

contact a family
for families with disabled children



Fathers

Information for families

UK

Incorporating **The Lady Hoare Trust**

Introduction

Having a disabled child affects all members of a family. Mothers and fathers can sometimes react in different ways to the news that their child has a disability or medical condition. As a father of a disabled child, you may find your partner or other members of the family looking to you for support at a time when you have to adapt to a new and sometimes difficult set of circumstances. We hope that this guide will help you learn more about the experiences of other fathers, dispel some of the myths and provide some practical information that might be of help to you.

In the development of this guide we met a number of fathers at two workshops held in Swansea and Bridgend. We thank all the dads who joined to help us write this guide, and others who have commented since it was first published.

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Your role

The dads we met all agreed that their role was a mixed one. Many highlighted the fact that they needed to be the breadwinner, particularly because of the extra costs of caring for a disabled child. But this often led to them being absent from meetings or from carrying out much of the day-to-day care of their child.

However, it seems there is a big problem which often lies with service providers and professionals - fathers who are not seen at meetings are presumed to be not doing anything. And dads might see their roles differently.

"Dads are the sparks that push. Dads often are pushy about moving their child on; mums have had it all the time and may get despondent." A dad

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

How does it feel to be a father?

Here are some of the things the dads we met said:

"It just hits you - you don't hear anything else other than the diagnosis. It took about two days before I looked on the internet."

"The way I feel about her is pride; she is special"

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 'Facts for fathers', a factsheet produced by BLISS, helpful. Freephone helpline: 0500 618 140 Web: <http://tinyurl.com/3j3qyl>

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"We knew from hour one that he had Cerebral Palsy. We knew we just had to get him home and survive with him."

"I cried for half an hour because he took his first steps."

The needs of fathers

Like any parent, when you find out your child has a disability the first thing you're likely to look for is information. Most fathers feel this is the most important issue - but most soon learn that it is vital not to forget the child in their search for information.

"When we were in the hospital we kept watching the bleeps on the monitor. The nurse came in and said don't worry about looking at the monitor so much, the child is here on the bed."

"I spent hours looking for information on the internet. In the end I realised I was just torturing myself. My time is better spent with my children."

Tips from dads

Most of the dads we met felt their most important need was to be listened to - to have someone that would just be a sounding block. Try to make use of all your support networks; this might be your wife or partner, family, friends or neighbours.

Other tips from dads included:

- try not to keep your problems or feelings to yourself. Share them with someone you trust, it may help you come to some solutions
- try to find some time to be with your



- partner without your child
- try to take care of yourself - you can't be as supportive of your family if you're tired and stressed
- you may find it helpful to spend time on your own or with some friends doing things for yourself
- remember it's OK to ask for help from the people around you.

See page 14 for more tips from other dads. Call the Contact a Family helpline as we may be able to find you a local service that can help.

Feeling excluded?

In 1998¹, research into the experiences of fathers of disabled children was carried out in West Lancashire. Twelve fathers were interviewed about their experiences of a number of different aspects: the birth of their child, school, family holidays, relationships, their marriage, advocacy, childcare, the ups and downs of parenting, and the exclusion that they felt from support services. One of the consistent comments fathers made

was that they felt excluded from certain aspects of their child's life. For some fathers this had started at birth when partners were told about their child's disability without them being present.

Generally, fathers felt the support systems that were in place were beneficial for their partners, but not for them. They felt that some type of support for fathers would have been or would be helpful.

Involving fathers

In the report 'Just a Shadow'² the researcher made some similar observations. Improved support, information and the opportunity to access services, could lead to fathers feeling much more involved in the care of their child. Carpenter³ reports on further research to look at how schools were involving fathers of children with special educational needs. The schools admitted that they could improve their practices by arranging home visits when fathers were there and holding review meetings in the evenings. Generally, it was felt that "when fathers could be enabled or encouraged to attend, their contribution was invaluable."

A project called 'Recognising Fathers' is being run by The Foundation for People with Learning Disabilities. For more information see page 24.

Lone fathers

Some dads become the sole carer for their disabled child.

"From a dad's point of view, what a big role mum's play - what it really means to be a mother. I didn't know how to sew

Like any parent, when you find out your child has a disability the first thing you're likely to look for is information.

socks or organise things." A dad whose wife had died a year earlier.

For different reasons, other dads might take on the sole care of their children. It is important to access as much help, support and advice as you can. See the 'Useful organisations' section on page 24 for details of organisations that may be able to help.

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. There is particular support for stepfamilies - see our list of useful organisations on page 24.

"Those wonderful men - not knowing what they are letting themselves in for when they fall for a single mum with special needs children. What a steep learning curve!"

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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 the issues concerning your child. It is important to talk them through and sometimes you might need to compromise.

