

Early Support

for children, young people and families

Looking after yourself



About this resource

Many parent carers caring for a child with **additional needs** are juggling lots of balls and dealing with complex issues. Getting appropriate support and information for your child becomes paramount and in many cases your own wants and needs get lost and forgotten about – as individuals, couples and families. The focus of this guide is you and looking after yourself and your relationships.

Taking care of yourself – is this important? Absolutely, if you don't look after yourself you may become stressed and/or ill and as a result be unable to support your family the way you would wish.

Raising a child with additional needs brings many strong emotions and issues to the surface. You and your partner, if you have one, may react differently and have different opinions, as a result of different life experiences and personalities which can lead to tension and potential conflict.

This publication has been laid out in sections that parents felt were important. You can read the sections in whichever order most appeals to you and can dip in and out as you wish. As you explore each section please remember you are not alone, many families have similar experiences, and take heart that even a small change can make a difference.

If you wish to do some further reading on any of the areas covered in this publication there are suggestions in the resources section. There is so much information available but not all of it will be relevant to your situation and you can pick and choose the strategies that will work best for you.

“If you always do what you've always done – you will always get what you've always got.”

Henry Ford

This resource was developed by **Contact a Family** for Early Support.

Early Support

Early Support is a way of working, underpinned by 10 principles that aim to improve the delivery of services for disabled children, young people and their families. It enables services to coordinate their activity better and provide families with a single point of contact and continuity through key working.

Early Support is a core partner supporting the implementation of the strategy detailed in Support and aspiration: A new approach to special educational needs and disability, the Government's 2011 Green Paper. This identified Early Support as a key approach to meeting the needs of disabled children, young people and their families.

Early Support helps local areas implement the Government's strategy to bring together the services families need into a single assessment and planning process covering education, health and care. Early Support provides a wide range of resources and training to support children, young people, families and service deliverers.

To find out more about [Early Support](#), please visit www.ncb.org.uk/earllysupport

Where a word or phrase appears in colour, [like this](#), it means you can either; look them up in the [Glossary](#) at the back of the resource or that the contact details for the organisation or agency identified are listed in the [Useful organisations and websites](#) section.

[Explanation of the term parent carer](#)

In this resource the term 'parent carer' is used. It means any person with parent carer responsibility for a child or young person with special educational needs or disability. It is intended as an inclusive term that can cover foster carers, adoptive parent carers and other family members.

Contents

How do you feel?	Page 6
Emotional rollercoaster.....	Page 6
Emotional support.....	Page 9
Taking care of yourself	Page 10
Healthy eating.....	Page 10
Exercise.....	Page 10
Sleep.....	Page 11
Making time for yourself.....	Page 11
Work-life balance.....	Page 13
Social life.....	Page 14
Training, workshops and information.....	Page 15
Relationships: Family, friends and neighbours	Page 17
Partners.....	Page 17
Being a single parent.....	Page 18
Siblings.....	Page 18
Extended family.....	Page 19
Friends.....	Page 20
General public.....	Page 20
Communication	Page 22
Choosing the best method.....	Page 22
Importance of body language.....	Page 22
Take time to communicate.....	Page 22
Differences of opinion and conflict	Page 24

What helps in a conflict situation?.....	Page 24
Conclusion	Page 25
Top tips	Page 26
Resources	Page 28
Useful organisations and websites	Page 30
General	Page 30
Healthy lifestyle.....	Page 32
Relationships support.....	Page 33
Parenting support.....	Page 34
Glossary	Page 35

How do you feel?

There are many suggestions and ideas in this booklet about how to look after yourself, but we are going to start with looking at 'How do you feel?' If this is something you really don't want to think about just now, don't worry – just skip to page 10.

Being a parent, particularly the parent carer of a child with additional needs, can be an emotional rollercoaster - on the one hand, great joy, and on the other, intense sometimes negative and painful feelings.

Sometimes it is hard to acknowledge your feelings and it can be just as difficult to acknowledge how somebody else might be feeling about a situation – *“You cannot be upset about that!”*

Emotional rollercoaster

Any significant experience in your life will affect your emotions and you will go through a series of emotional responses, for example, being made redundant, a significant relationship ending or a new child joining the family. Different members of your family may have a different emotional response to the same situation – this may be because of their personality or their life experiences – these emotions are valid and real for each person.

If your child starts missing milestones, you may have concerns about their development or they become ill you may experience a range of emotions. Raising your concerns, being taken seriously and accessing the right information or specialist can be a frustrating and anxious time. You may have to wait for a referral, you may get passed around services or your paperwork may get misplaced. You may have a different opinion about whether there is something wrong and what should be done about it.

Feelings and emotions are complex and sometimes you may be anxious or alarmed about how you feel about something. As the years go by you may think you are done with one set of emotions only to find they return. This can happen when you see other children in your family, or amongst your friends, who reach milestones that perhaps your child will not and strong feelings might emerge that you weren't expecting.

Whilst your child is being assessed it is likely that you will start searching for answers yourself. In today's technology driven world a large majority of people turn to the internet, there is so much information that can be either misleading or terrifying.

Finding out about your child's condition or diagnosis may take years – some families never get a **diagnosis**. It is likely you will be very worried and afraid about what the future may hold because you don't know what to expect or how your child might progress. This can be particularly difficult if your child has a **rare disorder or condition** and there is little or no information available.

At the time of diagnosis many parents say they feel shocked and numb and cannot take in all the information that is being given to them by professionals. You are likely to experience a range of emotions which could include:

- **Denial:** Some parents tell themselves it is a mistake and their child will get better, the professionals must have got it wrong, “This can’t be happening to us”.
- **Anger:** It is not unusual for parents to feel angry and look for someone or something that is to blame.
- **Guilt:** You may experience feelings of guilt, was it something you did or didn’t do during pregnancy, or blame yourself even when you know the reason for your child’s condition is out of your control.
- **Grief:** You may experience a profound feeling of loss and grief. Grief is a personal and highly individual experience. How you grieve depends on many factors, including your personality and coping style, your life experiences, faith, culture and beliefs. Different people will deal with grief in different ways and you and your partner (or family) may be at different stages. There is no “normal” timetable.
- **Relief:** For those parents who do get a diagnosis there may be a sense of relief that finally professionals are taking your concerns seriously and now you know the name of the condition you can find out how best to support your child.
- **Acceptance:** After some time has passed, and again there is no set timescale, you are likely to reach a stage of acceptance and become hopeful about the future for your family – different to the one you may have envisaged, but hopeful nonetheless.

