

A report of experiences and feedback from parents and carers

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Introduction

SOFT UK Families (excerpts from family stories - <http://www.soft.org.uk/family-stories>)

Darra

“Darra's first birthday was a huge celebration of life and was enjoyed by all, I was an emotional wreck as I had never allowed myself to accept that I would see that day. In many ways I still don't allow myself to accept that she does and should continue to live a normal life, I always fear the worst. Darra is now 4 years and 4 months old...

She continues to meet all her developmental milestones, is on the centiles she's been on since birth, no major health issues, no concerns at all.”

Jack David

“There is no way you can prepare yourself for news like this. We had known it would happen but never really believed it. We felt so helpless, all we could do for him now was cuddle him and let him know we were there..

Jack had only been with us for 31 days but it was suddenly impossible to imagine how our lives would be without him. How we would miss the funny faces he pulled, hearing his little cry and kissing his velvety soft cheek.”

As illustrated by the excerpts above, from stories kindly shared by some of the families connected with SOFT UK, their experiences of having a baby affected by Trisomy syndromes can vary widely. However, at their core, they also have much in common: that they are going through new and often distressing circumstances, that they require clear and accurate information, and that they may benefit greatly from having someone to listen to them and feel that somebody cares. SOFT UK has provided support to hundreds of families throughout the UK since the charity was founded in 1991. This research was designed to help them to evaluate the services they currently provide for families and to gain feedback on how they might improve these services for the future.

Summary of findings

Feedback was sought from families in the South West and across the UK, via means of direct conversations and written comments gathered at two family days, and through an online survey and emails. Families talked about their appreciation for the current support which SOFT UK provides, which includes a website, regular events, information booklets, social media groups, a befriending service, email updates and a newsletter.

The benefits of these services were that families were able to share their experiences with others and feel as though they were not alone, obtain social and emotional support at a difficult time, and get accurate information produced by people who were knowledgeable on the subject of Trisomy conditions, given difficulty obtaining this information from other sources. This support also gave them hope and what they felt was a more balanced picture of what to expect, in the context of many families having encountered negative attitudes from medical professionals.

When asked what they would like medical professionals to know, families responded that they would like better information to be available via the NHS, based on current research and written in layman's terms. They would also like medical professionals to have increased awareness of Trisomy syndromes, so that they can respond with sensitivity and more balanced attitudes, treating their children as individuals and loved-ones rather than regarding them as statistics.

With regard to the services that SOFT UK currently provide, families had a number of suggestions regarding what might be added to these in future, including:

- more frequent events, and further afield, to reach those families who might feel isolated,
- more information, based on the expertise of families, current research and advice from professionals,
- practical support such as help with accessing specialist equipment,
- and a continuation of SOFT UK's work on lobbying for children's rights and raising awareness.

Background

Who are SOFT UK?

SOFT UK (<http://www.soft.org.uk>) is a charity which was founded in 1990 by two mothers, Christine Rose and Jenny Robbins, after their personal experiences of a lack of support and information for families affected by Trisomy syndromes. SOFT UK now provides support, information, advice, and practical help to families from across the UK who have been affected by Trisomy 13 (Patau's syndrome) and Trisomy 18 (Edwards' syndrome). They also work in partnership with multiple agencies, to increase awareness of Trisomy conditions and the support which they provide, and provide training for a variety of medical professionals, in the hope of improving the experiences of affected families. The charity supports these families at a time when they may feel isolated, emotionally vulnerable and overwhelmed, due to the rareness of these genetic syndromes, their geographically scattered nature, and a lack of knowledge and positive attitudes amongst many medical staff.

What are Trisomy syndromes? (information adapted from SOFT UK website)¹

Trisomy syndromes are genetic conditions caused by the presence of extra chromosomes in the body's cells, affecting the development of unborn fetuses. There are typically 46 chromosomes in a human embryo. This embryo divides repeatedly to form every new cell in the baby, each of which would have an identical copy of those 46 chromosomes. However, random errors in the process of cell division, before conception or during embryo development, can cause an embryo or cells to have too few or too many chromosomes. The *tri* in trisomy refers to the fact that one of the numbered sets of chromosomes contains three copies instead of the usual pair. There are several different ways in which this may happen:

Full Trisomy is the most common type. Each sperm or egg should have 23 chromosomes, but if a sperm or egg has an extra chromosome, the embryo inherits 47 chromosomes instead of 46, so that every cell in the body has an extra chromosome.

