



Are you worried about your child?

A GUIDE TO SUPPORT FAMILIES
OF CHILDREN WITH COMPLEX
NEEDS AND THE PROFESSIONALS
WHO CARE FOR THEM

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INTRODUCTION

Dear Parent,

Do you sometimes feel tired and stressed? Do you feel tired and stressed most of the time? Perhaps you have been told your child will need extra help from professionals for some time to come. Perhaps you feel your child never has time to just be a child because there are so many treatments and therapies. You and your child have so much to get done every day!

Being tired and stressed all the time is not a good way to live. It is not good for your mind and body, it is not good for your child. It is not good for your family relationships, for your other parenting tasks, for your work or for your social and leisure activities. Exhaustion and stress can spoil everything. Living under these strains will make it harder for you to have quality time with your child and it will probably mean you are less able to do everything with your child that you need to do.

Being tired and stressed can take away your quality of life and your optimism about the future. Problems may seem bigger than they really are and you can come to feel things are never going to get any better.

This guide is here to help you and to help your professionals understand what your life is like. It is for families, no matter how they are made up, who have a child with health complications, disabilities and uncertain futures. It has been written by a group of professionals (some of whom are also parents) in Canada, Australia, New Zealand, South Africa and the United Kingdom.

Wouldn't it be nice...

- ...if your child received the same welcome to the world as every child?*
- ...if you were seen as the expert on your child by everyone?*
- ...if you felt you were listened to and knew people who share your concerns about your child?*
- ...if you felt cared for and supported by an understanding community?*

LET'S START AT THE BEGINNING



Dear Parent,

“And it has been hard and it just feels like a constant fight and when you have, and I hate the word, normal, but when you have a normal child you don’t have that fight on your hands that you have with a disabled child to get the right care and to get the right equipment and to get the right house.”

You might be reading this guide because you are worried about your baby or infant. Perhaps you have been told your child will need extra help from professionals for some time to come. Or perhaps you know of a family who may be in this situation?

This guide has been written by people working with families across the world; it seems that families everywhere have similar experiences. Reading this guide might help you, or the family you are concerned about.

Many families have children who need treatment and therapy for a long time to help them be healthy, grow and learn. Everyone is affected in some way by this – the child, the parents and others in the family circle.

Some parents worry so much it affects everything they do, day and night. Some parents take it in their stride. We are all different. Some babies and infants have so many appointments to go to they hardly have time just to be a child doing the natural things they need or want to do.

This guide is to help you and your family manage everything without getting too stressed and exhausted. It will also help you create enjoyable moments together with your child every day. Part of this is for you and your child to have time to relax with each other and get to know each other properly.

You might want to show some things in the guide to professionals helping your child so that you can talk things over with them. Professionals know a lot, but they may not know or understand some of the things you know as a parent or carer. No one will know your child as well as you do and you should be listened to. You can also show the guide to other families you know.

Dear Professional,

This guide is offered to you and the families you help who have children with ongoing health and development needs. It can support you and your team in helping families do everything they have to do without them getting too stressed and exhausted. It can also help the child have the best possible experience of life no matter how many interventions are needed or for how long. Throughout all interventions the wellbeing of the child and family will be foremost in everyone's mind and we believe that professionals working in partnership with families leads to the best outcomes for everyone.

The aim of the guide is to help everyone think about how best to support the family through difficult times and promote the best possible quality of life for child and family. An important part of this is for professionals to help the parent or main carer form the best possible relationship with their baby or infant. This supports the parenting role and is crucial for the child and family's wellbeing.

There might be parts of the guide you want to show to particular families to open supportive discussions. Some families might bring the guide to you to show you something they want to talk about. You might also use the ideas here as a basis for discussions with colleagues.

RESPECT

All children are equally deserving of full respect as children.
All families deserve respect whatever challenges they are facing.



Dear Parent,

“Your friends who have healthy babies, kind of, not didn’t want to see them, but it was hard to see them because you kind of, you were in a completely different world to where they were .”

When a baby is born, everyone celebrates and sends their best wishes to the happy family. When the child has an illness or disability it is just as important to celebrate and welcome the baby to the world and for everyone to join in the joy that a new life brings. Some families find this easy, and have friends and family who join them in the celebration. Other parents can find that their family members or friends feel awkward and don’t know what to say or do. This can lead to them not getting in touch; or you may feel like you are being avoided.

