issues such as financing activities were raised by the befrienders, as those who were seeing their young people weekly were more likely to use up their budget than those with less frequent meetings. Parents were also unsure at times whose responsibility it was to be financing activities.

“Well maybe they did mention it when they came to the house, but I cannae recall it, and the first time he had money with him, but god, only about £3-4 and I thought ‘Who pays for it?’” FD2 P
Education Liaison personnel's perceptions of support and training needs of befrienders includes sharing good practice with other befriending organisations, reflection of befriending experiences amongst peers, and making explicit the commitment needed by the befrienders to the project, with a minimum of six months given as a suggested length of commitment. This is in keeping with findings from Grossman and Rhodes (2002) study which suggests successful relationships usually occur in those that have lasted a year or more.

**Potential for development of the befriending role**

Health and education workers could see how the befriending service could complement and support their own roles. Their suggestions about how they could work with the befriender has potential for how the service could be developed, and would enhance the education and social wellbeing of the child through joint working.

When asked about the potential for working together with befrienders, play therapists saw that befrienders visiting in hospital would allow the parents to have a break and perhaps help to reduce their own workload, allowing them to focus on other young people.

> “If the wards are really busy, and you know that the befriender is coming in tomorrow then you can think ‘I’m not going to have to worry – I can go and see other children” PL 2

Befrienders felt they could contribute to multidisciplinary meetings, e.g. case conferences, but recognised that this would involve an increase in communication from either the school, hospital or Butterfly Trust and place an increased burden upon themselves. Befrienders are busy people with multiple roles outside the befriending one. Full time jobs mean attendance at meetings during the working day are problematic, but not impossible, but limited attendance at such venues confines their level of involvement in decisions and
multidisciplinary working. However, Education Liaison personnel also recognised the potential of befriender involvement in review meetings to advocate for the young person and explain how the world works from their point of view. For example, non attendance at school and for the

“… more social side of things … sitting around a table talking about the child because we want a more holistic approach” EL 1

The Education Liaison officer could see the potential for befrienders to help with educational projects when the young person was in hospital.

“If there was a piece of follow up work, ….if we were able to say to the befriender, look we’re studying Vikings and there’s a thing on at the museum….that kind of thing, one way of linking us together” EL 1

The size and scope of what education liaison personnel do coupled with time constraints, mean their educational remit is focused on literary and numeracy skills. Including the befriender in the more ‘sciency type things’ would help the young person to engage in a more rounded educational experience. Currently this is not happening.

More could be made of the befrienders in terms of informing the play staff and Education Personnel of their existence to allow them to engage in one to one educational projects as previously described with young people. In this way, benefits from the service would be wide reaching as multi-agency working would have a direct impact on the overall social care and educational support of the child. Furthermore, knowledge of this befriending service would encourage direct referrals from other personnel young people encounter as a consequence of having CF. However, it should be remembered that this is a new initiative and as with any new project, it may take a while for news of it to be disseminated before it becomes fully established.
SUMMARY OF THEME 2

Befriending is seen as a good thing by all parties in the project. It offers a fun distraction for young people, impacts positively on self esteem and helps them raise issues of personal importance. It helps relieve the burden on parents physically and emotionally and gives them some time out for themselves. They saw the befriender as helping with the ‘big questions’ and difficult issues about their child’s prognosis. Befrienders themselves saw that activities could broaden young people’s horizons, and the nature of their relationship with young people could help foster trust to discuss difficult subjects.

The associated prognosis of CF makes befriending young people and children with this disease exacting. Ongoing support and training for the befrienders was seen as important, especially as the parents and young people themselves were perceived as experts of their own condition and situation. As yet, befriending has not widened the young peoples’ social networks beyond that of the befriender. Communication processes are at times unclear and exit strategies have not been addressed. Befrienders want more support both from the families they work with and from The Butterfly Trust. Referral processes can be slow and there is potential for the befriending role to develop further.
CHAPTER 5:

RECOMMENDATIONS and LIMITATIONS

Limitations:

Sample cohorts

The original remit of the research was to interview two cohorts of young people about their experiences of befriending. We were unable to do this, within the timescale of the project as the reasonably high turnover of befrienders meant that some of the original cohort had to be matched with a second or third befriender. A second cohort was therefore not established during the timescale of this project. In addition, there would appear to be some delays evident in the screening and matching process of young people and befrienders which prevented a second cohort being established. The numbers in this project are therefore quite small. We have however managed to interview young people who are both in the early stages of having a befriender as well as those in long established relationship, which gives long term and short term views on the project.