Partial Trisomies are much less common. When this happens, the baby's cells each have two copies of the numbered chromosome *and* one partial copy. Occasionally this partial copy will attach itself to another chromosome, making diagnosis more difficult.

Mosaicism can occur when there is a problem with cell division during embryonic development. If a fertilised egg or embryo does not divide evenly, cells will be created which have different numbers of chromosomes, so that some cells have 47 chromosomes whereas others will have the typical 46.

The numbers 13 and 18 (in Trisomy 13 and Trisomy 18) refer to which chromosome pairs are affected by the extra genetic material. The effects of these extra chromosomes are seen at all stages of development, with higher rates of miscarriage (loss before 24 weeks) and stillbirth (loss after 24 weeks), which reduce as pregnancy progresses. Babies born with trisomy syndromes are likely to require greater levels of medical intervention during their first few weeks and months and to face significant health and developmental challenges throughout their life-span. Both conditions are considered to be 'life-limiting', meaning they affect how long babies are expected to live.

Although around half of infants with trisomy 13 or 18 die within the first few weeks², recent research suggests that a significant number of babies now survive beyond one year³, and that children who survive the first six months of life may live ten years or more⁴, with prognosis being dependent on the particular medical complications which individual children face⁵. Survival rates have gradually increased over time, possibly due to changing attitudes, with some physicians being more willing to pursue 'aggressive medical intervention' during early stages of life, such as cardiac surgery, and to continue with therapeutic procedures for older children. These findings have led some researchers to conclude that Trisomy syndromes should no longer be routinely regarded as 'uniformly lethal malformations'³. There have also been a number of documented cases of children surviving into adulthood (Dr Deborah A. Bruns from the TRIS Project <https://tris.siu.edu/>, May 13, 2019; unreferenced).

Down's syndrome is also a trisomy condition (Trisomy 21) but is much better known, with a number of campaigns conducted to raise awareness and reduce stigma. This greater familiarity may be due to its higher incidence rates, with approximately 1 in 1000 babies born with Down's every year⁶. In England and Wales during 2014, there were 574 live births of children with Down's, out of 1698 diagnoses, made either pre or postnatally. By contrast, only 47 babies with Edwards' syndrome (Trisomy 18) were born alive in 2014, out of 508 diagnoses, and 20 babies with Patau's syndrome (Trisomy 13) were born alive, out of 165 total reported cases⁷. This represents a rate of 2.5 per 10,000 births for Patau's syndrome and 7.6 per 10,000 births for Edwards' syndrome, and it may be these

lower incidence rates which contribute to a lack of awareness amongst the public and some medical professionals.

Why was this research needed?

Whilst SOFT UK has always supported families at all stages of their journey with a Trisomy child, the high infant mortality rates have meant that much of this support has inevitably focussed on bereavement and memorial support. However, given a growing number of children now surviving for longer, these services need to be continually reviewed to reflect families' changing needs. SOFT UK wanted to understand the variety of current support needs that families may have and how those might be met. This small project was therefore developed with the aim of identifying the support needs of families, in the South West and across the UK, giving them an opportunity to share their uniquely expert knowledge with the charity, medical clinicians and other families.

Methods of study

Aims

This study was aimed at gaining feedback from parents, carers and wider family members, regarding their experiences of support from SOFT UK, medical and other services. This was so that SOFT UK might

- identify the current needs of families who use the charity
- find out which aspects of the services they provide are working well
- identify any gaps in provision by SOFT UK or other services
- inform medical professionals about the experiences of families regarding support
- adapt and improve their services in response to the changing needs of families

Data collection

Data collection was carried out using informal methods so as to help obtain the views of families in a friendly and accessible way. The researcher collected data from two family days, one in the West Midlands and one in Scotland, using informal discussions with parents, carers and wider family members (at the West Midlands event), and also using a board with questions where post-it notes could be used to write answers to questions (at both events). They also used an online survey, created at www.smartsurvey.co.uk. This survey was shared in the SOFT UK Facebook group, on twitter and via email. One participant also sent a follow-up email after a family day with more detail regarding their experiences.

Analysis

All data was aggregated in NVivo (a software program used for analysing data) and thematic analysis was carried out so as to summarise the range and breadth of responses, using the research questions as a guide.