When you are looking forward to the birth of your baby you will probably imagine what they are going to be like and how you will enjoy life as a family. Having a child with health or development difficulties can bring challenges that interrupt usual family life. But all children need the same things: love, warm responsive predictable care from their parents, safety and fun. You may feel sadness at times about the aspects of life that you and your child miss. It is important to build fun times into your routine as well as everything else.

You may feel comfortable telling people about your child, or you may prefer to keep certain information private. It can be difficult when people ask you questions that you don’t know the answer to. Some parents avoid going out at times as they don’t want to face any awkwardness. It can be very supportive for example to find a parent and toddler group which is welcoming and where you and your child can relax.

Some parents have good friends who they still spend time with after the birth of their child. For others, it can be painful to see babies who are developing well and who don't face the same difficulties as your baby. Parents sometimes feel isolated and this can bring more stress. It might help you to find other parents in the same or similar situation to spend time with. They often understand what you are going through and you don't have to provide as much information.

It can also be helpful to talk openly to sympathetic professionals who are involved with your child and ask them for additional support.

Dear Professional,

Parents who have a child with health or development difficulties can experience multiple sources of stress. Firstly, it is natural for them to grieve for the child they were hoping for, even where they are able to celebrate the child they have. They may need to cope with traumatic health crises or face the potential loss of their child, which can leave them with long-term stress and distress. They may be dealing with so many unsettling emotions that at times it may be difficult for them to take in the information you provide. It is essential, even when you are busy, to ask parents about their priorities at that time and together come up with a plan for when they will be ready to tackle other issues.

Having a child with extra needs can make it difficult for parents to receive support from family and friends. Many families in this situation experience isolation and often feel that no one understands what they are going through. It can be enormously helpful for them to meet other parents in a similar situation to ease their sense of isolation – is this something that you could help with? Do you know of a support group or could you arrange for them to meet other parents? This can be very powerful in providing families with a sense of belonging and being cared for.

In situations where there has been a prenatal diagnosis of a condition, it is important that professionals take extra care to refer to the unborn child in ways that respect that child's right to life and to dignity.

"I actually found it easier to be with children with other special needs and their parents than be in the community of people without additional problems because for me I could see the differences with Philippa and their babies who were even six weeks old, so that wasn't somewhere I wanted to be."

A QUALITY OF LIFE

We all need a healthy balance between the things we must do and the things we value and enjoy – whether we are adults or children or babies.



Dear Parent,

“She could have half an hour in the hydrotherapy pool which is lovely and we both go and it was just really nice and we weren’t really doing that many fun things with her because we were spending a lot of time either feeding her or you know, going to the hospital, yeah, so it was enjoyable really.”

The families of children who need extra help can become very busy very quickly. There can be many appointments requiring travel and organisation. Each week there might be assessments and treatments with professionals asking you questions and offering advice. There might be nurses, therapists and others coming to your home. All of this is to help you care for your child, but may leave you and your child feeling exhausted and talked at rather than talked with.

Some parents feel overwhelmed with so much happening. This is stressful and can be difficult to manage. Parents are all different and no two families have the same experience. For some families, it can be very busy and stressful at the beginning but then calm down. For others, life gets difficult every time their child becomes ill or needs to be admitted to hospital. How has it been for you and your family so far?

Babies and infants are all different too. Some seem to take everything in their stride. For some children, all these appointments and treatments are exhausting and stressful. Such a busy life can mean routines for sleeping, feeding and playing baby games are interrupted and there is hardly any time just to be a child. There might not be enough quiet time for you and your

child to relax with each other, enjoy each other and get to know each other properly. And then when there is time, you or the child might be too worn out.

Some families may encounter incredibly difficult and painful experiences which could include dealing with the possibility of losing their child or grieving for the loss of their initial hopes, dreams and expectations for their child.

For most parents of children with complex needs, at the same time as they are struggling to cope themselves, they also have to think about their other children, and their relationships with family and friends. Circumstances can lead to parents being depressed and experiencing marital problems. Sometimes the extra costs they face can add to the stress and worry.

What is it like in your family? Are you all doing well? If you feel you are not coping well, please do not think you are unusual. But being stressed and exhausted is not good for you, your child or your family. Somehow there needs to be a balance between getting all the help your child needs and keeping you and everyone in the family healthy and as happy as possible. You may need to prioritise addressing some of your child's difficulties and not add to your stress by trying to do everything. It is important that you get the support that you feel is making a difference.