“I was very upset at first... it was hard for my family to accept. We had to grieve for the child we expected to have and make adaptations for the new [Sam].” Parent carer

You, your partner and your extended family may experience some or all of these emotions, but not necessarily at the same time. You may grieve for a shorter period of time and reach acceptance of the situation before they do. Remember, emotions are individual but it is important to acknowledge whatever feelings you are experiencing – there is no right or wrong experience or pattern.

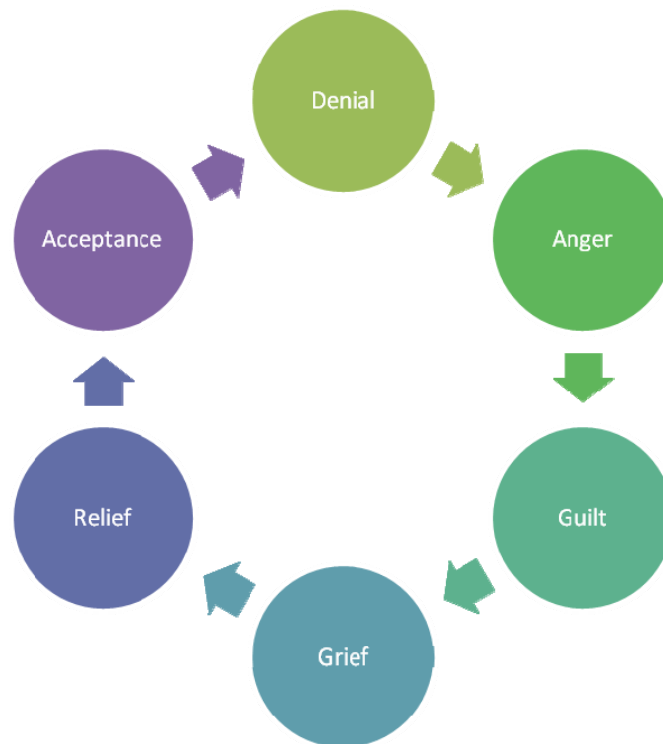
“It was the worst day of my life. We were crushed beyond belief ... I went into melt down for about a month, I couldn’t function very well and then I went into action mode.” Parent carer

As the above Mother reflected she “went into melt down for about a month” this may have been while she processed all the information and experienced some of the emotions on the previous page. Some people withdraw and you may experience a period of reflection. This can help you come to terms with the situation and what needs to be done next – it may be scary and you may feel alone. This same Mother then went into “action mode” –

after a period of time she now needed to sort out the support her child needed and find out all she could about her child's condition.

Finding out about your child's condition or additional needs won't necessarily stop you from worrying about the future as a whole set of new worries may kick in, for example, decisions about treatment or education. Emotions can bubble up at any time and take you by surprise.

"I saw all the children in their brand new uniforms going to start school and it hurt knowing my child would not be one of them." Parent carer



Cycle of emotions: you may not experience all of these emotions and not necessarily in this order – each person is different - and you can come back and go round many times.

Emotional support

Taking care of your emotional health is as essential as caring for your physical health.

Emotional struggles and unresolved feelings can lead to a build up of tension and stress. Feeling really low is a common response to too much stress, being constantly tired and in an anxious emotional state. Talking about feelings with people who understand and do not judge can be enormously helpful. Partner, friends, family and other parents may provide this kind of support where you can express yourself without being judged and work through your feelings.

“I don’t know what I would do without my family and friends. They are very involved in supporting [my child] but perhaps more involved in supporting me.” Parent carer

Sometimes the build up of feelings becomes more serious and professional help is needed. Talking to someone outside your family can be a huge relief and help you to express your feelings in a way that will not damage your relationships. **Counselling and therapy** can help you resolve negative feelings so that you feel better about life. If you are offered this kind of support it may well help you.

“... the family wasn’t working because of how I was feeling and I was offered counselling. I think it is really, really important initially to get some help as a parent dealing with this illness.” [Parent carer]

If you are thinking of seeing a counsellor or therapist there are some options available. You could ask your GP to refer you to someone appropriate, although many GPs have a waiting list to see a counsellor, some charities offer **counselling services** and there are also a number of professional organisations that provide **counselling**.

Quite often therapy and counselling are offered by people in private practice and a fee is charged. Many offer a reduction in their fee to people on benefits, do discuss this directly with the counsellor if this is something you are interested in doing. In some areas there are places where counselling or therapy is available free or at a very low cost to carers, your local **Carers Centre** (see **Carers Trust** in **useful organisations and websites**) may be aware of appropriate local support.

Therapy and counselling can be extremely useful but do not feel you have to keep on with it if it is not meeting your needs. Most people find that having a willing listener giving them full attention for a period every week is a real luxury and offers the potential for you to feel cared for once in a while and it is time to talk about you and your feelings and needs.

Be aware that there are a number of different styles or types of counselling/therapy, for example, as a couple, an individual or a family. You can find information about the different options on the **Counselling Directory** website.

Emotions and feelings are complex. If you wish to look more deeply at the issues discussed above please look at the resources section for some further reading.

Taking care of yourself

Some of the aspects of taking care of yourself won't come as any surprise – start clicking around on the internet or browsing in a book shop and it won't take you long to become immersed in a wide range of information – some helpful and some not. Your local library may have some suitable books or can order books in, at your request, and if you don't have internet access at home most libraries have computers for public use.

Anyone who watches the news or regularly reads a newspaper or magazine cannot have escaped the wide range of information available about healthy eating, exercise and sleep.

Healthy eating

There is so much information about healthy eating (see [NHS choices](#) in the [useful organisations and websites](#) section) we are not going to delve deeply into this. Feeding the family can be expensive but it is possible to eat healthy food on a budget. Do:

- check out the special offers in your local shops
- buy in bulk
- stock up your freezer
- use discount stores, vouchers and coupons
- grow your own

Exercise

It is well known that exercising moderately, regularly releases endorphins (good chemicals in your brain) and can help you feel more energised. A simple daily brisk walk can be very effective. If you are feeling under pressure, a walk round the block, a cycle round the local park or a quick dance to music at home - can help you relax and clear your head.