Scope of the research

In terms of the aims of the project, we as researchers feel that we have demonstrated that befriending does impact positively on young people's self esteem and independence and can help them address and raise issues of personal importance. Furthermore, befriending offers support and precious time out for carers and can help relieve issues such as boredom and social isolation for the young people in this sample. We have not been able to address whether befriending influences concordance with treatment, perhaps because the young people did not wish to disclose this to us for fear of recrimination, or alternatively
because this group were particularly concordant. A third explanation is that perhaps we as researchers were not direct enough in our questioning on this issue.

**Interview methods**

Originally the method of choice for data collection from parents was focus groups. Looking after a young person with CF means parents’ lives are incredibly busy and perhaps it was naive of us as researchers to think we could get them together in one place, given the individual demands placed on them and their families. The method of data collection was therefore changed to one to one interviews to allow the researchers to go to the parents at a time convenient to them. Whilst the research suggests that focus groups are an efficient way of data collection and capitalises on members reactions to what others in the group say (Polit and Beck 2004), it was just not practical for the parents to do this. Conversely, a one to one approach may have elicited richer information than in a group as the research also suggests that some people feel uncomfortable disclosing information in a group setting.

**Conclusion**

This is a pilot study and the researchers are aware that during the 18 months of this study in response to demand, the scope of the original befriending project has been extended outwith the Lothian area and there have also been requests from older adults with CF and siblings of young people with CF to have a befriender. More research needs to be carried out to evaluate the effectiveness of the wider project.

Feedback of initial findings from the first round of interviews, enabled The Butterfly Trust to implement some of the following recommendations* in advance of this final report. These recommendations have still to be formally evaluated.
RECOMMENDATIONS:

- A minimum commitment of one year is given by the befriender to the project.
- The Butterfly Trust makes explicit what that commitment entails and the possible consequences of non-commitment, for each party in the relationship.
- Exit strategies are discussed with the young person, their family and the befriender at the outset of the project and managed throughout the duration of the relationship.
- Recognise that befrienders need extra support at the beginning of the relationship, which should include supported visits to families.
- Regular training updates for befrienders should include, peer reflection, information giving and networking with other befriending agencies.
- Examine ways of working which would allow the young person to expand their social circle to that other than the befriender (e.g. outings with users from other non CF befriending organisations)
- Encourage chains of communication in both directions between the Butterfly Trust, other organisations (e.g. hospital, school), the family and the befriender to increase awareness of the project and improve communication on ongoing personal, educational and social issues.
- Befrienders should have ongoing dialogue with The Butterfly Trust re costs of activities according to frequency of outings.
- Explore ways of working between young people and befrienders which meets their continued mutual development within Child Protection legislation.
- Investigate ways of streamlining the referral, screening and matching processes to reduce delays.
- Facilitate processes to ensure more joined up working between befrienders and outside agencies; for example in assisting with educational review meetings or school projects.
REFERENCES


APPENDIX 1:

The Befriending/Mentoring Model

In recognition of the many variances and practices of befriending/mentoring projects in existence, the Befriending Network (Scotland) (2005) has developed a model which attempts to clarify the Befriending/mentoring spectrum. The Befriending/Mentoring spectrum is

“based on the nature of the objectives of a supportive relationship, and on the importance given to achieving those objectives through the relationship” Befriending Network (Scotland) (2005 p52-53)

The model lists six broad types of befriending/monitoring through the spectrum. All definitions are taken directly from The Befriending Network (Scotland) (2005) report and are as follows:

**The Befriending / Mentoring Model**

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<tr>
<th>----- MENTORING--------</th>
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<td>----- BEFRIENDING-------</td>
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1. Befriending - The role of the volunteer is to provide informal social support. The primary objective of the relationship is to form a trusting relationship over time usually in order to reduce isolation and to provide a relationship where currently none exists. Other outcomes may occur e.g. a growth in confidence but are never set as objectives for the relationship.

2. Befriending - The role of the volunteer is to provide informal social support. There may be additional stated objectives at the start of the relationship e.g. increasing involvement in community activities. The success of the relationship is not dependent on these objectives being achieved, but seen as a potential benefit of befriending over time.

3. Befriending/Mentoring - The role of the volunteer is to provide informal social support and through this supportive relationship to go on to achieve stated objectives e.g. increasing the client’s confidence to enable them to do activities independently in the future.