Sometimes parents are reluctant to ask for help and continue struggling alone. It can be difficult to take the first step to ask for help, but we all need this at times. Allowing people to support you in the way that you need can help you feel stronger. Professionals, family members and friends like helping too!

- If you have been keeping it all to yourself, can you find someone to talk it over with?
- If you live with a partner, is your relationship under strain? Do you have time to support each other?
- Are you finding it difficult to ask your questions in appointments? Maybe you can take a friend with you and discuss what you need from the appointment before you go. It can help to write your questions down in advance. You can ask professionals if you can tape their answers to help you remember them.

- Can the appointments be organised so they are easier to manage? Professionals might not realise how many appointments you have to go to or how much time the travelling takes. Let them know and see if they can help. You might want to choose only those appointments that help you and say 'no' to others.
- Would you like more professionals doing home visits or not so many? Let professionals know.
- If you feel your child gets tired and stressed from too many appointments and being handled by too many 'strangers', ask one of the professionals to help you find a solution.
- If you feel unsatisfied with the care you and your child are receiving you might want to ask to talk to alternative professionals who may understand your situation better. Have you considered accessing a children's palliative care service?
- Does your child sleep badly? Are you losing sleep night after night? Let your professionals know. Help can be available.
- Can you get a break sometimes? What help would you need from relatives, friends or professionals to help you arrange this? Even a short break can recharge your batteries.
- Are you struggling financially? Ask professionals what help might be open to you.
- Do you feel isolated? Perhaps there is a parent support group or children's hospice where you could meet other people going through the same things.
- Do you use a diary or a calendar? How about looking ahead and marking some days as 'FAMILY DAYS!' They can then be kept free of appointments except for emergencies.

Dear Professional,

Life can be very busy and stressful for families with so many appointments to get to and so many things to be anxious about. Some parents experience what has happened to their child as traumatic and feel they are hardly coping. Tiredness and stress are real threats to wellbeing for any of us.

Parents may be reluctant to ask for help even when they really need it, or they may feel uncomfortable asking for something for themselves when all the focus is on their child. It can also be difficult for parents to raise issues they are worried or unhappy about with professionals. Because many parents do not talk about being exhausted, being sleep deprived and living in a state of anxiety, it can help if you open the conversation. Listening to parents can be the start of a way forward. Some parents might need professional support, for example from a counsellor.

If the infant's life is taken over with too many treatments and too many non-family people making demands, can the pattern of interventions be re-thought with the infant's quality of life in mind? Is there someone who could help parents get all the appointments well organised so they do not add unnecessarily to fatigue, expense and time taken? Is there someone who could help parents focus on their areas of priority for their child and help them discuss this with their professionals?

Can you help parents get occasional breaks from caring? Is there an organisation that offers breaks, such as a children's hospice or short break service? Perhaps there are grandparents or friends that could baby-sit if they were helped to become competent and confident? Can your team help train them?

KEEPING IT ALL TOGETHER

It will help you and your child if the professionals work together to keep in mind the whole child and family.



Dear Parent,

“And I am a mum, I am not a trained physio and I have just come into the world of cerebral palsy... So we were flabbergasted that how I am supposed to pick all this up and know what I am doing and I have got all these papers with it written out and it is hard because you are working from different papers but really you need somebody there helping you and telling you what to do.”

It is really helpful when everyone working with your child works together with the same aims. Parents often find it falls to them to pull everything together and help everyone keep a whole picture of their child. Some families have a lot of appointments in different places with a variety of professionals. Some of these professionals see the child at home. You may feel you and your child are kept too busy with too much going on. While it is good to have all the help your child needs, two problems can arise for your child and family.

Firstly, your calendar can fill up with no sensible pattern about where and when you have to meet all these professionals. This can make it difficult for your child to settle into the usual infant routines for meals, sleep and play and most importantly time with you. A busy and disorganised calendar can keep parents exhausted and waste a lot of time and money on travel. Everything is harder if there are preschool or older siblings to cater for at the same time.

