



investing in children

*“ I am in control of my Cystic Fibrosis, my
Cystic Fibrosis does not control me”*

A report on how to improve health services for
young people with Cystic Fibrosis
in
Bishop Auckland and Darlington

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Introduction and Brief

'I am in control of my Cystic Fibrosis, it doesn't control me'

This quotation from a 16 year old boy with Cystic Fibrosis (CF) highlights the need of a young person with CF to live as normal a life as possible. This can be achieved by successful control of their CF through the co-operation of the young person, their CF medical team and the young person's family.

Living with Cystic Fibrosis is very stressful, and occasionally communication and treatment problems arise between the young people and their medical team. The staff at the specialist Cystic Fibrosis clinic based in Bishop Auckland Hospital acknowledge these difficulties, and in a desire to address them, they want to find out from the young people who attend the clinic, what they think of the appropriateness of the services provided to them at present.

In the Autumn of 2003 Godfrey Nyamugunduru Consultant Paediatrician and Veronica Moreton, specialist Cystic Fibrosis nurse approached Investing in Children to act as independent facilitators for this project. Investing In Children (IiC) is an organisation, which supports children and young people and enables children and young people to have a say in the decisions that effect them.

The following report is a resume of the issues raised by the young people and the suggestions they have made for the improvement of the service they receive.

Issues

1. Personal Life

- Isolation
- Bullying
- Frustration
- Motivation
- Knowledge - teenage issues and CF

2. The CF Paediatric Clinic

- Staff
- Communication
- Knowledge about treatment and CF related illnesses
- Adult clinic
- Appointment times
- Entertainment

3. Hospital

- Staff
- Communication
- Treatment
- Isolation
- Entertainment

1. Personal life

In order to understand the issues the young people have raised about their medical treatment, it is first important to know from them some of the challenges that they face in their personal lives living with CF.

The young people who have contributed to this report have a very mature attitude towards their daily treatment routine, which is accepted by them all as a means of remaining healthy.

Young people with CF do not want to be viewed as being different from everyone else, and they often don't tell their friends that they have CF. As one young person said 'When you are young you don't fully understand about CF, when you get older it becomes more of an issue, and you know you are different to everyone else'. Another young person summarised how living with CF makes the teenage years more difficult; 'It is only in the last few years that having CF has really hit me. When I compare myself with my friends, I feel frustrated'

- **Isolation**

Many of the young people with CF said that occasionally they felt isolated from their friends by their CF. 'It's nice to chat to someone who knows what it is like' is a common sentiment expressed by the young people. The older teenagers particularly felt frustrated by lack of contact with CF teenagers, because previously in the clinic waiting room, they had been able to talk to young people with CF. Now, because of concerns about cross infection, socialising in the clinic waiting area has been stopped.

Parents would also like to talk to other parents who have children with CF in an informal environment, and in they miss being able to sit in the waiting area at the clinic and chat as they had done in the past.

To help them feel less isolated the young people wanted to be able to talk to CF teenagers outside their family with whom they could share their concerns and problems. These are their suggestions.

Suggestion:

1. The young people would like to set up a database of contact details (either text or email) of young people in the area who have CF, so if they want to, they can contact each other. Not every young person wants to talk to other young people with CF.
2. As not every young person has access to a computer the young people have also suggested that a newssheet could be produced with any interesting information about the people who attend the CF clinics. So young people in the area can keep up-to-date with what is happening to each other.

- **Bullying**

Some young people with CF have experienced teasing and at worst bullying at school. Younger children are often quizzed about the medicine they take at meal times and their frequent hospitalisation. One young person was teased about their portacast ; 'Some people say that I have a third nipple'.

The young people felt that the best way to handle teasing at school was to be able to tell their friends about their treatment so that they could answer their questions easily. Another young person said that being questioned by their school friends had; 'Made me more curious and want to find out more about CF, so that I could answer their questions'. The young people have made the following suggestions on how to handle awkward questions.