The objectives do form a basis of discussion between project, volunteer and client at an early stage, and are renewed over time.
4. Mentoring/ Befriending - The role of the volunteer is to develop objectives with the client over time. Initially the role is to develop a relationship through social activities in order to establish a level of trust on which objective setting can be based. Due to the client’s changing circumstances, objectives may take time to set and may be low key.

5. Mentoring - The role of the volunteer is to work with the client to meet objectives which are agreed at the start of the relationship. These are achieved through the development of a trusting relationship which involves social elements but which retains a focus on the objectives agreed at the start.

6. Mentoring - The role of the volunteer is to work with the client solely on agreed objectives which are clearly stated at the start. Each meeting focuses primarily on achieving the objectives, and the social relationship if achieved is incidental.
APPENDIX 2

Parents’ coding tree

1. Child vs. parent perceptions
   1.1. Compliance
   1.2. Differences in reality
   1.3. Of child’s health

2. Parents perceptions of child’s reactions to having CF
   2.1. Being in the moment
   2.2. Wanting to be the same / normal
   2.3. Locus of control / pushing boundaries
   2.4. Despair
   2.5. Embeddedness
   2.6. Embarrassment
   2.7. Social restriction
   2.8. Using CF to own advantage
   2.9. Accepting info as absolute
   2.10. Why me?
   2.11. CF doesn’t dominate
   2.12. Ignoring it
   2.13. Feeling Blue
   2.14. Taking responsibility
   2.15. Taking responsibility
   2.16. To other CF sufferers

3. Parents reactions
   3.1. Fears for future (immediate)
   3.2. Fears for future (long term)
   3.3. Guilt
   3.4. Emotional burden
      3.4.1. Switching off
   3.5. Getting on with it
   3.6. Desperation
   3.7. Anger at others incompetence
   3.8. Playing mediator
   3.9. Letting go
   3.10. Advocate
   3.11. Respecting child’s autonomy
   3.12. Positive outlook (now 13.5)
   3.13. Fatalistic
4. Effects of the disease
   4.1. On children
      4.1.1. Segregation
      4.1.2. Isolation
      4.1.3. Treatments
      4.1.4. Physical triggers
      4.1.5. Schooling
      4.1.6. Mood swings
   4.2. On parents (X ref to Number 3)
      4.2.1. Social activities
      4.2.2. Sleep
      4.2.3. Career
      4.2.4. Debt
      4.2.5. Relationships
      4.2.6. Pulled in different directions
   4.3. On siblings
      4.3.1. a) Sharing the burden of care
      4.3.1 b) Being side lined
      4.3.2. Feeling jealous
      4.3.3. Displaying deviant behaviour
      4.3.4. Overcompensating
      4.3.5. Absorbing/normalising

5. Parents as experts
   5.1. On their child
   5.2. On CF

6. Parents as care givers
   6.1. Primary care giver - physical
   6.2. Monitor
   6.3. Provide emotional support and reassurance
      6.3.1. Answering difficult Q’s
   6.4. Following / making a plan
   6.5. The physical burden of care
      6.5.1. Uncertainty about required skills
   6.6. Protecting them from others with CF
   6.7. Motivator (X REF 13.0)

7. Biography
   7.1. Siblings
   7.2. Parent
      7.2.1. Career
      7.2.2. Relationships

8. Support
   8.1. Family members
8.2. Activities / time out
8.3. Friends
  8.3.1. CF
  8.3.2. Non CF
8.4. Other CF parents (X ref 3.4)
8.5. Hospital personnel
8.6. Role Models
8.7. Cool Friends Staff
8.8. School
8.9. Befriender

9. Befriending
  9.1. Expectations
    9.1.1. Some else for the child to talk to
    9.1.2. Joint decision making/negotiation/involvement
    9.1.3. Support for self
    9.1.4. Getting to know them
    9.1.5. Taking the initiative
    9.1.6. Knowledge of CF
    9.1.7. Realising limitations
    9.1.8. Time out/peace
    9.1.9. Confidence building
    9.1.10. Sense of purpose
    9.1.11. Getting out and about
    9.1.12. Sharing the big questions
  9.2. Feeling let down
  9.3. Activities
    9.3.1. Wanting others with them
  9.4. Communication
    9.4.1. Ways of keeping in touch
  9.5. Processes and procedures – clarity of and monitoring
  9.6. Befrienders commitment to agreements and plans
  9.7. Hopes for the future
  9.8. Enabler/supporter/mentor
  9.9. Good thing
  9.10. Mitigating systems
  9.11. Accessible
  9.12. Exit strategies
  9.13. Biographies
    9.13.1. Maturity/age
    9.13.2. Gender
  9.14. Focused attention
10.0 Relating to other with/without CF
   10.1 Parents comparison of their CF child to others with CF
   10.1.1 “ ” “ ” WITHOUT CF
   10.2 Learning from others with CF
   10.3 Parents relating to other CF parents