Secondly, the professionals helping your child with treatment or therapy might not be in touch with each other. This can lead to a fragmented approach with no one looking at the whole child. It can also mean you have to tell each one what the others are

doing. Is it like this for you and your child? Do you feel you have the impossible job of trying to fit all the bits together? If so, you need help. Here are two approaches that have helped lots of families:

Some families have a keyworker who knows the child and family very well and works with the parents to keep everything linked together and as joined up as possible. This is a professional you get on well with, see regularly and trust who you can go to when a new problem arises. Some parents find that the baby-care tasks of feeding, changing and bathing are not very relaxing or enjoyable. Perhaps eye contact, cuddling and baby games are also difficult. A keyworker who gets to know you well can help or organise appropriate help. As the situation improves you and your child get to know each other better and build the important bonds that make life satisfying and rewarding. A keyworker can help support you to organise the family calendar or become a shoulder to cry on when you feel down. She or he can also help you get answers to all your questions. If you do not yet have a special person like this, talk about keyworking with the professionals who are helping your child and find out if they can arrange to work this way. You might already have one person you get on with best so ask them if they can be your keyworker.

Sometimes the two or three professionals who see the child most regularly join together with parents as a Team Around the Child or TAC. One of them becomes the keyworker but the parent is the most important member of the TAC. The TAC can meet in the family home and its job is to discuss the child's treatment and therapy as a whole. This small team keeps everything well organised and families feel cared for and supported. If you do not have a TAC and if you think it would help, ask the professionals you value most to join together as your child's TAC.

“Everyone is hitting you from every angle and you have then got speech and language, you have got OT and you have got physio and you have got your consultant and you have then got kind of Theraplay people who come from the hospital and people who I can't even remember what their job title really was... but everybody seems to be knocking on your door.”

Dear Professional

“With all the hospital appointments and things like that and I have to juggle all of that and I think that is what I find hardest is the impact and how many appointments she has had to have. And when you are working and things like that and just trying to juggle everything and I think that is the massive thing really.”

We all know how complicated life can become for a family when the child needs ongoing help from a number of professionals. In most families, the only people who know the whole picture of which professionals are involved and what they are doing are the parents. Well-meaning professionals make appointments in ignorance of other appointments. This can mean the child and their parents become overloaded with places to go to for appointments and professionals coming to the home. It can mean the family is wasting time and money and becoming stressed and exhausted. It can also mean the child cannot develop regular feeding, sleep and play routines, particularly as these children are frequently unsettled and need more time and care to be calm.

Parents may need to answer the same questions multiple times, struggle to remember all the professionals and what they do and need to keep their diary free to be ready for appointments. On top of this parents will have very many questions to find answers to and many conflicting thoughts to sort out. They may also get different and conflicting answers to their questions. Parents might need practical and emotional support from someone who is not in the family.

The first step to helping families is to ask them how many people they are seeing and what their days and weeks are like. This first conversation might show how full and difficult their calendar is. Long experience shows that families will benefit from having a special person or a keyworker helping the family to reduce the number of appointments and integrate those they keep into family life. It works best when families choose whom to have as their keyworker so that it is a professional they see regularly, whom they get on with and whom they trust.

It might be that a nurse or social worker becomes a keyworker if the baby stays in hospital for weeks or months after birth. This keyworker can help the parents become competent and confident in the baby-care tasks, which helps infant and parents to bond with each other. The keyworker has a role in being alongside the parent observing and getting to understand their baby's social and emotional communications. This supports the building of a relationship between parent and child and building warm,

predictable and responsive parenting.

Later on, there might be a new person or keyworker from within community services. She or he can help keep all the therapy and teaching interventions integrated, delivered by only one or two professionals, into a whole system – as well as providing emotional support and helping find answers to questions. This can be effective in leading to better outcomes for the child.

Professionals need to be mindful when suggesting home programmes – for some families these will be helpful, for others they increase their stress. Parents often feel ill-equipped to deliver programmes and professionals struggle to find time to teach them at the parents' pace. Professionals can help families to support their children with minimal disturbance to normal family life. There may be suitable centre based programmes that professionals could inform parents about.

A Team Around the Child or TAC can help join interventions together so programmes are integrated, delivered only by 2 or 3 professionals, and treat the child as a whole. If the infant has a TAC the keyworker will be one of the professionals in it. Can your service organise TACs for families - remembering that parents will have a full place in their child's TAC?

"...felt actually really quite isolated, and I felt as though I was battling the professionals which should have been helping him."

GETTING THE FAMILY BACK ON TRACK

A family's journey is never finished, but most families have some resilience to help them through the most difficult times.



Dear Parent,

"I would say that I appreciate things more, yeah. I appreciate the smaller things now and yeah, I think that I try and worry less about the insignificant things because you start to realise what is important and what it is that you need to worry about and the rest of it isn't, no."

