

FATHERS



INFORMATION FOR PARENTS OF DISABLED CHILDREN



contact

*“The way I feel about
her is pride; she is
special.”*

Dad

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“It took a while to come to terms with the shock of the diagnosis. We went home after that dreadful day, closed the door and shut out the world. Years later I see things very differently. I have a wonderful son.”

Dad

INTRODUCTION

This guide is for fathers of disabled children. It aims to help you learn more about practical information you may need and help you understand how other fathers have experienced having a disabled child.

In the development of this guide we met a number of fathers and talked to them about their experiences and their advice for others. This guide is meant to help get you started in finding support and information. We hope it helps you.

YOUR ROLE

Having a disabled child affects all members of a family. No matter if you are a new parent, or an experienced one – everyone can react in different ways to the news that their child has a disability or medical condition. As a father of a disabled child you will have to adapt to a new and sometimes challenging set of circumstances.

We talked to a number of fathers about their experiences. They all agreed that their role was a mixed one. Many highlighted the fact that they often needed to work more than their partners, particularly because of the extra costs of caring for a disabled child.

Others, however became the main carer for their child and dealt with most of the appointments and professionals to get their child's needs met.

A survey of dads found that fathers of disabled children are doing all they can to be involved in their child's life, but face hurdles along the way.

HOW DOES IT FEEL TO BE A FATHER?

Becoming a dad is a big change in your life. Being a dad to a disabled child involves more changes than you might have imagined. Like any parent, when you find out your child has a disability or additional need the first thing you're likely to look for is information and possible solutions. Most fathers feel finding out the right information and where to go for advice or support is the most important issue – but stress it is vital not to forget the child in the search for information. Contact's website is a good place to start for trusted and verifiable medical information.



www.contact.org.uk/medical-information

INFORMATION FOR NEW DADS

If you have a premature or sick baby, or have just received a diagnosis for a new baby then you might find the organisation BLISS helpful. They have information and advice for parents with children born premature or sick.

0808 801 0322

www.bliss.org.uk

Most of the dads we met felt their most important need was to be listened to. They emphasised how important it is to tell someone you trust about how you are feeling, because if you don't it will build up. Talking may help you find some solutions and comfort. Try and make use of all your support networks – this might be your partner, family, friends, neighbours or other dads. Remember to be as positive as you can, when you can.

“We spent the first months in a state of anxiety and shock, the nurses were fantastic, but then we were on our own and that’s when you don’t want to say how scared you are.”

SOME CHALLENGES

Fathers tell us that they usually reach acceptance of their child’s disability at a different time to the child’s mother, and that often needs honest discussion. This can sometimes be challenging for couples who are together and parents who are separated.

Fathers often see their role as one of providing strength and stability – maintaining normality during a period of uncertainty, and very often ensuring their employment continues at times of uncertainty. As a result, they are often absent from meetings which can be seen as indifference by partners, family members and service providers.

As a dad, you may feel you have a dual role; you may need to offer support, but also provide the practical help when it is needed.

Mothers often take on the role of ‘keyworker’, dealing with all the professionals and sometimes becoming overwhelmed by a system that

“Dads often find themselves without the right information. Professionals don’t tell me what’s going on because I’m not at the meetings and her mum can’t remember everything they talked about. I’d say to most fathers – make it your business to find out what’s going on.”

is complex. At these times your partner may ask for support from you, mainly when trying to access a particular service, therapy or adaptation. Sometimes, without prior knowledge of decisions previously made, fathers will have to ‘enter the fray’ which can be very daunting. Many dads say they have been ‘tripped up’ by simply not understanding the complex systems surrounding their child – who does what and when do they do it?

TOP TIP

It is worth spending time getting knowledge together. In other words, do your homework. Make sure professionals are clear you are the father and ask for written information about decisions made about your child to be sent to you. Then it will be clear for all how to keep you updated.