[NHS choices](#) provide information about exercise options including getting fit for free! Many public parks have exercise equipment that is free to use. If you need an incentive, why not sign up to raise some money for a charity and take part in one of the many walks, runs or challenges available?

Sleep

When you are tired and run down your ability to cope is greatly reduced.

If you are not sleeping, why not? What is keeping you awake? Is it your child's sleep pattern that is disruptive, or do you have difficulty clearing your mind so you can fall asleep?

If the issue is around your ability to sleep what can you do? Here are some suggestions:

- Paint the walls a relaxing colour so the room feels calm
- No TV in bed – this stimulates your brain
- Try not to eat large meals, drink caffeine or alcohol before bed
- Have a relaxing bath
- Read – some people find after a couple of pages they drift off
- Write down the things that are on your mind – try keeping a journal or write a list of things you want to remember to do tomorrow or in the next few weeks
- Meditate
- Listen to relaxing music

The effects of sleep deprivation should not be underestimated and if you have tried different strategies to help you to sleep and you are still having trouble sleeping please seek advice and support. Speak to your GP in the first instance and think about childcare options, for example, accessing [short breaks](#).

If you need support managing your child's sleep some organisations offer sleep workshops and there are a number of useful guides available, including the Early Support *Sleep* resource available at www.ncb.org.uk/early-support/resources.

Healthy eating, exercise and sleep are important for physical and mental health, increase your ability to manage day to day and will keep your immune system healthy to protect you against general illness.

As well as healthy eating, exercise and sleep, what else will help you look after yourself?

Making time for yourself

Nobody wants to have every minute of the day planned, but writing things down can help you get organised and take the burden off trying to remember everything. And for some things to happen, you need to have planned and put some support in place, for example, childcare.

Many parents find having a “to do” list helps them to organise the priorities for a day, looking at which tasks are important, perhaps some things can be given to someone else to do and some things can be crossed off the list altogether.

“I keep the ‘to do’ list in a place where the family can see it – so the family can help with tasks without me needing to ask.” Parent carer

You may also find it helpful to have a schedule on the wall so you can see where all the members of the household are and when they will be at home. This can help with cooking dinner and help you remember all the relevant shoes/equipment/kit that your children need for school and other activities.

This may sound like looking after everyone else rather than yourself – but who gets the blame when swimming kits are forgotten or you run out of milk?

“I find it really helps me if I am organised, for example, preparing packed lunches the night before – sometimes I even lay out my clothes ready for the morning!” Parent carer

“Forward planning and the sharing out of chores helps make things go much easier.” Parent carer

Having something to look forward to can also help you get through the day. It need not be expensive or take a lot of time and it is useful to spread the treats out over a period of days, weeks and months.

- **Short term** – Each day do something for you. It might be watching a favourite television programme in peace, having a relaxing bath, reading a chapter of a book or calling a friend. Whatever it is, plan it at the beginning of the day and when things get tough, return to the pleasant anticipation of your treat for the day.
- **Medium term** – Try to arrange some time to yourself so that every week, or at least every month, you can enjoy a longer stretch of time doing something just for you. It might be an evening class, trip to the cinema, a hairdressing appointment or a meal with a friend/partner. It may not be easy to organise this, especially if you are a lone parent, but it is worth the effort.
- **Longer term** – If possible it is good to have a longer-term treat or plan to think about from time to time. Perhaps a holiday, a time when you might be able to return to work, or a visit to friends/family.

“At the end of the day I massage my feet while listening to my favourite radio programme.”
Parent carer

Sometimes your day may take a turn you were not expecting. If you find that your day is no longer going to allow you to fit in your short term treat grab it while you can. Be spontaneous, 10 minutes free now – fantastic –take a break!

Taking a break from caring for your child is not an admission of failure or a way of saying you don't care. Without an occasional break you are likely to become completely exhausted or even unwell. Having some time to do the things you can't do whilst looking after your child can make it easier to manage your time. Your child can also benefit from participating in fun activities: the change of scene, the break from you, contact with other people and new experiences.

Many parents/carers take breaks from caring by asking members of their family, friends or neighbours to take charge from time to time. You may find you need a more formal arrangement, for example, accessing **short breaks**, that don't depend on other people being available and willing to help you when you need it.

For more information about accessing short breaks see other titles in the Early Support range of resources, available at www.ncb.org.uk/early-support/resources.

Work-life balance

For some parent carers balancing work with caring responsibilities is impossible. Remember, although you may be away from the work environment for a period of time while you raise your family, you are developing a wide range of skills that might be useful in the future, for example, managing people, negotiating skills, organisation skills and prioritising tasks to name a few. These are what employers refer to as 'transferrable skills'.

Some parent carers find going to work has a positive effect and creates space for them to be a person in their own right and not a mother, father, wife, husband or carer. For this reason you may wish to continue to work – find out what your rights are – seek **specialist advice** about your entitlement to time for appointments, reduced hours, flexible working. Try to find something that matches your interests, the needs of your family and the money necessary to live on.

It is also important to ensure you are accessing all the financial support that you are entitled to. It is worth getting a **regular benefit check**, the benefit system is changing and you may now be eligible for something you previously were not.

If going to work is not an option or choice for you, but you wish to use your skills and knowledge, develop some new ones or get away from the home for a few hours a week, you might want to explore local **volunteering** opportunities. This can have a positive effect on self esteem and confidence, be a good way of meeting new people and has the advantage of being flexible.

“Getting involved in my local parent carer forum helped boost my knowledge of local services and how to access them, question local provision and work confidently with professionals.” Parent carer

Social life

Maintaining a social life is not always easy. Getting out and about when you have a child with additional needs can present some challenges. Not just in terms of getting childcare but also in terms of cost and **public attitude**.

Are there services you can access to help you maintain a social life, for example, babysitting services, **direct payments**, **short breaks**, **children's hospice services**? Please see the Early Support *Behaviour* resource at www.ncb.org.uk/early-support/resources.

