**CFMothers.com: Patient information relating to motherhood**

The following information is based on data collected as part of a doctoral thesis, completed by Dr Sophie Cammidge, as part of her training to become a clinical psychologist. Sophie’s research is entitled ‘When women with cystic fibrosis become mothers: Psychosocial impact and adjustments’. Sophie aimed, for the first time, to understand and explore in depth the experiences of mothers with cystic fibrosis, after noting a lack of research in this area. She presented her research at the European CF Conference in Lisbon in June 2013 and the European CF Society recognised the significance of this work, awarding Sophie the ‘Young Investigator of the Year’ award for her work. Below is a summary of her findings, written in a ‘question and answer’ format.

11 mothers with CF were interviewed. The average age of participants was 30 years, and average lung function was 68%, although ranged from 27% to 103%. Participants had 13 children between them, ranging in age from 7 months to 14 years. Four participants worked part-time, one full time, and the rest were homemakers. Mothers included those who had conceived naturally, been through IVF and those who had adopted.

**Preparing for motherhood**

*What kind of preparation might I do for motherhood?*

The majority of mothers in this study discussed how they had prepared themselves for motherhood, which involved taking advice from their CF team. Many mothers explained they felt it was important to discuss their pregnancy plans with their team, so that they could stop taking any potentially harmful medications. They also talked about the importance of getting as healthy as possible prior to the pregnancy or the adoption process. Some mothers also prepared by ensuring the help of family and friends would also be available should they require it.

Some participants felt their CF teams focused too much on preparing for, and getting through, pregnancy, and not enough on preparations, and planning, for motherhood. As a result, they felt it was hard to know what to ‘expect’, and the majority of mothers said having children was harder than they expected it to be in regards to issues such as the lack of time they had to themselves and the amount of care children require.

**Physical health**

*What might happen to my health if I decide to have children?*

Seven mothers in this study discussed their health status during pregnancy and/or after having children. Two mothers who had experienced some health deterioration during pregnancy noticed a quick improvement in their health within a few months of giving birth. However, five participants explained it took a long time to physically recover from pregnancy, and experienced a worsening of symptoms after having children. Most of these mothers attributed this health deterioration to not being able to complete all of their treatment after having children.

*Will my health make it harder to be a mum?*

The mothers in this study discussed the impact of their health status on their ability to carry out mothering activities and the more poorly they felt, the harder it felt being a mother. Most mothers described feeling that their health sometimes limits them to an extent, such as in regards to the kind of play they can engage in.

*Will being a mum impact my health?*

The mothers in this study discussed the impact that mothering has on their physical health. Many participants discussed feeling sleep deprived, particularly during the first few months, which they often felt had a negative impact on their health. Some participants also described sometimes feeling physically exhausted as a result of activities such as carrying their children, pushing the pushchair long distances, and engaging in play time.

**CF Care**

*Will my CF team support me if I decide to have children?*

Participants in this study described a range of experiences in regards to how supportive their CF teams had been. Over half of the participants had experienced, at one point or another, at least one doctor being unsupportive of their decision to have children. However, most doctors and teams were supportive provided that patients were in the correct health and had fully thought through their decision.

*Will my CF care need to change when I have children?*

The mothers in this study discussed the ways they felt their CF care needed to be adapted after having children. Helpful adaptations included the following:

* Increased contact with the CF team (particularly in the first few months after having a baby)
* Being seen at home rather than in clinic where possible
* Discussions with the team about ‘life’, and not just a focus on ‘medical’ issues
* Increased emotional support
* The ability to complete IVs at home rather than in hospital.

Participants also highly appreciated CF teams’ understanding if they had not managed to complete all their treatment due to the demands of motherhood, and suggestions as to alternative techniques they may use for physiotherapy that may be easier to fit in to their new routine.

**Treatment**

*Will I still manage to be compliant with my treatment after having children?*

Two mothers in this study reported no disruption to their treatment routine after having children. However, nine mothers reported extensive disruption to their treatment routine, at least temporarily, with some or all of their treatment getting missed. The first few months were described as being particularly difficult. Physiotherapy and nebulisers were described as being particularly difficult to complete, although the mothers generally were able to keep up with their tablets. Reasons for experiencing this disruption included:

* A lack of time (particularly during the new born stage)
* A break in existing treatment/daily routine
* Exhaustion.