BALANCING THINGS

Balancing work with responsibilities of caring for children and running a family can leave little time to devote to yourself or your partner. The unpredictable nature of some conditions, and difficulties getting time off work for hospital appointments means that information will need to be shared and discussed between you and your partner. Think about ways you can best support each other, particularly when decisions about your child need to be made.

“It can be a balancing act between keeping your employers sweet, spending time with your family, keeping abreast of what is happening with your child and supporting your partner.”

LONE OR SINGLE FATHERS

Some dads become separated from the mother of their child and some become the main carer for their disabled child.

If you are or will become the main carer it is important to access as much advice and information as you can. Call our freephone helpline, see our list of useful organisations at the end of this guide and remember to share what you find out with other members of your family.

STEPFATHERS

Stepfathers need just as much information and support as any other father – perhaps more when they come into a child’s life without experiencing all of their history. If this is you, you might our information for families helpful.

www.contact.org.uk/familylife

Family Lives

Support for stepfamilies, tips on family life, parenting and teenagers.

Free helpline: 0808 800 2222 www.familylives.org.uk

“I found he has most of my interests - cars, lorries and motors in general. We have more in common than his real father and certainly more than his mother! I married into the perfect family.”



RELATIONSHIPS

YOU AND YOUR PARTNER

Having a disabled child may put pressure on your relationship with your partner, or you may react in very different ways to issues concerning your child. All relationships go through periods of change and challenge. It is important to keep talking, and recognise that at times you might need to compromise. Talking to others about your relationship is fine, but remember the main person you need to talk to is your partner.


“Acknowledge your partner when you come home instead of going straight to your child. Your kid will have been well looked after, whereas your partner may need some tender loving care”

MAKING DECISIONS

All the fathers we met said there was a real difference in the way that information and situations are handled by each parent. Of the dads we spoke to, most felt their partners wanted to know everything, whereas they were only interested in the key facts. Your partner may be the one who talks the most with professionals and service providers.

Lots of the dads we met were keen to mention that “decisions are made jointly.” They felt there is a real need for a lot of talk and discussion between parents.

It is important to try and find a way through that you are both happy with. Talking about how each of you handle situations is important. Remember that all families are unique and each of you might use different methods.


 Our **Relationships** guide talks about looking after your relationship, recognising each other's role and ways of coping, managing differences and what to do if things break down.

“Lots of information goes to my wife. Make it your business to read the letters too and find out what’s going on.”

HAVING A BREAK

Having some time together as a couple can be really valuable, so make use of any help that might be available.

Social service departments (social work in Scotland) are legally responsible for arranging support for disabled children and their carers. You have a right to have your child and family's needs assessed for services, including short breaks for your child. Short breaks can be a way of giving your child different experiences away from you, to help their learning and independence. They can also give you and your partner a break from your caring responsibilities, so you can spend time with each other, or your other children.

 For information about getting a break see www.contact.org.uk/social-care or call our free helpline. You can also ask for a copy of our guide to **Services and support from your local authority – England**.

TOP TIP

Have a date with your partner every now and then. It will be hard not to talk about the kids, but see a film, have lunch or make sure you find something else to concentrate on. Time for the two of you is important even for just a couple of hours.

RELATIONSHIPS WITH YOUR OTHER CHILDREN

If you are a dad with other children, you may find you need to juggle your time even more.

Most families recognise that siblings are often mature for their age and do enjoy the opportunity of being involved with their disabled brother or sister. However, it is important to allocate time spent doing something just with them. Also, make sure that siblings have the information they need to understand the disability and explain it to their peers.

Some siblings benefit from attending local young carers groups, where they have the opportunity to meet other children in similar circumstances.

TOP TIP

Plan times to spend with your other children and stick to that.