“It is really important to get in contact with people who understand what you are going through.” Parent carer

Meeting other parents/carers who are in the same position as yourself can help you feel less isolated. It can be such a relief to discover others feel the same way and be a source of strength and practical ideas.

“The best information you can get is from other parents sometimes.” Parent carer

Where can you meet other parents?

- Local parents support group – usually for children or young people with a range of long term conditions or additional needs; the great thing about local support is that you can access it regularly and share information about what is available in your area. Although not everyone finds this useful, you may find local parent support groups a life line. Some groups have activities for children/young people and/or the whole family and they are a space where your child with additional needs can be accepted whatever they do.
- National condition support group – usually focus on a particular condition. Many of the national groups are a source of medical information, some have access to medical professionals (some run clinics), and you can meet other parents to share experience of the same condition as your child, for example, assessment, medication, therapies and research.
- Online forums, for example, **Facebook**, **MakingContact.org** and **Parent carersNet**. The benefit of an online forum is you can access it at the most convenient time for you, which may be midnight!
- Local children's centres run groups for parents/carers – your Family Information Service can provide information about your nearest centre. Many children's centres are changing the age range of the children they support. Contact the centres in your area to ensure you are not missing out on accessing support for you and your children and young people. The Family Information Service can also signpost you to local carers support organisations and other suitable community groups.

If you are looking for information about what is available locally to you, your local **parent carer forum** can also be an invaluable source of support both in terms of meeting local parents and gaining local knowledge about services. Whilst Parent Carer Forums are not support groups, joining a Forum can offer so many opportunities and many parent carers find they gain confidence in realising they are not alone, in working with others to try to improve services for all children, as well as those who are disabled or have additional needs, in their local area.

Training, workshops and information

You may have heard people say things like “information is power” and “you don’t know what you don’t know”. Contact with other parents will definitely help with both of these issues but there may be opportunities to gain knowledge through training and workshops. Some charities offer courses free to parents who have a child with additional needs and some offer courses at a reduced rate. To make sure you are aware of all the opportunities you can register to receive local newsletters or newsletters produced by organisations that you think are particularly helpful.

Some parent carers have attended workshops to support their children, for example, managing sleep, behaviour or benefits.

“I took away some good ideas that were easily achievable.” Parent carer

“Enjoyed it – thanks, felt relaxed and supported.” Parent carer

“I feel much stronger about the everyday things I need to deal with.” Parent carer

“The recognition that our child had a range of cultural requirements as well as his impairment requirements was very helpful and culturally sensitive” Parent carer

Early Support offer a series of parent-led Parent Carer Workshops which offer opportunities for parent carers to meet others in their local area and find out what is available locally. They above all offer parent carers an opportunity to build their confidence and increase their skills, whilst also building up resilience to face the challenges of this ‘unknown world’. For full details visit the Early Support website at www.ncb.org.uk/early-support.

“A fantastic opportunity to meet others and learn that your experience is not an isolated case. Very constructive techniques to arm parents with the skills to deal with professionals and difficult situations.”

“Particularly enjoyed the last workshop and realising I am not only a parent but also a carer- makes me feel less inadequate against all the other parent carers with their ‘typical’ children who seem to cope with motherhood better than me. Actually I’m doing two jobs! I’d probably cope better with only one!”

“For 17 years I have stayed at home and hidden my son away. NO MORE! We are going to enjoy life so much more now.”

If you are interested in exploring other training opportunities **Carers UK** can provide information on accessing funding to help towards the cost of training or carer development.

Relationships: Family, friends and neighbours

All relationships go through periods of change, for example, when children arrive and there will be periods of adjustment as new roles and routines develop. In the usual course of things you make adjustments and move through these periods with little difficulty.

Sometimes you don't even notice this happening and on other occasions it can be difficult, particularly if a child is born with additional needs that are recognised before or at birth or at the time of a later diagnosis. If you can get support to help you cope with difficult times, or if you have a good support network, this can provide a cushion to protect you and your relationships.

Partners

You can find yourself using up all your patience on your child with additional needs and then taking out your frustrations on your partner or other children. Try not to keep your emotions to yourself, but actually say "I have had such a frustrating day dealing with all the paperwork and now I need 10 minutes to myself." Try not to get drawn into repetitive patterns of blame and resentment. Conflict with your partner or children will only make things worse.

"In other ways it has brought us closer together because we have had to work on a common goal which is getting the best we can for [our son]. ... 11 years on I suppose we have come to recognise that life is going to be a continuing set of challenges and we are going to try and face them together". Parent carer

If you have a partner, remember:

- You are a team – support each other.
- Acknowledge how hard the task you share can be.
- Notice when the other person is tired and needs a break.
- Make sure that it is ok for each of you to ask the other to take over for a while when you are reaching the end of your tether.
- Do share the humour that all children and young people bring into your life and the positive things that happen.

"The hardest bit for our relationship occurred when we disagreed on what was best for our daughter, Rachel. What helped was acknowledging to each other how difficult it was to know the right thing to do."* Parent carer

Sometimes when family life is so busy it is hard to focus on your couple relationship and maintain intimacy, both physically and emotionally. If you and your partner are struggling

you may find it helpful to speak to a **counsellor** or **therapist**. You or your partner may be reluctant to seek outside support or feel anxious about talking to someone about your relationship. It is worth noting that if one person in the couple seeks support there can still be a positive effect on the relationship.

Being a single parent

If you are bringing up a child with additional needs alone you are not the only one; there are many other single parent families (see **Gingerbread** in **useful organisations and websites**). In some ways it can be easier to set clear boundaries and make decisions about how to manage your child's condition. But the stress and loneliness can sometimes be overwhelming. Single parents will need to pay particular attention to organising practical support and taking care of themselves as you may have less people around you who can share the responsibilities. This is when support groups are particularly useful – teaming up with another parent who understands may well help you.

Siblings

All brothers and sisters fight, argue and wind each other up and the siblings of children with additional needs are no different. No matter how your family is made up, it is important that you have a consistent approach. Changing rules and boundaries is very confusing for children and young people and they may start saying different things to each of you.