However, after around three months, most of the mothers who experienced this disruption were able to reintroduce their full treatment regime. The mothers described treatment as getting easier to complete over time due to the following factors:

* Increased amounts of time to oneself
* Being able to re-establish a routine (all mothers discussed this as being a crucial thing to do in order to comply with treatment).

All the mothers in this study explained how much of a priority treatment is for them, particularly since having children, and how their need and desire to stay well for their children, both in the short and longer term, is their major driver for complying with treatment.

*How will I juggle caring for a baby or child with caring for myself?*

The mothers in this study noted the amount of care and attention their children required, but also emphasised the importance of completing their own treatment. They frequently described motherhood as a ‘balancing act’-having two people to care for instead of one. It appeared that finding this balance between meeting both their own and their children’s’ needs was difficult, particularly in the early stages. However, the mothers noted this balance as being particularly important to find, given that not finding this balance led to a disruption in their treatment. They talked about prioritising their own care, as well as their children’s, feeling that ultimately their own well-being was for that of their children’s too.

The mothers in this study utilised a range of strategies in an attempt to balance both their need for rest and treatment with their children’s needs for care and attention, including the following:

* Drawing on social support from friends and family, in addition to utilising the support of their partner
* Ensuring their children’s ‘core’ needs were met, enabling them to feel comfortable in taking ‘time out’ for rest/treatment
* Establishing a new routine that works for both mother and baby e.g. complete treatment during baby/child’s nap times
* Involving children in treatment.

**Emotional considerations**

*What kind of emotional issues might I face or need to consider?*

The mothers in this study expressed feeling a wide variety of emotions on having children. The mothers discussed the overwhelming joy, disbelief and happiness that they felt on having children, and continue to feel as a result of being a mother. They discussed the unique and special relationship they have with their children, the enjoyment it brings, and the unconditional love and sense of achievement they feel. Many mothers discussed other feelings that were more difficult, such as feelings of guilt due to sometimes feeling limited in their energy, sometimes needing to have time away from their children, and due to an awareness of their limited life expectancy. Some mothers also discussed feeling upset and frustrated due to poor or fluctuating health or due to finding certain activities difficult. Mothers described coping with these difficult feelings by drawing on a range of coping mechanisms detailed below.

**My child**

*Will CF impact on my child?*

The mothers in this study discussed the impact that CF has on their children and in discussing this they mentioned issues relating to treatment, their children’s understanding of CF, time away from their children, and issues associated with life expectancy.

*What will my child think about my treatment?*

Most of the mothers in this study said that their children notice and show an interest in their treatment, which was reflected in things such as copying behaviour. A few mothers explained their children appear to get frustrated when they see their mother completing treatment, experiencing a kind of ‘jealousy’ and frustration that their mum is unable to play at that time. However, the majority of mothers also discussed feeling that having their children witness their treatment is helpful. Some discussed how they actively chose to complete treatment in front of their children, as a way of normalising it.

*What will I tell my child about CF and will they understand?*

Some of the mothers in this study explained how their children often ask questions, such as why they need to do treatment. All of the mothers explained that they wanted their children to have a good understanding of CF from a young age, to reduce any feelings of ‘shock’ later on. The mothers discussed trying to explain CF to their children by explaining symptoms and treatment, but sometimes found this difficult to do in a way that wasn’t too ‘scary’. Some mothers talked about how they purposely completed their treatment in front of their children, as they felt this helped children to understand their condition better and opened up lines of communication.

Many mothers in this study expressed feeling that their children having an understanding of CF was not only beneficial for the children themselves, but also beneficial for them. The mothers of older children discussed how, as their children’s’ understanding of CF has increased as they’ve grown older, this has allowed them more time to themselves to complete their treatment, as they’re able to explain to their children their need to complete treatment, meaning the children allow them the time they need to get their treatment done.

In regards to issues relating to life expectancy, only one of the children (who was older) appeared to have an understanding of this. Other mothers had much younger children which may be a reason for the lack of these discussions. However, only two mothers made reference to plans to have these discussions in the future. Therefore, it appeared that having conversations around life expectancy felt, understandably, much harder.