Research questions

Both methods sought answers to the following questions:

- What information, advice, support, practical help have you received
 - from SOFT UK?
 - from doctors and other medical professionals?
 - any other support services?

- How has receiving this support made a difference?

- What support would you have liked but couldn't find?

- What would you like medical professionals to know?

- What support would you like SOFT UK to provide?
 - for yourself or other families in similar circumstances?
 - and how could current support be improved?

Findings

Participants

The families which took part were either attendees at the family days in the West Midlands or Scotland, or they completed an online survey. They included both families who had been bereaved and those with a living baby or child. Attendees of the family days travelled from various parts of the UK, with 57 attendees in Scotland and 96 at the Midlands event. The online survey elicited 18 fully-completed survey responses, and a demographic question added to the end of the survey showed that respondents from every region in the UK except Northern Ireland were represented (i.e. Scotland; Wales; England: South West, South East, London, West Midlands, East Midlands, East of England, North West, North East).

What services do families currently access through SOFT UK

The following were described by families as being beneficial services which they accessed through SOFT UK:

- family days/conferences, with opportunities to meet other families and to see speakers on particular topics
- the SOFT UK website, with articles, information and advice on issues such as feeding, growth, common health issues, and coping with loss
- parent stories and case studies sharing personal experiences
- the SOFT UK Facebook group
- email updates and a regular newsletter
- telephone befriending support, for information, advice and reassurance
- being put in contact with other families who have had similar experiences
- information leaflets and booklets produced by SOFT
- support for siblings

What are the benefits of this support?

Theme 1: Sharing of experiences

“Learn[ing] from their experiences made us feel we weren’t on our own.”

Many families spoke about the benefits of having people to talk to who shared similar experiences to their own, at a time when others around them might not be able to understand. Respondents described how support and information from SOFT UK made them feel ‘less isolated’ as a family, because ‘there were other families out there’, and this helped them feel ‘less alone in [a] completely unexpected and life changing situation’. The information which other families can provide is very specific and based on first-hand experiences. This can help fill the gaps in information which might be available to families from other sources. The family days also help them build links with others in a place where people can ‘come together, [and] learn from each other’, and see their children ‘as part of a community rather than “that disabled child over there”’. Some participants also reported feeling satisfaction at being able to share what they knew with others, with one respondent describing how it gave them a ‘focus away from what was happening to me, as I wanted to share my experiences with other families’.

Theme 2: Social and emotional support

“Got us through a very tough time”

Families spoke about the comfort they gained from receiving support at a time when they often felt lost, alone, confused, anxious or in despair. Again, speaking to families who had experienced bereavement or were caring for children with trisomy syndromes was helpful, as they were able to understand the emotions they were experiencing. Emotional support, whether via the telephone, messages, emails, or face-to-face at family days, was a source of solace, due to knowing that others had got through similar experiences before and that ‘other people care and want to help’. One respondent described the support as making ‘a truly difficult and heart-breaking situation just bearable’. Another said that they ‘didn’t know how we would have coped without SOFT’. Yet another described SOFT UK as their ‘family’.

Theme 3: Availability of information

“Everyone knows what Down’s syndrome is.. there is very little information about Edwards’ & Patau’s out there.”

The information provided by the charity was reported as filling a gap which exists for many families when receiving a diagnosis of Trisomy syndromes, with the information provided by SOFT UK felt to be ‘more informative than [the] hospital’. SOFT UK provides information booklets to be given out to families⁸, describing in plain language what trisomy syndromes are, what the implications of these diagnoses are, what options are available, and how to obtain more support. Through their website, and befriending support provided by parent volunteers, families can also obtain advice on a range of topics, from how to look after surviving children to information on support after bereavement. Family days provide information on the most recent medical information and research, which may give families the confidence to have informed conversations with medical professionals. For example, one respondent described how ‘having speakers at the events [has] given me medically relevant information to present to medics involved in my daughter’s care’.

Theme 4: A balanced picture of what to expect

“The variation in their abilities and life gave hope at a time there was none from medical services.”

Respondents felt that SOFT UK was able to provide information in a neutral, unbiased way, which gave them a more balanced picture of what to expect after receiving a diagnosis. The sharing of real-life stories also demonstrated the range of possibilities in terms of outcomes and challenges. This was particularly helpful for those families who had encountered very negative attitudes from some medical professionals. Also mentioned frequently was the idea of ‘hope’, which was felt necessary by many, whatever the final outcome might be for their child in the longer term, allowing them to keep going. One respondent described the support as providing ‘a glimmer of hope and a light to a dark journey’. These findings corroborate previous research in the USA, showing that parental support groups provide opportunities to access alternative viewpoints about their children, regarding possible outcomes, and the quality of life and happiness of children with disabilities.⁹

Which other sources of support are there for families?