Some siblings can feel angry and resentful both towards the children and young people with additional needs as well as towards their parents. This can lead to feelings of guilt. You may not be able to give as much attention as you would like to your other children and they may feel as a consequence that they are loved less. You know this is not true – what can you do to reassure them?

- Try to find some time to spend with them having fun, helping with homework, listening to their tales of what happened at school or college today. Making this happen takes thought and **planning** (see section 5) but it is really important. It may be as little as 10 minutes a day but focus on them for that time. If you are not able to do it you may find that siblings come to believe that misbehaving is the best way to get attention and this will add to your stress.
- Help your children to understand why their sibling behaves as they do and prevent them jumping to their own conclusion by providing appropriate information. It can help reduce resentment and help your children feel included. It can encourage them to ask questions about their sibling's condition and arm them with information they can share with their peers.

- Help your children to identify their feelings and emotions and reassure them that these feelings are normal and natural. Encourage them to find ways to deal with their feelings without hurting anyone else. For example, if they feel angry what will help them to feel better?
- If you are using **behaviour management techniques** or strategies for your child with additional needs you might find it helpful to share them with your other children and ask for their support. So everyone in the family is giving the same response – this will make things easier in the long run.

A child who has a sibling/young family member with additional needs is more likely to have a stronger social awareness, sense of fairness and empathy towards others.

For information about support organisations that can help you with any sibling issues or concerns see the [useful organisations and websites](#) section.

For further reading on talking to children and young people see the [resources](#) section.

Extended family

You may find visits to relatives (for example, grandparents, aunts and uncles) a supportive experience or they may be very tense occasions. It can help to explain as fully as possible what your child's needs are and how you are supporting them. Explain to family members how they can help, perhaps by ignoring unacceptable behaviour and allowing you to deal with things in ways the child understands. If this is not possible or doesn't work it is probably best to keep your visits short.

If family members are not as supportive as they could be or you would like – what is holding them back? Do they need information – perhaps talking to other families would help them. There are a number of organisations that offer support to [grandparents](#) and some national support groups welcome all family members, including extended family, at their annual family event.

Sometimes extended family members can be very helpful and will offer to sit with your child or children while you have a break. If this opportunity is offered, use it. Remember to share any behaviour management techniques that you are using so your child will feel secure. This will also help your family feel valued and trusted and confident that they can support your child in your absence. They may even be able to offer insights of their own that may help to resolve some problems.

Friends

Having a child with additional needs is also likely to bring you into contact with new friends who share similar experiences and who can be a vital source of support.

For many families the reality is that:

“We have a smaller group of friends who really understand and who are willing to let [my son] be [himself].” Parent carer

Sometimes maintaining old friendships is not possible. Try not to give them or yourself a hard time or regret it too much. It is better to put your energy into developing and sustaining friendships with people who like your children and the whole family will feel more comfortable with them.

General public

Occasionally, the kindness of strangers will take your breath away and move you to tears.

On other occasions the attitudes and responses of people in the general public can leave you feeling angry, frustrated and sad. Assumptions or beliefs and attitudes about additional needs/disability or behaviour develop as a result of our life experiences and upbringing – for some people disability has not been part of that experience. Some parents caring for a child with additional needs say that before their child was born they too had little or no exposure to long term conditions or additional needs and the affect on the family.

Staring and comments

Some people, children, young people and adults, may stare and make hurtful remarks about your child and your ability as a parent. If your child has autism the **National Autistic Society** produce cards – about the size of a business card – that you can give to people who stare or comment when you are out and about. Some parents have found this to be a very effective strategy to manage their own response and effectively explain the condition to others. If your child has a **rare disorder**, perhaps the charity providing support for that condition produces something similar – you could even produce something yourself. If appropriate discuss this idea with your child/young person, ask how they feel about this strategy – they may have other suggestions on how to deal with this situation.

It may also be useful to look at the Early Support resource called *If your child has a rare condition*, available at www.ncb.org.uk/early-support/resources.

“One family memory of [George] being young was his lack of understanding that each picnic belonged to someone else. He used to run around helping himself. We laugh about it now.” Parent carer

If your child has a condition affecting their appearance there are organisations that can provide support for you and your child to help deal with the attitudes of other people.

“The most difficult thing is the social inclusion ... you stay at home more because it’s easier ... before you know it you have found that inadvertently you have shut yourself off from the rest of the world...” Parent carer

Handling complaints about your child’s behaviour

It is possible to understand the anger some parents in public places might display if their child has been hurt by yours, particularly if it appears to them that nothing is being done about it. Listen to what they have to say and try to defuse their anger by acknowledging how upset they are. Just saying that you agree that your child’s behaviour was out of order and that you will do what you can to ensure that it doesn’t happen again can defuse a volatile situation.

Neighbours can be hostile, complaining about damage to property or refusing to let their children play with yours or make you feel uncomfortable about taking part in local or community based events. There are no easy answers to this. Do try to stay calm and reasonable. If you are able, offer to pay for any damage which you are sure your child has caused. If there are one or two neighbours who are more sympathetic cultivate their friendship. At least you will feel that you have an ally and they are likely to talk to others. If they see that the child’s or young person’s behaviour is not caused by your parenting and that in fact you are doing a very good job, they are likely to let others know so they become more understanding.

Do check that the events you are being presented with did really happen as described by talking to your child and anyone who was present. Children with additional needs acquire such reputations that they tend to be blamed for all sorts of things they have not done and foul intent is attributed to pure accidents. For example, a child who is unsteady or has co-ordination difficulties may knock something over unintentionally or a child with a learning disability might be encouraged to do something by a peer without understanding the consequences.

“On more than one occasion I have found myself chastising my son for things he either did not do or where he was not to blame.” Parent carer

Finally, try to spend time with others who treat you well and who boost your self-confidence. Raising a child with additional needs can be a difficult job with fewer immediate rewards and people who may criticise you. You need to have confidence in yourself. Steer away from those who constantly criticise or tell you how it should be done when they have never had to do it themselves.

Communication

In any relationship whether with your partner, a neighbour, your boss or your children, one of the essential ingredients is communication. Communication is about sharing information, thoughts and feelings – everyone wants to be listened to and understood.