Our guide *Siblings* has information about local sibling or young carers groups, plus information on supporting brothers and sisters. It's available free from our helpline: **0808 808 3555** or at www.contact.org.uk/siblings

DEALING WITH OTHER PEOPLE'S REACTIONS

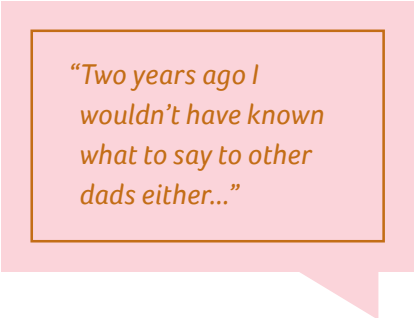
Often dealing with how other people react to your child's disability can be one of the most difficult issues. The best way is to approach other people directly and talk openly about your child being disabled.

You might find that other people you work with or socialise with do not know much about disability. You might also have to prepare yourself for the fact that some people may try to avoid you. Remember that before your experience as a dad of a disabled child, you might have felt this way too.

Sometimes people will feel as though they have to offer advice. Tell them what support you want and this will help you to communicate with each other. This may make it easier for others to 'be there' for you when they may have little, or no, experience of disability themselves.



"Give children the words so that they can explain disability to their friends."



"Two years ago I wouldn't have known what to say to other dads either..."



DEALING WITH EMPLOYERS

For working dads, finding a balance between work and home life might be a challenge. As a working parent you may have a legal right to take time off in certain circumstances. You may also be able to request a change in your working week to help you juggle your work and caring responsibilities. For the purposes of the information below a disabled child is one who qualifies for Disability Living Allowance or Personal Independence Payment. Relevant employment rights can include:

- ***parental leave***
- ***paternity leave***
- ***time off for dependents***
- ***adoption leave***
- ***flexible working.***

PARENTAL LEAVE

Most working parents have the right to take parental leave. This is the right to take time off to look after your child if they are under 18. Parental leave is normally unpaid but you should check your contract of employment in case your employer has a more generous policy.

To have a legal right to take parental leave you must have worked for an employer continuously for one year. You are entitled to at least 18 weeks of unpaid leave for each child aged under 18, regardless of whether they are disabled or not. Both parents have a right to parental leave so you can each take 18 weeks leave per child, to be used before their 18th birthday.

Most parents need to take leave in blocks of one week or more but parents of a disabled child can take leave a day at a time. This means you can use parental leave for things like hospital visits. Normally you are only allowed a maximum of four weeks' leave in one year, but your employer may agree to a longer period of leave within a year if they wish.

If you want to take parental leave you must give at least 21 days' notice. Your employer may ask you to postpone your leave if it will cause disruption to their business. Seek further advice if this happens to you.

Some employers may have more generous rules such as paid parental leave, or may agree to give leave to parents who don't qualify under the rules above.

TIME OFF FOR ANTENATAL APPOINTMENTS

You have a right to take unpaid leave to accompany your partner to two antenatal appointments. This can be no more than 6 and a half hours per appointment.

PATERNITY LEAVE

This is leave fathers can take after a child is born, or has been placed with them for adoption. There are two types of paternity leave – ordinary paternity leave and shared parental leave.

ORDINARY PATERNITY LEAVE

This is for one or two weeks shortly after the birth or adoption of your child. To be eligible you must:

- ***have worked for the same employer for 26 weeks. The 26 weeks' work must have happened before week 25 of the pregnancy or by the week in which you are notified of being matched for adoption***
- ***be the biological father of the child, or the mother's husband, civil partner or cohabiting partner (same sex partners are included)***
- ***have, or expect to have, responsibility for bringing up the child.***

You can take either one or two weeks of ordinary paternity leave. This must be taken within 56 days of the baby's birth, or 56 days of the due date if the baby is early. The law gives you the right to take two consecutive weeks. There is nothing to stop you asking for separate weeks, or to take a day here or there instead, but you have no legal right to insist that this happens.

“Most people at work have been either overly kind or ignored it – I’ve made a point of bringing it up, explaining her disability and my shock, which has made it easier. It’s a classic ‘elephant in the room’ situation.”