Bullying contd:

Suggestion:

1. One idea was to explain to children, even very young ones, that the medicine they take and physiotherapy exercises they do is to help to keep them healthy. Just as the rest of the class try to keep healthy with regular exercise and a good diet. The medical team could advise families on the type of information to give to their children and how to tell them about it.
2. Most young people have very supportive teachers at their schools, but the teachers do need to be well informed about CF and to be aware that some children may single out a child with CF and pick on them. In order to handle these problems successfully, there needs to be regular communication between the CF medical team and the school.

• Frustration

The young people occasionally view their physiotherapy and medical treatment as a great nuisance, which interferes in their daily lives. They particularly feel frustrated when they compare themselves with their school friends who have more freedom. 'I can't be spontaneous and say yes to sleepovers after school because of having to do my physio'. They are even more frustrated if they have to have their antibiotics administered intravenously (IV's) as this further curtails their normal daily activities, schoolwork, social life and sports.

Some of the young people have felt very rebellious about having to have IV's and when their parents have administered them they have reacted by pulling out the line.

Acknowledging this problem and in order to make the administration of IV's less stressful the CF clinic have in some instances asked the community nurses to administer the IV's in the young people's home and during school. This has made a huge difference to the young people's lives and their attitude to IV's. In one case the community nurses visited a young person at home during the summer holidays so that they didn't have to go to hospital.

This flexibility is greatly appreciated by the young people who have been offered it, and they would like this to treatment option to be available to everyone.

• Motivation

Many teenagers commented on how hard they find it to motivate themselves to do their physiotherapy exercises. Many of them have to get up very early to do their physiotherapy (using a PEP mask too) before they leave for school; 'It's very hard to do your physio when you feel well and haven't got a cough, and even harder to do your IV's before school'

Some young people said that they had become more motivated to do their physio after they had been in hospital and had seen how poorly some CF children were. Other young children had been told by their parents that if they didn't eat properly they would have to be fed through tubes. These shock tactics may work to motivate some children to look after their health but not all. Not every family would feel comfortable with having to explain these serious consequences to their child. As it is very important for young people with CF to be motivated to look after their health, the young people have made the following suggestions as to how this can be achieved.

Motivation contd:

Suggestions:

1. Taking part in sporting activity helps to keep CF children healthy so the young people suggested that role models could be used to encourage families to involve their CF children in sporting activity from an early age. They suggested that by using examples of young people who excel at sports they could show how this positively affects their general health and therefore their medical treatment. For example one young person with CF who is an excellent footballer, has not had to have IV's for 3 years despite the fact that he is colonised with Pseudomonas. The young people would like this information presented on a leaflet or on a chart, which they hope, would motivate other CF children to look after their health.
2. The young people also suggested that the clinic should start a reward chart to show how well each attendee (identified only by a number) was looking after their health. This could be measured by how much weight they had put on or how tall they had grown, or how few Ivs they have had to have in a year. A prize could be awarded every 3 or 6 months to the clinic attendee who has managed their health most successfully.
3. In hospital the young people suggested that good health management and co-operation with the medical team could be awarded by the young people being given privileges such as a Pizza or DVD treat on the ward.

• Knowledge -teenage issues and CF

None of the young people had been given specific information about adolescent issues by their CF medical team. One young person who has had a delayed puberty stated that; 'No one told me that my growth rate may be slower. I would have found this information helpful and reassuring, because when I compared myself to my friends in early teens I was much smaller than them'. This had worried the young person. Issues such as alcohol had not been discussed with any of the young people by the medical staff. In fact one young person had found out from a CF friend that if they took certain tablets it was possible to have an alcoholic drink but; 'I would like to know what drinking alcohol could do to my health. They tell us about smoking and the damage it does, but nothing else'. This is an example of where partial information from friends could be dangerous, because the full medical implications of drinking alcohol have not been explained.

Other CF teenagers who are in relationships would like advice on how explain to their partners about their CF.

Some young people would also like advice about Careers and if there were any jobs that their CF would prevent them from doing.

The young people would like to know more about social issues and CF, and they have made the following suggestions about how this information can be given.