11.0 Being in Hospital
   11.1 Conflict with staff
      11.1.1 Communication difficulties
      11.1.2 Getting conflicting info
      11.1.3 Getting snippets of info
   11.2 Burden of travel (time)
      11.2.1 “ ” (cost)
   11.3 Being kept waiting
   11.4 Lack of partnership in care
   11.5 Getting away for a while
   11.6 Knowing child is happy in hospital
      11.6.1 Knowing child is unhappy

12.0 Diagnosis
   12.1 Age
   12.2 Being palmed off
      12.2.1 Having to keep coming back
   12.3 Reactions
      12.3.1 Grief
      12.3.2 Shock (X Ref to parents reactions)
      12.3.3 Denial
      12.3.4 Distress
      12.3.5 Accepting
      12.3.6 Feeling overwhelmed
   12.4 Implications for sibs
   12.5 Symptoms
   12.6 Family History
   12.7 Knowing something not right
<table>
<thead>
<tr>
<th>Theme 3</th>
<th>Fears for the future 3.1/3.1.1</th>
<th>Hopes for the future 3.2</th>
<th>Guilt 3.3</th>
<th>Feeling inferior 3.3.1</th>
<th>Emotional burden 3.4 / 3.4.1</th>
<th>Getting on with it 3.5</th>
</tr>
</thead>
<tbody>
<tr>
<td>AA</td>
<td>Leaving school with precious little despite being bright. P8 Disappointed P5 x ref Could die of his illness P7</td>
<td>Potential to do whatever he likes in terms of his education P8</td>
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<td>AB</td>
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<tr>
<td>AD</td>
<td>Big blow when he finds out he can’t have children P11</td>
<td></td>
<td>Nippy staff Nurse made me feel like a bad mother P10.</td>
<td></td>
<td>Too much pressure. Putting life on hold P3</td>
<td></td>
</tr>
<tr>
<td>AE</td>
<td>Bit of a struggle coz he doesn’t know what’s happening down the line P1. X ref 2.1 Good quote P11</td>
<td>Feel guilty and emotionally drained. Its constant. P2 Xref 3.4 Guilt is tremendous I cant be there … when he’s ill P13 Xref 3.6</td>
<td></td>
<td></td>
<td></td>
<td>X ref 3.3. Doesn’t want to talk about it – switching off P4. Just do day by day – friends with kids who have died P11.</td>
</tr>
</tbody>
</table>

**APPENDIX 3: Thematic chart-parents**
Background: 7.0
- 5 children
- 5 adults: (4 mothers, 1 father) div, sep, married
- All primary carers
- GSOH, copers, +ve outlook

Effects of disease on child 4.0
- Exclusion from school
- Social isolation
- Compliance issues
- Physical symptoms
- Moody/rebeling
- Hospitalisation: likes it/hates it

Reactions 3.0
- Get on with it
- Struggle
- Want to switch off
- Guilt
- Fears for future

Personal sacrifice: life on hold

Results in

Effects of the disease (parents)
- Lost careers
- Guilt
- Financial burden
- Relationship tensions
- Trapped
- Fatigue(interrupted sleep)
- Difficulty juggling/prioritising responsibilities
- Pulled in different directions

What support do parents get? 8.0
- Family (esp. granny)
- Boyfriend
- Siblings
- Sometimes unsupportive
- Formal: hospital/school
- Informal: other CF parent

How do parents manage their child’s care? 6.0/5.5
- Give treatments (feeds, nebs, physio)
- Monitoring
- Assessment
- Emotional support
- Parents as experts in care/knowing child
- Nagging
- Routinising tx

How do parents see their child reacting to CF? 2.0
- Normalising
- Using CF to own advantage
- Fall behind at school
- Become clingy
- Denying it
- Fed up/ depressed
- Get desperate
- Living in the moment

Effects on others 4.0
- Sibling rivalry
- Jealousy
- Overcompensation
- Worry about sibs
- Worry about mum

APPENDIX 4: Concept map; parents’ stories