ADOPTING A CHILD?

If you are adopting a child you may be entitled to adoption leave and adoption pay. You may also be able to make use of statutory shared parental leave (see page 19). Call our free helpline for further advice if you are adopting a child

You must tell your employer how much leave you want to take and when you want it to start. You should tell your employer as soon as possible and are normally expected to give this notice at least 15 weeks before the baby is due.

Depending on your earnings, you may qualify for statutory paternity pay whilst on these two weeks ordinary paternity leave. Statutory paternity pay is 90% of wages or £145.18 per week, whichever is less. Some employers may pay extra via contractual pay – check your contract of employment. If your earnings are very low you may not qualify for statutory paternity pay. Seek advice about whether you can claim Income Support instead.



STATUTORY SHARED PARENTAL LEAVE

If the mother of your baby is entitled to maternity leave or pay or to Maternity Allowance and returns to work early, you may be able to take some additional paternity leave under rules known as statutory shared parental leave (SPL). You may also be able to take SPL if you have jointly adopted a child and your partner returns to work before they have used up all of their statutory adoption leave.

Employed mothers have the right to take up to 52 weeks' maternity leave. However, if your partner chooses not to take all of this leave, she can instead share the remaining leave with you. She must take at least two weeks' maternity leave immediately after the birth but has the option of swapping all or part of the remaining 50 weeks for SPL. This means that there can be more flexibility in how you share the care of your child

TIPS FROM DADS FOR DADS



◀ Adore your child for their individuality and be proud of the things they can do



◀ There is no such thing as a stupid question – don't walk away until you understand.



◀ Make contact with other dads whose children have the same condition – talking to someone who knows what you're going through is priceless



⤴ Never be embarrassed to explain your child's disability. Other people can be embarrassed by disability. This is their problem, not yours



⤴ You need sleep – tiredness causes irritability and arguments

✓ Take some time for yourself – it's not selfish, it's essential



^ Don't be too proud to accept help and take advice. If you qualify for benefits or grants you deserve them, so make use of them

< It's normal to feel confused, dazed, angry and annoyed. Don't keep your problems or feelings to yourself – share them



└ Take information from the internet with a large pinch of salt unless you trust the publisher



^ Make time for your partner. Even if all you talk about during this time is your child, it is healthy to do this without your child there



during the first year of birth or adoption. For instance, you may decide to both be off at the same time or take turns in having periods of leave to look after your child.

You don't have to take SPL all in one go. Normally you can book up to three separate blocks of leave, although your employer may agree to taking leave in more blocks. You must give at least eight weeks' notice to your employer.

To qualify for SPL, your partner must be eligible for either maternity pay or leave, or Maternity Allowance or adoption pay or leave. In addition, you must have been employed continuously for at least 26 weeks by the end of the 15th week before the due date (or the date you are matched for adoption).

"I had a guy at work that had a child with a disability but not the same one as my child. He offered support and said it's not all doom and gloom."

WILL I RECEIVE WAGES WHILE I AM ON SPL?

If you earn at least £116 per week and meet certain other conditions you may be entitled to statutory shared parental pay (ShPP). ShPP can be paid for a maximum of 37 weeks. It is paid at 90% of wages or £145.18 per week. However, your partner must end a period of statutory maternity pay, statutory adoption pay or Maternity Allowance early, in order to make ShPP an option. For more information about shared parental leave and ShPP go to www.acas.org.uk or contact Working Families, see page 24.

TIME OFF FOR DEPENDANTS

This is the right to take time off work in order to deal with an emergency, such as your child becoming suddenly ill, or an unexpected breakdown in care arrangements. This right is available to most employees no matter how long you have been in the job for. Time off for dependants is normally unpaid but check your contract of employment as some employers offer paid leave.

You must notify your employer of the reasons for your absence as soon as possible and tell them how long you expect to be absent. The amount of time you can take off must be reasonable in all the circumstances. Normally this will only be a day or two. Seek further advice if you think you will need more leave than this.