Suggestions

1. Many of the young people felt embarrassed about asking their CF team these personal questions. Instead they would like to be offered the information by, either the CF specialist nurse or another member of the medical team whom they trust.
2. They would like to be given leaflets about adolescent issues and suggestions about where they can find more information or help if they need it.

By offering this information the CF team gives the young person a chance to make a choice about whether they want to know more about adolescent issues or not.

2. The CF Paediatric Clinic

- **Staff**

Without exception the young people all have a good relationship with their CF team, the consultant and specialist nurse. Being treated by the same staff over a period of some years has created a trusting relationship between both parties, and the young people find this very reassuring. The young people felt that this relationship and the nurturing environment of the paediatric clinic help them to cope more ably with the rigours of living with CF.

- **Communication**

On the whole the young people felt that communication between themselves, their families and the medical staff is good. The staff at the clinic speak to the young people as equals; as one 14 year old said; 'They treat me as a grown-up'.

However there are occasions when communication breaks down and then the young people and families feel reluctant to call the clinic with any health concerns. They feel guilty about bothering the staff because they know how busy they are. When communication breaks down like this the young people lose their faith in the medical staff who are treating them.

Some young people felt that when they were younger it was acceptable to telephone staff if they had worries about their health. Now they feel guilty about phoning for advice. They wondered whether the staff felt that the young people are more able to look after themselves now that they are teenagers, and therefore they need less support from the clinic.

Once they had reached their teenage years the young people said that on the whole the consultant discussed their treatment with them thoroughly, explaining reasons for doing it and it's outcome. However on occasions they have felt that they have been excluded from decisions about their treatment, and that the staff talk to their parents about their treatment rather than to them. To improve communication between the young people and the clinic they have made the following suggestions.

Suggestions

1. The young people would like to be included in decisions about their medical treatment from around the age of 10/11.
2. All young people would like to be spoken to as equals and on a level that they can understand.
3. There should always be good communication between the clinic and the young people and the staff should be approachable, so that no one feels they are being a nuisance by asking for help.

- **Knowledge about treatment and CF related illnesses**

In most cases the young people are happy about their medical treatment, although they all find IV's a nuisance to administer. However occasionally they have been uncertain about some treatment they've been prescribed. This has increased their anxiety about CF particularly if they feel that they haven't been properly consulted with; 'I was prescribed IV's and the Doctor hadn't even seen me'

Another young person explained that; ' If I have more information about my treatment, I feel less worried about what is going to happen to me'.

Many of the young people felt that they knew very little about how CF can affect other parts of the body. In one instance a young person had developed diabetes. The possibility of this had never been discussed with them by their consultant so; 'It came as big shock and I have found it hard to accept'. Although one young person had had the opposite experience; 'I have known diabetes is a possibility for at least a year now'.

Knowledge about Treatment contd.

In another case a young person had been given a body scan and had been sent the results in the post which showed the beginnings of liver disease. This was a big shock to the young person and their family. They would have liked to have been told beforehand by the Consultant about the possibility of liver disease and given the results in person so that the consequences could have been discussed. Good information would prepare the young people more thoroughly about their future health and lessen the shocks, they have made the following suggestions:

Suggestions

1. The young people would like as much information as possible from the CF medical team about their treatment so that they can be make informed choices relating to their health.
2. As they get older the young people would like more information about how CF can affect other parts of the body. They would like to be well prepared about further health problems.
3. If they develop a further illness the young people would like to be able to talk to the specialist consultant about this to reassure them about future treatment and prognosis.

• Adult clinic

The teenagers who attend the paediatric clinic are very anxious about having to move away from the secure environment of the paediatric clinic to the unknown adult clinic. Some older teenagers have stayed longer in the paediatric clinic and; 'I feel a bit silly sitting their with the little kids now'. They are worried that the staff at the adult clinic won't be as good as the staff at the paediatric clinic and that this will have an adverse effect on their long- term health. To help with the transition between the paediatric and adult clinics the young people have suggested the following ideas.