The information which families receive, at the time of diagnosis and beyond, appears to be very variable, depending on the area in which they live, and the medical professionals and other staff they encounter. Some hospitals were described as providing signposting to SOFT UK or giving out SOFT UK booklets. Others talked about having a lack of information, being offered information which was difficult to understand or contradictory, or perhaps being left to search for more information themselves from sources such as the internet. A lack of information can leave families feeling confused and lonely, at a time when they are processing the shock of diagnosis.

“The very very little information we were given was as helpful as it could be but more information is needed to be put out there rather than leaving parents having been told that their baby isn’t compatible with life to then find out information for themselves. It’s too hard to process to begin with but then having to figure out what you’ve been told because you have no idea what you’ve been told”

Some families reported receiving good support from a number of sources. These included mention of paediatricians or cardiologists with sympathetic attitudes and a willingness to take ‘time to listen and talk’, specialist complex-care nurses who helped new parents learn how to care for their babies, and emotional support from hospital pastoral teams and hospices. Some respondents felt supported by their GP practices and community nurses, health visitors and nursery nurses, social services or schools. Two respondents mentioned Cruse Bereavement Care¹⁰ as a source of support after losing a child. Again however, these experiences were very variable, with other respondents reporting that ‘support varies from issue to issue’ depending on who they encountered, that ‘levels of awareness amongst [many] medical professionals [was] very limited’, or that even those staff who showed caring attitudes didn’t quite know ‘how to deal with us’. Similarly, support from schools and social services might be available or might be ‘non-existent’.

What would families like medical professionals to know?

Theme 1: Clear, up-to-date information readily available via the NHS

“Leaflets of what Edward and Patau’s are, [are] not readily available to those parents who have recently been diagnosed”

Not all parents had easy access to sources of information such as leaflets.

“We didn’t really know what Edwards was when it was first diagnosed for our son. There wasn’t any handy leaflet or anything giving us an overview of the syndrome. We ended up having to google which was not helpful because it just confused us more.”

Families wanted the information on T13 and T18 to be clearly explained in ‘layman’s terms’ without too much medical jargon, rather than ‘having to fight to find information and then decode what it actually meant!’. They also want these leaflets to reflect up-to-date information and research, and for it to be created by ‘parents and professionals who really know’. This information should include practical advice on aspects such as what might happen if a baby died during pregnancy, and caring for surviving children after birth, with follow-up support from hospitals afterwards.

One parent suggested providing a 'new Trisomy parent' starter pack, which would provide information about SOFT UK but also any support provided by other agencies. Another respondent suggested that it would be useful if NHS professionals could provide them with direct access to counselling services, in what was clearly an emotionally distressing situation, as it was difficult to gain access as they might not have enough points ‘on [the] scoring system.. unless you’re suicidal’.

Theme 2: Positive attitudes towards their children

“Neo-natologists and midwives hold negative assumptions – they need to trust parents to make decisions”

Several families talked about the ‘pessimistic language’ used by the medical profession, saying that NHS factsheets were worded very negatively, providing no opportunity for

hope. A number of parents at the family days related stories of being told that their child's condition was 'incompatible with life', which they contrasted with the more balanced picture they had encountered through contact with others through SOFT UK. It was suggested that a greater use of parent stories would help 'represent all possibilities', raising awareness that some children may survive, and about the variety within Trisomy syndromes such as Mosaicism. This would give them 'freedom of choice'. Parents also felt that medical professionals should treat their children equally, having a 'greater willingness to treat individual problems and not be deterred by the overall trisomy diagnosis', and providing the 'same access to feeding [and] advice'.

Some researchers and parents have challenged the use of language such as 'incompatible with life', suggesting it may serve to 'distance, divide, and stigmatize children [and those] caring for them'¹¹. Others suggest adopting a more balanced approach to counselling parents at diagnosis, with respect for individual family choices regarding treatment levels, provision of accurate statistics on survival rates¹², the avoidance of value-laden language and assumptions about quality of life for disabled children, and the provision of support to those parents who choose to continue pregnancies, with a recognition of the value to many parents of spending time with their babies, regardless of lifespan^{13,14,15}.