EQUALITY ACT 2010

The Act makes it unlawful to discriminate on the grounds of gender, age, marital status, race, religion and belief, and disability. The Act also makes it unlawful for people to be discriminated against or harassed because they have an association with a disabled person. This can apply to a carer or parent of a disabled person.



Information and advice is available from the Equality Advisory Support Service on freephone: **0808 800 0082** www.equalityadvisoryservice.com

FLEXIBLE WORKING


The legal right to request flexible working is available to most employees. This is the right to apply for a change in your working pattern, which may be to work from home, reduce the hours you work, or change the times you work. Fathers, as well as mothers, have a right to apply for flexible working. Under these rules your employer must consider your request in a reasonable manner and can only refuse the request if there is a business reason for doing so.

To have a legal right to apply for flexible working you must:

- ***have worked for the same employer for 26 weeks prior to the application being made***
- ***not be an agency worker or member of the armed forces***
- ***not have made an application for flexible working in the past 12 months.***

If you don't meet these tests, there is nothing stopping you still from asking for flexible working but it will be up to your employer whether they agree to this.

It is important when considering flexible working to also look at the effects on your money and income. You may earn less, but be able to claim some benefits. More about benefits can be found on page 26.

 Our free helpline has benefits specialists who can give detailed advice on how a change in your working hours might affect benefits and tax credits:
0808 808 3555 helpline@contact.org.uk

Working Families

Information and advice for working parents of disabled children.

Legal helpline for parents and carers: 0300 012 0312

www.workingfamilies.org.uk

Dad.info

Online advice, information and support.

www.dad.info

Dad at Home

UK support for stay-at-home dads.

www.dadathome.co.uk



MONEY

As the father of a disabled child, make sure you claim all the benefits you are entitled to, to help ease some of the other pressures on family life. We have outlined some of these benefits on the next pages.

DISABILITY LIVING ALLOWANCE (DLA)

DLA is the main benefit for disabled children. A claim can be made for each disabled child in your family. DLA is not means tested, so you can claim no matter how much income or savings you have. If your child is awarded DLA this may lead to an increase in any means-tested benefits or tax credits you get.

There are two parts to DLA – a care component and a mobility component. Your child may be entitled to one or both of these components.

The care component is for children who need extra care or supervision because of their health problems. It is paid at one of three rates depending on your child's needs. It can be paid from three months or from birth if your child's condition is terminal.

The mobility component can be paid where a child has difficulties in walking or where they need extra guidance and supervision in getting around. It is paid at one of two rates depending on your child's needs. The earliest it can be paid is from the age of three years.

DLA FOR ADULTS AND YOUNG PEOPLE AGED 16 AND ABOVE

DLA for this age group is being replaced by Personal Independence Payment (PIP). DLA will still remain for children aged under 16. For more information on PIP, call our helpline and ask for our factsheet and guide on ***Personal Independence Payment and other benefits at 16.***

CLAIMING DLA

To get a claim pack call 0800 212 4600.



Our in-depth guide to **Claiming Disability Living Allowance for children** is available free from our helpline or to download at www.contact.org.uk

CARER'S ALLOWANCE (CA)

If your child gets DLA care component at the middle or highest rate or the daily living component of PIP, you or your partner may also be able to claim CA as their carer. In order to qualify for CA you must be:

- ***caring for your child for at least 35 hours per week***
- ***over 16 years of age***
- ***not treated as in full time education***
- ***if you work you must earn no more than an earnings threshold. This is £120 per week after taking off certain childcare costs and other expenses. Only the claimant's earnings are taken into account – a partner's earnings are ignored.***

If your earnings are too high to get any CA you may still qualify for an extra payment known as a carer's addition as part of any Universal Credit award you have.