The birth of any child brings change to their parents. Families need to adapt in many ways. A child with complex needs may require more adaptation. When you are in the middle of worrying about your child and family, dealing with lots of people and appointments, and trying to learn everything you need to know, it can be difficult to feel positive about the future. Some parents may find everyday life a struggle without much time to relax or have fun. If you have space to think about the future it may look rather bleak. Many families have had these feelings, but as the years go by the situation tends to change.

Getting used to being the parent of your child and learning how best to care for them will help you to feel more confident and in charge of your life. You will be able to choose which friends to see and join groups that support you if you want to. You and your family will gradually feel stronger and able to face challenges.

Instead of all your focus being on one child you will be able to think about the rest of the family too. You will find time to do things that you like, and activities for the family to enjoy together. There will be individuals and organisations that will help you to feel less alone, less stressed and tired. You may wish to seek out friendships with people that understand and can support you.

Some relationships can become stronger than before and you may make deeper connections with people. You need to remember that one of the best ways of caring for your child is to look after yourself.

As you gradually adapt and make changes you will find that you will have a new and different life. You may spend time in new ways and find different things important. Your child will bring you joy through just being themselves.

Dear Professional,

In the early days of living with a child with complex health needs or development difficulties parents may feel helpless and hopeless. It can be enormously helpful to find an empathic person to discuss some of their worries with, to help them face the future with a greater sense of hope. Parents need to see that their child is receiving the highest possible degree of development and learning support by competent practitioners. The family as a whole needs to be at the centre of professional attention while the parents get their family back on an even keel.

An important role for a keyworker or supporter is to accompany families through the most difficult times and on their journey to what they consider to be normal family life. At the beginning of this process the family may focus primarily on the child with complex needs but over time that child might gradually become less the centre of attention, less thought of as 'special' and eventually more just a member of the family. Families need to find time and energy to enjoy being together, to develop strength and resilience. Families need to move at their own pace, without pressure to conform to other people's timetables.

However, they may also benefit from you helping them with information and offering services when they say they are ready for them. Some families will be very good at advocating for themselves and need to be listened to, others may need help with identifying and asking for what they want and need. The journey to a more balanced family life will be different for each

"I'm used to struggling with doing everything on my own so with people helping is like something that is new to me and it is nice. I don't know if somebody else has said this to you but sometimes taking help is a hard thing to do when you are used to being independent and strong. Something like this makes you stronger in other ways but emotionally you are a lot weaker and you find the strength that you don't know that you have got when you end up in these situations."

family, and will not be a return to what was there before the arrival of the child. It may be helpful to reassure the family that life can still be happy and fulfilling.

Lastly, while it is a professional instinct to be positive and upbeat about the child, this can sometimes discourage parents from voicing their anxiety and other negative emotions. They might feel guilty for not being as positive as you are. They might feel their negative thoughts and fears are inappropriate or unacceptable and should be kept hidden.

Can you be positive and at the same time leave space in which parents feel comfortable and safe to voice their more negative thoughts?

Do you want to know more?

USEFUL ONLINE RESOURCES

ICPCN: International Children's Palliative Care Network

The ICPCN's mission is to achieve the best quality of life and care for children and young people with life-limiting conditions, their families and carers worldwide, through networking and communication, advocacy, research and education.

Website: <http://www.icpcn.org/>

Early Childhood Intervention without Tears: Improved support for infants with disabilities and their families

By Peter Limbrick. Published by Interconnections in 2017.

This book for parents and professionals was written as background reading for this Guide.

Website: <http://www.tacinterconnections.com/>

Choosing Quality Early Childhood Intervention Services and Supports for Your Child: What you need to know

This booklet provides information for families on choosing quality early childhood intervention (ECI) supports for their child (birth to eight years) with disability and/or developmental delay.

Website: <https://www.ecia.org.au/resources/family-booklet>

Strong Foundations: Getting it Right in the First 1000 Days

The 'first thousand days' refers to the period of development from conception to age 2. Their significance supports an urgent need to reform policies, practices and systems in response to the evidence.

Website: https://www.rch.org.au/ccch/research-projects/Strong_Foundations__Getting_it_Right_in_the_First_1000_Days/

ISEI: International Society on Early Intervention

A professional society providing a framework for communicating advances and promoting international networks in the field of early intervention.

Website: <http://depts.washington.edu/isei/>

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