Choosing the best method

You communicate in a range of ways, as well as what you say directly to someone (face-to-face) many people freely send emails and texts as well as make phone calls. Before communicating with someone decide which is the best method for the message you want to send. For example, if you are late to meet a friend a quick text “Be there in 20 mins” would do the job. Or if you wanted to share information about an event sending an email might be best so you can include links to maps or other venue information. Some exchanges are just better face-to-face and communication starts as soon as you see the person and make eye contact.

Importance of body language

The communication process includes more than words – sometimes we communicate just by the way we hold our head! Surprisingly more than 90% of your communication comes from your body language including your tone of voice, the way you stand and eye contact. Interestingly, if your words conflict with your body language it is the body language people believe. Body language can also have different meanings in different cultures, for example, in some cultures averting one’s eyes is seen as a sign of respect but in others it is taken as a sign of disrespect. You may be communicating with someone who does not understand or consider these differences and this can lead to confusion or frustration for everyone.

Take time to communicate

For good communication to take place it is not just the words and how you say them that are important but also the ‘listening’ that you do. You may skim read an email or letter, only reading key words or phrases and miss out on some of the meaning. Or when someone calls you, you may be doing things in the house while you talk.

The environment also has a part to play, for example, music, someone trying to talk to you or distract you, the children having an argument, or worse, in the background.

When having a conversation with someone do:

- Take time to focus on the conversation you are having.

- Listen to what the other person is saying – don't be constructing your response in your head or thinking about what you will cook for dinner.
- Let the other person finish what they are saying – don't interrupt even if they are saying things you don't agree with.
- Remember your body language may give you away – if you are turned away, looking bored, reading something whilst someone is talking to you – they will not feel listened to.
- Use 'I' phrases – I feel, I am happy, I am concerned, rather than 'you haven't done X'.

Be aware that if you are feeling stressed, emotional, tired or hungry this can affect your ability to communicate well.

For more detail about effective communication with your partner see the [resources section](#). For more information about talking and listening to your children see [Afacic, I CAN](#) and [The Communication Trust](#) and the [resources section](#).

Differences of opinion and conflict

Sometimes, when you communicate with someone there is a difference of opinion or conflict. Whenever faced with a conflict situation (regardless of who this is with) it is always best if you can take a deep breath and stay calm. This is the hardest thing to do for even the most patient person. Within a family angry feelings are contagious and when dealing with some organisations the frustration of the situation can make you want to scream.

What helps in a conflict situation?

- Try to step back from the situation – leave the room, get up and open a window – give yourself time to think and gather your thoughts and breathe slowly.
- Think about what you are doing – is it helping the situation or is it making things worse? Even in some very difficult situations it can be useful to stop doing anything if what you are doing is not helping.
- What else could you do that might work better?
- What have you tried successfully on other occasions?
- Pay attention to how you are feeling physically – try to relax the most tensed up muscles, for example, jaw or shoulders.

“Once when my son seemed completely out of control I stopped struggling with him and went to phone for some advice. While my attention was elsewhere he calmed down and the next thing I knew he was bringing me a cup of tea!” Parent carer

Switching off the action for a bit and thinking about something completely different or at a different level rarely causes disaster and often does some good.

Find a way of thinking or talking to yourself that calms and encourages you. Positive self-talk will help you feel capable, caring and in control instead of impotent, angry and close to breaking point.

Conclusion

You need to be realistic about what you can cope with.

“When my son was ... admitted to hospital One wise staff member pointed out that there was a whole team of staff including nurses, psychiatrists, therapists, occupational therapists and teachers devoted to his care whereas at home there was just me to manage him and his sister. Later I realised that they also had an army of cleaners, cooks, administrators, managers and so on to do all the things I do at home apart from look after him. It was then that I realised I needed and deserved more practical help.” Parent carer

Living with a child/young person with additional needs is tough but it can be enormously rewarding. The more successful you are at the task the better you will feel, about yourself and your child. But to judge whether you are successful, you have to know what you are aiming for. What do you want out of life ... for you and your family?

If you think about these questions and answer them honestly, the answers may help you to adjust your priorities. In the future, will you want to be congratulating yourself on always keeping the house clean, or on ensuring that all your children had designer trainers upon request, because you put in more hours at work than any of your colleagues? Or is there something more fundamental you want to achieve?

The priorities you set yourself must be the right ones for you and your family – not those set by friends or neighbours. If it really matters to you that your house is clean and tidy then put your efforts into getting some help from somewhere with this task. Ask your social service or social work department to give you some practical help (for example, short breaks) or try and find the money to pay someone to do a good clear up once a week or month.

This publication has covered a range of ways that you can take care of yourself and provided further reading and useful organisations that can help you to achieve what is right for you. Remember, if you are well and happy in yourself you will be much better placed to support your family consistently and effectively and this will increase your confidence and self-esteem. Sometimes, it is not possible to do everything yourself, do ask for help. Your role is a demanding but vital one and the success you make of it will have long lasting effects not just on your family but on the community at large. Seek advice and be knowledgeable about what help you are entitled to and be assertive in asking for the help that you and your family needs.

Top tips

1. **Plan your time and reduce your to-do list**

Be realistic about how much you can achieve in a day, week or month and remember to include some 'you' time.

2. **Communication**

Make time for conversations with people who are important to you, for example, friends and family. Remember listening is as important as talking.

3. **Express your feelings**

Tell others how you feel don't bottle up your emotions. Try "I feel frustrated that I have to collect laundry from every room in the house instead of one laundry basket" rather than "How many times have I told you to put your laundry in the basket". In this example we are not nagging and blaming the person – but giving them the opportunity to see how it affects you and how they can help.

4. **Be willing to compromise**

Negotiate. If we use the example above of laundry, perhaps if everyone leaves their laundry outside their bedroom door it would be easier to collect it.

5. **Take control of your environment**

If a particular activity or environment is difficult or stressful how can you manage that differently to reduce the stress? For example, if a trip to the shops is hard for you and your child – can you shop online instead?

6. **Be positive**

If something goes wrong try to find a more positive way to view it. Try to focus on the things that worked or went well today, not the one thing that didn't.

7. **Ask for help**

There is no shame in asking for help – you are not a superhero and sometimes everyone needs a bit of help.