CLAIMING CARER'S ALLOWANCE

CA cannot be paid at the same time as Incapacity Benefit, Maternity Allowance, some bereavement benefits, contributory Employment and Support Allowance, contribution-based Jobseeker's Allowance or the State Retirement Pension. But if you already get one of these other benefits a claim for CA may still be worthwhile even if it cannot be paid, since it can help you to qualify for extra means-tested benefits.



Our factsheet **Carer's Allowance** has more information and is free from our helpline or to download from www.contact.org.uk

IF YOU ARE OUT OF WORK

If neither you or your partner work, or if you have low earnings, you may be able to claim certain means-tested benefits such as Income Support or income-based Jobseeker's Allowance. Normally you cannot claim these benefits if you work more than 16 hours a week, but some carers can claim Income Support regardless of their hours. You may also need advice on protecting your National Insurance record. Call our freephone helpline for further help.

HELP WITH RENT AND COUNCIL TAX

If you are on a low income and pay rent you may also be able to claim Housing Benefit. This can be claimed regardless of whether you are working or not, although your income will affect the amount of help you get. You may also be able to get money off your council tax bill.



For more information see our free guide *Help with council tax bills*, available from our free helpline or to download.

TAX CREDITS

There are two types of tax credit. Child Tax Credit (CTC) and Working Tax Credit (WTC).

CTC can be claimed by anyone with a dependent child, whether they work or not. You may get a higher amount of CTC if you have a dependent child who is on DLA or PIP or who is registered blind.

WTC can be claimed by some families in work on relatively low incomes. Depending on your circumstances it can include help with registered childcare costs. Whether you get any CTC or WTC and if so how much, depends on your income and family circumstances. Contact our helpline to see if you qualify.

UNIVERSAL CREDIT


A new benefit called Universal Credit is replacing new claims for Income Support, income-based Jobseeker's Allowance, income-related Employment and Support Allowance, Housing Benefit, Child Tax Credit and Working Tax Credit. These are known as the 'legacy benefits'.

Universal Credit is a means-tested benefit, so the amount you get depends on your income and capital as well as your other family circumstances. It can be paid whether you are in or out of work. If you are working it can include help with certain types of childcare costs.

If you have a disabled child, you can only be asked to claim Universal Credit if:

- ***You live in an area where the 'Universal Credit full service' has been introduced. The full service is being gradually rolled out across the UK and should cover the whole country by the beginning of 2019. To find out whether it applies to your area yet enter your postcode at www.universalcreditinfo.net; and***
- ***You have no more than two dependent children. You currently cannot claim Universal Credit if you have three or more dependent children although this is likely to change in late 2018; and***
- ***You try and make a new claim for a legacy benefit.***

So even if you live in a full service area and have less than three children, you cannot currently be asked to claim Universal Credit unless you try and make a new claim for a legacy benefit. However, eventually the government plans to move all existing claimants over to Universal Credit. This is scheduled to happen between July 2019 and March 2022.

 Call our free helpline for updates on the introduction of Universal Credit. For more information on the range of benefits and other financial help available to families see our guide to **Money Matters**.

DEBT

Sometimes the additional costs involved in looking after a disabled child can contribute to financial problems. If you are struggling free help is available.

National Debt Helpline

Free, confidential debt advice if you are struggling to manage.

Free helpline: 0808 808 4000 www.nationaldebtline.co.uk

Citizens Advice

Network of independent advice centres, giving advice about rights and entitlements. Use the website to find your local centre. Also has online advice and information.

www.citizensadvice.org.uk



Our free helpline can refer you to face-to-face debt advice. They can also give you details of charitable trusts you can apply to for financial help. These trusts don't usually offer help to pay off debts you already have, but can offer help with, for example, specialist equipment or essential household items: www.contact.org.uk/general-grants



WHEN YOU DON'T LIVE WITH YOUR CHILD

MAINTAINING CONTACT WITH CHILDREN

Living apart from your children means that it will be necessary to agree contact arrangements with your former partner. It is often best if both parents can discuss and agree appropriate arrangements informally. This may need a trial period to try out arrangements before settling on something more permanent. Where an agreement can't be made, it may be necessary to consider taking legal advice. Legally, a person with parental responsibility cannot be denied contact with their child without the intervention of the courts.