*How will I manage needing to have time away from my child?*

Most of the mothers in this study discussed the impact of sometimes needing to have time away from their children due to being poorly, hospital admissions, or needing to complete treatment, which often led to feelings of guilt. Whilst the mothers explained they didn’t like having time away from their children, they reasoned that it was necessary in order to stay well, which many felt was ultimately for the benefit of their children. A further reason some mothers discussed for wanting their children to have an understanding of CF was so that they understood why they sometimes needed to have time away from them. Many mothers also found ways to involve their children in treatment to limit the time they needed to have away from them, such as having their children help get the treatment ready, or copy the treatment on their teddies.

**Social Support**

*What might my partner’s role be?*

All the mothers in this study were in long term relationships with the fathers of their children. They explained how their partners have been the most significant source of support in coping with motherhood, and that their support was important no matter the age of their child. Partners supported them by caring for the children to enable them time out to rest and/or complete treatment. They were also involved in supporting mothers with activities they found harder, such as lifting/carrying prams or engaging in more ‘energetic’ play. Some participants explained that they felt less guilty about having time away from their children if they knew they were being cared for by their partner, and many mothers also accessed emotional support from their partners.

*Will my partner cope?*

The mothers in this study discussed the impact that having children had had on their partner, the children’s fathers. They acknowledged how their partners’ lives had also changed, and how he experienced many of the same issues as them such as a change in lifestyle and exhaustion. Some mothers expressed feeling that their partners also need support, particularly when they were poorly or in hospital. It appeared that the wider support system became particularly important here.

*Will I need lots of support from other people?*

Whilst a few mothers discussed drawing on the support of nurseries, most mothers acknowledged they had utilised the support of friends and family at one point or another, although some were reluctant to ask for it. Many mothers explained how they use this additional support when they’re ill, in giving them time to rest and recuperate. For many mothers, knowing their children were with close family members helped to reduced their feelings of worry and guilt about feeling ill and/or being away from their children. Some of the mothers also utilised family and friends support in completing their treatment. This was, in general, only the case if their partner wasn’t around. Some mothers also discussed others forms of practical support offered by family and friends such as cooking and cleaning, and some spoke to family and friends about any worries or concerns they had. Some mothers discussed how they had made a conscious effort to become closer to their family since having children, which they felt was important in managing concerns they had around their life expectancy.

**Coping and adjustment**

*Will I be able to cope with being a mum?*

As noted, the mothers in this study described a number of struggles after having children including feelings of guilt, exhaustion and a lack of time to themselves. Whilst the mothers acknowledged that motherhood is difficult for anyone, many felt that it’s harder for those with CF, due to existing tiredness and extra time pressures due to treatment. However, many likened the changes they’d made to their treatment routine to changes that any parent would need to make to their lifestyle. Some mothers also felt that ‘healthy’ mothers may take things for granted whereas they appreciated every day.

*What kind of coping mechanisms might I draw on?*

The mothers in this study described drawing on a range of coping mechanisms in coping with motherhood. These included the following:

* Drawing on one’s own personal strength and ability to think positively and look to the future
* Utilising the support of partners, friends and family in enabling time out to rest and complete treatment
* Accessing emotional support from partners, friends and family and the CF team
* Re-establishing a new treatment routine around the baby/child’s routine
* Planning ahead/getting organised
* Including the child in treatment. This may include altering physiotherapy techniques so that the baby can be held at the same time, or turning treatment in to a ‘game’ for older children
* Re-visiting CF care needs with the CF team.

**Summary**

The women in this study described how becoming a mother had a huge impact on them and their lives. They found themselves needing to quickly develop strategies for balancing their own needs for treatment and rest with their children’s needs for care and attention. However, whilst things appeared to be extremely difficult at first, there appeared to be a general theme of things getting easier with time, such as having increasing amounts of time to themselves. This appears to be largely due to factors associated with the child’s development, such as their developing routine and increasing independence. The mothers also described a process of ‘working it out’-learning from their experience and learning as they go along.

Whilst motherhood felt extremely difficult at times and was harder than expected, all of the mothers discussed extremely positive feelings resulting from being a mother, such as the sense of joy and fulfilment it brought, and the special relationships they have with their children.