Theme 3: Sensitivity

“[I] felt that my son's short time was an inconvenience and to them his death was the best outcome”

A number of respondents reported experiencing a lack of sensitivity from medical professionals, with news of diagnosis being delivered in a blunt or 'heartless' way, staff trying to 'bully' them into having a termination, or poor provision of support after bereavement. Such experiences have been highlighted elsewhere in the literature, with experiences of a lack of awareness regarding how siblings might be affected by hearing a brother or sister discussed in negative terms, or of parents being repeatedly asked questions about resuscitation at hospital admission¹⁶, leading to feelings that their child is valued and respected less than others¹⁷. These reports highlight the need for greater education of any professionals who might come in contact with families affected by Trisomy syndromes.

What would families like SOFT UK to provide (and continue providing) in the future?

Respondents had many suggestions about what would help families such as themselves and possible improvements for the future. They wanted SOFT UK to continue providing bereavement support, sharing case studies and parent experiences, and signposting them towards helpful services. They also appreciated the social, emotional and practical support available to them, such as having a 'point of contact and advice on caring for my child' and gaining 'reassurance that whatever decisions they made [were] right for them'

However, some also hoped that support could be extended further geographically, with more frequent opportunities to meet other families, at both formal and informal events. There was also a suggestion that sub-groups could be organised which had a different focus in each, to meet the differential needs of those families who required bereavement support, and those who needed advice on caring for surviving children.

Some additional suggestions on how SOFT UK might improve support included:

Information and advice

- Information sheets created by parents using shared knowledge, such as 'lists of tests to ask for, lists of signs to look for that child[ren] may be becoming unwell', as well as lists of specialist equipment which may be suitable for their children.
- Information regarding which hospitals have positive attitudes towards dealing with Trisomy children, including willingness to perform specific surgeries.
- Lists of relevant research papers on specific medical issues (e.g. cardiac, respiratory).
- Advice from professionals regarding topics such as physiotherapy, occupational therapy, educational options, teaching of life skills, or speech and language therapy.
- Lists of services and support available from charities and governmental bodies, and advice on how to access them, including social services, DLA, young carers, carers support, care and respite services.

Social and emotional support

- Access to counselling or a family support worker.
- Bereavement support offered at intervals as it may not be wanted right away, and available for whole families, including siblings.
- A list of parent volunteer contacts by region, including those with surviving children and those who have been bereaved.
- Ensuring support continues for those who choose to end a pregnancy or lose babies before birth, as well as celebrating those children who survive.

Practical support

- Support in accessing specialist equipment.
- Provision of toys and soft mats in the main event room at family days, for those parents who prefer to keep children with them rather than use the creche.
- Financial support.

Collaboration and advocacy

- Advice on how to talk to medical professionals or the provision of 'advocates' who could speak on their behalf at what is a stressful and emotionally difficult time.
- Links with other international bodies such as SOFT USA, given that children in other countries may be long-surviving.
- There was also a hope that SOFT UK would continue to raise awareness of Trisomy syndromes and lobby for the rights of children, pushing for better provision of information and providing continued education to medical professionals such as neo-natologists and other professionals who come in contact with families.

“Keep on the good work of educating medical professionals at all levels and in all areas.. consultants, midwives, GPs, hospital chaplains - anyone a family comes into contact with whether in the community setting or in hospital.”

Conclusions

SOFT UK is a small charity whose impact is significant for families affected by Trisomy, who otherwise risk feeling isolated at a time when they are at their most vulnerable. This report identifies aspects of support that families most value, and provides feedback to the charity about the importance of its work and the services which it needs to continue to provide.

This research also provides a clear evidence base for the areas of further support to prioritise in future: as a small charity this helps SOFT UK in planning future spend, as well as the areas which might form the basis of funding bids.

The charity would like to express its gratitude to the SWDTP for funding this research, to Helen Foster-Collins for carrying it out, and to all the families who took the time and trouble to participate in this project, which in turn will help SOFT UK continue to develop its support to meet the needs of current and future families.

Alison Pearson

(Parent Advocate & Trustee)

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The research was coordinated by Jan Fowler; Chair of Trustees. Initial contact was made via Alison Pearson; Parent Advocate, Trustee, and PhD researcher at the University of Exeter.

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