Suggestions

1. The young people would like the paediatric staff arrange a visit to the adult clinic for the older teenagers so that they can meet the staff who will be treating them.
2. If possible the adult clinic staff could also visit the paediatric clinic occasionally so that the young people get to know them.

• Appointments

The majority of young people were happy with their appointment times, although everyone complained about having to wait a long time in separate consulting rooms (common practice due to fears about cross infection) until they were seen.

Some older teenagers did complain that their appointments were during school time and this often meant that they missed out on important lessons, and therefore they resented their visits to the clinic.

In contrast to this some young people praised the clinic because the staff had arranged appointment times after college for them. As fewer people attend the clinic late in the afternoon the young people don't have to wait as long to be seen either. Staff from the clinic had also arranged to visit a child at home who for a short time had problems attending the clinic.

On some occasions the clinic staff have arranged for the community nurse to administer IV's in the young person's home or at school, so that a young person's daily life is disrupted as little as possible by their IV's.

Appointments contd:

The young people who have benefited from these flexible arrangements have really appreciated them. However not all the young people seemed aware that after school appointment times were available. So that young people didn't see visiting the clinic as a big deal, they have made the following suggestions to improve the appointment process.

Suggestions

1. The young people would like to suggest that later appointments are offered to all older teenagers and other young people who have difficulty attending the clinic.
2. Some young people felt that their appointments at the clinic in Newcastle were faster than at Bishop Auckland and they wondered whether this was due to more available staff or to a better appointment system?

• Entertainment

All the young people find waiting for their appointment in the individual consulting rooms very boring because there is nothing there to keep them occupied. To help to keep them entertained while they wait the young people have suggested the following:

Suggestions

1. To put a television/video, computer games console or radio in each individual consulting room.
2. To have a good supply of teenage magazines available to read in each room.
3. To have a hot drinks machine, as well as the current vending machine, in the waiting area so that they can buy a tea or coffee while they are waiting.

3. Hospital

• Staff

The young people's experience of the medical staff on the ward varied from; 'They are very approachable' to; 'I find them hard to talk to because I feel that they are very busy and I don't want to bother them with something small'. The young people often feel that they are a nuisance on the ward, and feel guilty if they have a query and have to ask the staff for something. On the whole the nurses don't seem to have the time to talk to them. The young people find that this makes their stay in hospital very boring and lonely, particularly as they have to be kept apart from other young people with CF due to concerns about cross infection.

The young people's experience of the ward staff at the old Bishop Auckland hospital was excellent and they knew them well and trusted them. However recently at both Bishop Auckland and Darlington Hospitals, some young people have had inexperienced nurses who don't seem to understand CF and it's treatment. This and the fact that the nurses on the ward are not specialist CF nurses causes them great concern. To make a hospital stay less lonely and worrying the young people have suggested the following.

Suggestions

1. The young people feel that the nurses should be trained in how to communicate with young people.
2. They would also like the nurses to have time to say hello or at least smile even if they are very busy.

• Communication

In general the young people in hospital have been treated by staff with respect and have been spoken to as equals.

In one case at the RVI in Newcastle the nurses had trusted the young people enough to let them stay up until the early hours watching Big Brother.

However many of the young people in other hospitals have had the opposite experience of being looked after by staff on the ward who had patronised them or were sarcastic towards them; 'When I was being sick she asked me if I had swallowed a ball'. This experience had increased the young person's anxiety and had not helped their recovery.

From these experiences the young people and their families have concluded that the staff on the ward are poorer communicators than the staff at the clinic, and this has made being in hospital an even more frightening experience than it needs to be. To improve their stay in hospital the young people have suggested the following.

Suggestions

1. The young people would like to be treated by nurses who respect them and have time to talk to them.
2. The young people would like the hospital Doctors to ask them how they are feeling and to explain to them the treatment they are going to have in hospital.
3. The young people would like to build a good relationship with the medical staff, so that they feel comfortable sharing their health worries with them.