PARENTAL RESPONSIBILITY

The law is different depending on whether you are, or were, married to your partner. The law presumes married parents both have parental responsibility (PR). Unmarried mothers have parental responsibility, but not all unmarried fathers do. If you are an unmarried father you can get parental responsibility, for example by entering into a parental responsibility agreement with the mother of your children or by a court order. A civil partner or member of a same-sex couple can also get PR in this way.

FAMILY MEDIATION

Family mediation services help separating or divorcing couples to resolve disputes and reach their own decisions on specific issues; particularly matters involving the children of a relationship. This can be a helpful service to use when going through the difficulty of a relationship separation. They can also help with disputes around finance and property. Although often helpful, mediation is not a substitute for legal advice. Services vary from area to area, and there may be a fee (although help from publicly-funded legal services might be available).

Family Mediation Council

www.familymediationcouncil.org.uk

BENEFITS AND TAX CREDITS WHEN A RELATIONSHIP HAS ENDED

If you are in receipt of benefits or tax credits seek advice immediately following the break-up of a relationship. This is because some benefits are assessed and paid for the whole family, and a change in the family circumstances, such as a person leaving the family home, will affect entitlement. With tax credits you risk a fine if you do not report when you

stop being part of a couple. You may also risk an overpayment of benefits if you delay reporting a change of circumstances, which you may have to pay back. Depending on your circumstances, you may be eligible to claim again as a single claimant after you have separated.

If you share the care of a child with your ex-partner, seek detailed advice. It is not possible to split a benefit payment between two ex-partners. Instead the whole amount must be paid to one parent – usually the parent who is seen as having the main responsibility for that child.

USEFUL ORGANISATIONS

Families Need Fathers

Information on shared parenting issues arising from family breakdown and support to divorced and separated parents.

Helpline: 0300 0300 363 www.fnf.org.uk

Gingerbread

Provides lone parents with personalised advice and puts people in touch with local support groups.

Free helpline: 0808 802 0925 www.gingerbread.org.uk

Family Rights Group (England and Wales)

Advice and information to parents and other family members whose children are involved with or require social care services.

Free helpline: 0808 801 0366 www.frg.org.uk

“Although I can’t always control things, I can always choose to respond positively, and plan for the future rather than lament the past.”

ONE FATHER'S STORY

“BEN HAS MORQUIO DISEASE”

I made an effort to avoid contact with support groups. They were for people that needed support and I certainly didn't. I was facing up to things and planning for the future. I was being sensible and logical... and miserable. I didn't feel sorry for myself and nor did I once think, why me?', So therefore I was coping. I flew a banner that stated, Ben's attitude to his disease would be a reflection of mine. So I made sure that my attitude was positive. On the inside I was contorted with grief.

Ben grew. He didn't grow quickly but he grew. He carried on walking. He didn't walk very quickly but he walked. He played football, swam, canoed and rode his bike. He talked and, my word, he talked. I never expected so many questions. His wit and intelligence amazed me. His reaction to his now obvious set of disabilities made me burn with pride. I had never figured that Ben would appear to be facing his 'problem' so positively. I was also acutely aware that my grief was based on how I imagined Ben



would feel about this disease, and in reality there was no way that I could foresee how he would feel. With Ben feeling positive we could all feel positive.

I plucked up the courage and decided to attend a conference. Yes, we had heard of the conference and even seen the photographs but have never wanted to go. I really didn't want Ben to see how things might turn out. I didn't want to see how things might turn out. I did, however, want to see how research into the control of the disease might be progressing.

We met other people with Morquio disease; we met people with all manner of Mucopolysaccharide (MPS) diseases.