8. **Be assertive – just say no!**

Know your limits and stick to them. Why take on more tasks than you can manage – say no.

9. Avoid people who stress you out

If spending time with a particular person makes you anxious and stressed, limit the amount of time you spend with them.

10. Be forgiving

Sometimes events will not happen as you would like them to or a meeting is more frustrating than helpful. Do let go of anger and resentment – if you hold onto these emotions you will find it more difficult to move on. Forgive others and yourself.

“As a single parent with a disabled child or as a parent of a child who has a life limiting illness of which I am both, it is easy to only fall into seeing the negatives each day but I make a conscious effort to reflect on the positive things too, the good things, the many blessings and to plan ahead but to live for each day and I encourage my children to do the same. Having taken this stance we see balance and feel better for it” Parent carer

You may find some of these tips easy to implement yourself or you may find you need to speak to your partner or family, or someone outside your family, to get started.

The choice is yours – there is no time like the present!

Resources

Contact a Family guides:

- Helping your child's sleep
- Relationships and caring for a disabled child
- Fathers
- Grandparents
- Siblings
- Understanding your child's behaviour
- A guide to dealing with bullying: for parents of disabled children

For the full range of guides, visit their website www.cafamily.org.uk

Early Support publications on issues that can impact on you and your relationships:

- Behaviour
- Living without a diagnosis
- Rare conditions
- Sleep

For the full range of guides please go to www.ncb.org.uk/early-support/resources.

Other resources

Faber, F. and Mazlish, E. (2001) *How to Talk so Kids will Listen and Listen so Kids will Talk*. Great Britain: Piccadilly Press Ltd.

Faber, F. and Mazlish, E. (2006) *How to Talk so Teens will Listen and Listen so Teens will Talk*. Great Britain: Piccadilly Press Ltd.

Hein, S. (2012) *EQ for Everybody - A Practical Guide to Developing and Using One's Emotional Intelligence*. <http://core.eqi.org/eqe2012d.pdf>

For tips about effective communication with your partner download [How to Talk so your Spouse will Listen](#).

www.lifewithoutanxiety.com/sites/lifewithoutanxiety.com/files/communication.pdf

Useful organisations and websites

General

Afasic

Afasic is the UK charity established to help children and young people affected by the hidden disability of speech, language and communication impairments

www.afasic.org.uk

Enquiries: 020 7490 9410

UK helpline: 0845 355 55 77

Carers Trust

A UK charity formed by the merger of The Princess Royal Trust for Carers and Crossroads Care in April 2012. Carers Trust works to improve support, services and recognition for anyone living with the challenges of caring, unpaid, for a family member or friend who is ill, frail, disabled or has mental health or addiction problems. Together with their Network Partners, they aim to ensure that information, advice and practical support are available to all carers across the UK.

www.carers.org

0844 800 4361

Carers UK

A UK charity providing information advice and support to anyone with caring responsibilities. Information about many aspects of caring including looking after yourself and information about finding funding to assist with training.

www.carersuk.org

0808 808 7777

Changing Faces

A UK charity for people and families whose lives are affected by conditions, marks or scars that alter their appearance. They aim to help individuals lead full and satisfying lives by giving practical and emotional support to adults, children and their families.

www.changingfaces.org.uk

0845 4500 275 or 0207 391 9270

Contact a Family

A UK charity providing information advice and support to parents with disabled children, whatever their condition. For information about benefits, meeting other parents and your rights, call their freephone helpline.

www.cafamily.org.uk

Freephone helpline 0808 808 3555 Monday to Friday 9.30am to 5pm

Early Support

Supports children, young people and their families to take control of their lives, gain a firm basis of knowledge and communicate their expertise in a way that enables them to make informed choices. Produces resources and delivers training to bring service providers together, with parents, children and young people at the centre of a holistic and integrated planning process.

www.ncb.org.uk/earlysupport

0207 843 6350

Early Years Equality

Provides disability equality and other protected characteristic equality support, guidance, advice, discrimination casework and training to children, families, organisations, providers and policy makers across the UK.

www.earlyyearesequality.org.uk

0114 270 0214

Equality and Human Rights Commission

The Equality and Human Rights Commission has a statutory remit to promote and monitor human rights; and to protect, enforce and promote equality across the nine "protected" grounds - age, disability, gender, race, religion and belief, pregnancy and maternity, marriage and civil partnership, sexual orientation and gender reassignment.

www.equalityhumanrights.com

Telephone 0800 444 205

Textphone 0800 444 206

Family Information Services

You can find Family Information Services (FIS) across England, Wales and Scotland and each one provides information about local services that families can access. Use this link to find your local FIS.

<http://findyourfis.daycaretrust.org.uk/kb5/findyourfis/home.page>

Gingerbread

A UK charity providing advice and practical support for single parents through their helpline, and website and also offer training.

www.gingerbread.org.uk

Freephone helpline 0808 802 0925

I CAN

I CAN is the children's communication charity. I CAN's aim is to ensure that no child is left out or left behind because of a difficulty speaking or understanding.

www.ican.org.uk

0845 225 4071 or 020 7843 2510

Include Me Too

An organisation supporting disabled children, young people and their families from Black, ethnic minority and other marginalised backgrounds. Aims to promote and support all disabled children and young people's rights.

www.includemetoo.org.uk

01902 399 9888

National Autistic Society

A UK charity for people with autism (including Asperger's syndrome) and their families. They provide information, support and campaign for a better world for people with autism.

www.autism.org.uk

Freephone helpline 0808 800 4104 Monday to Friday 10am to 4pm

National Network of Parent Carer Forums (NNPCF)

The Network aims to ensure that good practice, knowledge and shared expertise about parent participation continues to grow and strengthen, and to develop a cohesive and coherent structure to sustain and develop the effectiveness of parent carer forums across England, individually and as a collective voice. You can find your local forum through their website.

www.nnpcf.org.uk

The Communication Trust

The Communication Trust is a coalition of nearly 50 voluntary and community organisations with expertise in speech, language and communication. They harness their collective expertise to support the children's workforce to support the communication needs of all children and young people, particularly those with SLCN.