• Treatment

The Doctors on the ward have on the whole explained to the young people why they have been admitted to hospital and what their treatment will entail. One young person was asked by the hospital Doctor; 'If I minded being admitted to hospital'. The Doctor continued by giving the young person a number of choices about their treatment. They were very reassured by this approach and trusted the Doctor to treat them successfully. In contrast to this reassuring behaviour a number of the young people whilst in hospital had been assigned a new nurse who didn't know how to administer IV's. Instead she had asked the young person or their parents to show her how to do it. This caused the young person to worry about the nurse's capability to look after them.

In the larger hospitals the physiotherapists have involved the young people in decisions about their treatment and have given them a choice of whether to use a PEP mask or to do exercises. This has made the young person feel involved and respected. On the other hand a few young people had experienced incidences in smaller hospitals where

their parents have had to be called in to come and do their physio for them, as no one else has been available to do it. This has caused the young people and their families to worry about the efficiency of the hospital and the effectiveness of the treatment. Is it because of financial cuts that there are not enough physios to do the treatments? As one mother has said; ' I don't mind travelling to a hospital further away, despite the problems of getting there and parking, if I know that they are getting the best treatment available'. To ensure that each young person is receiving the best possible treatment available they would like to make the following suggestions.

Treatment contd:

Suggestions

1. The young people would like the nurses who look after them to be competent in the administration of IV's. If they are not uncertain how to do this they should ask their colleagues for help and not the patient!
2. The young people would like greater involvement in decisions about their treatment.
3. The young people would like more physiotherapists to be available to treat them.
4. The young people and their family should be given a choice of which hospital they are admitted to. This decision to be based on where the best available treatment is for that person.

• Isolation

Young people with CF who are admitted to hospital are unable to be in the same hospital ward as other CF teenagers because of concerns about cross infection. This makes a stay in hospital very lonely and boring for young people who are hospitalised for a long time. The experience is similar for young people who are admitted to smaller hospitals as there are rarely any other CF young people to socialise with anyway. Some young people have had a more positive experience in a larger hospital. Here two young people on the ward with CF have had the same infection and so the staff have allowed them to socialise together. This has not only helped the young people entertain themselves, but it has also helped them feel less isolated and less different from their peers. The larger hospitals also allowed the young people to watch DVDs together and even order in take-aways, the young people found this socialising very beneficial. The parents are also happy to know that their children have someone to talk to in hospital. So if they can't easily visit their child, particularly if the hospital is some distance away then they are much happier and less worried knowing that their child is not alone in hospital. To help relieve these feelings of isolation and boredom the young people have made the following suggestion.

Suggestions

The young people would like to be allowed to socialise in hospital with other CF young people who have the same infections. This would make for them feel happier and maybe aid their recovery. However they are aware that because of the problems of cross-infections this may not always be possible.

Conclusion

This report has highlighted the many discrepancies found between one individual's experience of the clinic, hospital and their medical treatment. While taking into account that each person is different and that Cystic Fibrosis varies from person to person the young people still feel that the treatment they receive and the relationship they have with the medical staff should be consistent. To this end they are recommending that a set of guidelines should be drawn up for all staff treating Cystic Fibrosis to adhere to, so that each young person and their family are given the same opportunities for treatment and choices in their medical care.

The research project has also highlighted the essential role of the specialist Cystic Fibrosis nurse. The specialist nurse is as important to the young people as their consultant. Not only does she provide a high standard of service to them and their families, but she is also a reassuring presence in their lives which enables them to manage their Cystic Fibrosis more successfully. The young people frequently measure the service they get from other medical staff against the Cystic Fibrosis clinics efficiency and this is how have discovered that the other medical services they receive are frequently lacking.

To ensure that all young people with Cystic Fibrosis get the same level of care the medical staff should follow the young people's proposed guidelines. The essential role and importance of the specialist Cystic Fibrosis staff to the young people should also be acknowledged. So that in the words of one teenager all young people with Cystic Fibrosis will truly be able to -'Control my Cystic Fibrosis and not let it control me'.

Having worked on this project the young people are hopeful that their opinions and ideas expressed in this report will be valued and as a result of this the service they receive and the delivery of their treatment will be improved.