We met parents and carers. We met specialists. In speaking to people we found support. I found support and only then realised we had always needed it. Not in any cathartic way, just to know we weren't alone. And we weren't. We found hope. We found inspiration. Ben has Morquio disease. That's just the way it is. He has a disease. A disease that at the moment is incurable. We are a family. We are not your usual family. One of our three boys has Morquio disease. There is nothing that we can do about it so we mustn't let it eat us up. We can however, learn to live with it. It is not always negative.

We have all come to know Morquio disease, but none more closely than Ben. He amazes me and I love him deeply. I will always look up to him.



Morquio disease is part of a group of rare disorders called Mucopolysaccharide diseases, each caused by a different enzyme deficiency. In most children it restricts growth and can cause progressive mental as well as physical disability. The Society for Mucopolysaccharide Diseases: **0845 389 9901** www.mppsociety.co.uk

SUPPORT AND ADVICE

SUPPORT IN THE FAMILY

Support and understanding from other family members, such as grandparents, can be a lifeline. Emotional support can help you feel understood. Practical help can create time to deal with essentials or opportunities to spend time together with your partner.

Some fathers can feel disappointed by the lack of help they receive. It isn't always easy for family members to know what to do or how to help and it may feel that you have to support them. It's okay to seek advice from others about this.



We have guides written for grandparents, and for parents about supporting siblings. Call our helpline for a free copy or download them from www.contact.org.uk/resourcelibrary

"I couldn't manage without grandparents. Families can really help if you are lucky enough."

SUPPORT FROM OTHER DADS

Information from others who have been in the same situation can be helpful. A support group is a good place to start. Support groups don't only have to be about sitting and talking. One group set up a football team for their children, so the children could play sport while the dads talked to each other. Other dads meet in the pub to play darts.

If you want to start a group in your area we have guides about how to set up a support group. You can download them from our website or ask for them to be sent to you, free from our helpline. Our dedicated local groups officer can also help and get you linked in with our Local Groups Network.



Call our free helpline for details of local support groups near you. Or search our online map: www.contact.org.uk/map

“You need local support from people who ‘get it’ – only parents who are in the same situation can really understand.”

SUPPORT FROM PROFESSIONALS

Sometimes there is a key professional who can open the door to lots of information or contacts. Call our free helpline to find out about local contacts and support.

TALKING AND ADVICE SERVICES

You might find a professional counselling service helpful. Your GP should be able to tell you about any local services. Some employers also have a confidential counselling scheme for employees.

British Association for Counselling and Psychotherapy

Help to find an accredited therapist.

01455 883 300 www.bacp.co.uk

USEFUL ORGANISATIONS

The Foundation for People with Learning Disabilities (part of the Mental Health Foundation)

For fathers of children with learning disabilities.

020 7803 1100

www.mentalhealth.org.uk/learning-disabilities

NHS Choices – Care and Support

Information and advice for carers

www.nhs.uk/carersdirect

GOV.UK

Information on your rights from the government.

www.gov.uk

USEFUL READING

Different Dads – Fathers’ Stories of Parenting Disabled Children

Stories from fathers about their experiences in bringing up disabled children.

Edited by Jill Harrison et al. Published by Jessica Kingsley Publishers (2007)

Uncommon Fathers: Reflections on Raising a Child with a Disability

Collection of essays by fathers who were asked to write about their experience of having a child with a disability.


Edited by Donald J Meyer. Published by Woodbine House (1995)


Written by Derek Sinclair




GET IN CONTACT


Our helpline advisers can support you with any issue about raising your disabled child: help in the early years, diagnosis, benefits, education and local support.

 0808 808 3555

 info@contact.org.uk

 www.contact.org.uk

 twitter.com/contactfamilies

 facebook.com/contactfamilies

 youtube.com/contactfamilies

Contact Head Office
209–211 City Road
London EC1V 1JN



We are Contact, the charity for families with disabled children.

We support families with the best possible guidance and information.

We bring families together to support each other.

We help families to campaign, volunteer and fundraise to improve life for themselves and others.