www.thecommunicationtrust.org.uk

0207 843 2526

Volunteering England

An independent charity and membership organisation, committed to supporting, enabling and celebrating volunteering in all its diversity. Their work links policy, research, innovation, good practice and programme management in the involvement of volunteers.

www.volunteering.org.uk

020 7520 8900

Healthy lifestyle

NHS Choices

Provides a range of information to help people make healthier lifestyle choices including healthy eating and exercise.

www.nhs.uk/livewell/Pages/Livewellhub.aspx

Relationships support

Cerebra – stress helpline

Together with the Swansea Metropolitan University, Cerebra offer a free telephone counselling helpline for carers of children affected by neurological disorders (including autistic spectrum disorders), to give you somewhere to talk things through and get some advice on dealing with stress.

www.cerebra.org.uk

Counselling helpline 0800 043 9385

Counselling Directory

Use this website to find local counsellors or therapists. The Counselling Directory only lists counsellors and psychotherapists who are registered with a recognised professional body or those who have sent copies of their qualifications and insurance cover. The website contains information about the different types of counselling.

www.counselling-directory.org.uk

Marriage Care

A UK Charity provide relationship support through marriage preparation, relationship counselling, relationship education and a telephone helpline (in partnership with Family Lives). No matter what stage you're at in a relationship they can offer support and don't charge a set fee for their work. They ask clients for a contribution to support their services where they can and have 50 centres across England and Wales.

www.marriagecare.org.uk

020 7371 1341

Relate

A UK charity providing counselling services that include relationship counselling for individuals and couples; family counselling; counselling for children and young people and sex therapy. They also provide friendly and informal workshops for people at important relationship life stages.

www.relate.org.uk/home/index.html

0300 100 1234

Sibs

A UK charity representing the needs of siblings of disabled people. They offer a range of support including workshops and information to young siblings, adult siblings and parents of siblings. They also have a young siblings forum where children can share their experiences.

www.sibs.org.uk

01535 645453

Parenting support

The following organisations do not specifically or solely support families with disabled children but their websites do contain useful information around being a parent – some of this information might be useful to you.

Family Lives

A UK charity providing help and support with all aspects of family life.

www.familylives.org.uk

0808 800 2222

NetParent carers

Online forum for Parent carers to share experiences, does have a special needs section.

Also offer some online courses.

www.netparentcarers.com

0808 800 2222

Glossary

Additional needs – The term ‘additional needs’ used in this and other Early Support resources is used to refer to any child or young person who has a condition, difficulty, challenge or special educational need, whether diagnosed or not, who is likely to need additional support beyond universal services.

Counselling – Counselling tends to be more low key than therapy and the commitment may be less. Ask questions, especially about the counsellor’s training and experience. Choose an individual who is right for you – you are going to be telling them personal stuff it is essential you feel comfortable and trust them.

Direct payments – If your local authority agrees that your child needs services, you can choose to get money to buy these services yourself. These are called direct payments. Parents using direct payments often find they have more control over the services they receive, with care being provided in a more convenient and flexible way. For more information about direct payments see [useful organisations and websites](#).

Facebook – A free online networking site where you can connect with friends, family and organisations you are interested in. Many rare disorder support groups now have a facebook page because it is free and easy to use.

Family Information Service (FIS) – Provides a range of information on all services available to parents, to help you support your children up to their 20th birthday, or 25th birthday if your child has additional needs. FIS also hold up-to-date details of local childcare and early years provision in your area. Your FIS is usually located within the local authority/council and has close links with children’s centres, Jobcentre Plus, schools, careers advisers, youth clubs and libraries. As well as offering information about local childcare services and availability, FIS can give extra help if you need childcare for a child with additional needs, or if you need out of hours childcare.

Children’s hospice services – Provide palliative care for children and young people with life-limiting conditions and their families. This service is delivered by a multi-disciplinary team usually in partnership with other agencies. Children’s hospice services take a holistic approach to care, aiming to meet the needs of both child and family – physical, emotional, social and spiritual – through a range of services which include support for the entire family, specialist short break care, provision of information, support, education and training to carers. Contact your local Children’s hospice for full details of the services they provide and whether you and your family are eligible to access them.

MakingContact.org – A free online linking service provided by Contact a Family. This is a confidential site that offers the opportunity to email other parents whose children have the same condition(s) as your child from around the UK and the world.

Parent carer forums – A group made up of parents and carers of children with additional needs who work with local authorities, education, health services and other providers to make sure the services they plan and deliver really meet the needs of children with additional needs and their families. Forums do not advocate for individual families, but represent the views of parent carers in the local area. There is usually a steering group of parent carers who help to lead this and listen to the views of other parent carers in the local area to make sure they know what is important to them. Forums are keen to make contact with as many parent carers as possible. Find your nearest forum by visiting the website of the National Network of Parent Carer Forums: www.nnpf.org.uk

Rare disorders – The European Union say a condition is rare if it affects fewer than five people in every 10,000. EURODIS, a support organisation for those living with a rare condition in Europe, estimate that there are between 6,000 and 8,000 known rare conditions and this number is constantly increasing as new rare conditions are identified. Although each rare condition will affect relatively few people, the total number of people affected by a rare condition is quite large. For more information about rare disorders see the Early Support publication.

Short breaks – Provide opportunities for disabled children and young people to spend time away from their primary carers and for you to take a break from caring. These include day, evening, overnight or weekend activities and can take place in your home, the home of an approved carer, a residential or community setting. Accessing this service might allow you to attend a training course or go for an evening out with friends. Contact your local Family Information Service for information on which short break services are available in your area. For more information about short breaks visit Every Disabled Child Matters website at www.edcm.org.uk and see other Early Support resources at www.ncb.org.uk/early-support/resources.

Therapy – A qualified therapist (or psychotherapist) usually has a particular theory of therapy that they work to. The Counselling Directory provides comprehensive information about the different therapy options. They may expect you to enter into a commitment to attend for a number of sessions. You should ask lots of questions before you decide to see a particular therapist. You need to decide which therapy is right for you and whether the particular therapist is right for you.

Early Support

for children, young people and families

www.ncb.org.uk/earlysupport

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contact a family
for families with disabled children

Early Years Equality
removing racism • defying discrimination

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