Making decisions

Lots of the dads we met were keen to add that, "Decisions are made jointly." They felt there is a real need for a lot of talk and discussion between parents. Dads might sometimes feel a bit uninformed because their partner sees all the information first and may filter it.

"Lots of information goes to my wife. She opens all the letters and information we get that explains things like benefits."

Your wife or partner may be the one who talks most with professionals and service providers. You may be at work or doing other jobs at these times. There are often also key differences in the way that mums and dads deal with information. Of the dads we spoke to most felt their partners wanted to know everything, whereas they were only interested in the key facts.

All the fathers we met said there was a real difference in the way that situations are handled by each parent.

"There is a difference between partners about when and what is discussed about the child's disability."

It is important to try and find a way through that you are both happy with. Do also remember that all families are unique; each of you might find different ways through difficult times.

Pursuing other interests

Going out or pursuing your own interests might cause a few difficulties, but if you do, it can make all the difference to how you feel about your situation.

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

"Sometimes it's hard to go out together and when you do, you talk about the kids!"

For help and information around getting a break ring our helpline. You might also find our guides 'Disabled children's services' and 'Getting direct payments for your disabled child' helpful, available free from our helpline.

Help and information around relationship issues

If you have a partner and are having a difficult time in your relationship, you may find our 'Relationships' guide helpful. This is full of tips from parents with disabled children on relationship issues, and has practical information about services and benefits which can help relieve some of the stresses in a relationship. A free copy can be obtained from our helpline.



Relationships with your other children

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

"It's hard trying to give all the children equal attention."

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 can help the sibling if you allocate time spent doing something just with them. Make sure that siblings have the information they need to understand the disability.

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

There is now a lot of information written for siblings by some of the national specific condition organisations which your children might find helpful. Some siblings have benefited from attending local siblings support groups, or a young carers group, where they have the opportunity to meet other children in similar circumstances.

For information about local sibling or young carers groups call the Contact a Family helpline. You may also find our 'Siblings' guide useful, available free from our helpline.

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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 son or daughter having a disability.

You might find that other people ask awkward questions like, "Didn't you know your child was disabled before they were born?" These can often be best answered with stock replies such as, "My daughter's disability was caused by complications at birth."

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 others may try to avoid you. Remember that before your experience as a dad, you might have felt this way too.

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

Dealing with employers

For those dads who work, finding a balance between work and home life might be a challenge.

"We have to use a lot of annual leave for meetings."

It is important to know your rights with your employer so that you can take the time off if you need it. A low level of awareness about current employment legislation, for parents generally and specifically in regard to disabled children, was found amongst the fathers responding to a survey conducted by Contact a Family. The survey also found that many fathers had changed their work pattern, or given up working all together, in order to support their disabled child.

Fathers have a range of employment rights which they can use including rights around:

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

Parental leave

Many working parents have the right to take parental leave. This is the right to take time off to look after your child. To be eligible you must have worked continuously for your employer for at least a year. Parents with disabled children are entitled to 18 weeks' leave for each disabled child, and 13 weeks for non-disabled children. The leave can be taken up to the child's fifth birthday, or 18th

To be eligible for paternity leave fathers need to have worked for the same employer for twenty-six weeks ending with the fifteenth week before the baby is due.

birthday if your child is disabled (your child is considered disabled for parental leave rights if they get Disability Living Allowance).

In most cases parents must take the leave in blocks of one week (up to a maximum of four weeks in any year), but in the case of disabled children leave can be taken in multiples of one day. There is no statutory right to pay during parental leave. Seek advice from our helpline about whether you could claim any extra benefits if you are on unpaid leave.

Paternity Leave

To be eligible for paternity leave fathers need to have worked for the same employer for 26 weeks ending with the 15th week before the baby is due. In addition the baby must have been born after 6th April 2003.

Fathers are entitled to take either one or two consecutive weeks up to the 56th



day after the actual or expected week of the child's birth. During his leave a father may be entitled to receive Statutory Paternity Pay. This is paid at £117.18 per week or 90 per cent of earnings, whichever is less.

Adoption leave

Those who adopt children are entitled to up to 52 weeks' adoption leave. If you have worked for your employer for at least 26 weeks by the date you are matched with a child, you can be paid statutory adoption pay for the first 39 weeks. This is paid at the rate of £117.18 per week or 90 per cent of earnings, whichever is less. There is also the option of taking a further 13 weeks leave, usually unpaid.

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Fathers can begin the leave on the date of placement or a fixed date up to 14 days before the expected date of placement. This leave is not available where a child is not newly matched, for example where a step-parent is adopting a partner's child. Only one partner in the relationship is able to take adoption leave.

Please note that if your average earnings are less than the lower earnings limit (£90 per week at the time of writing) you may not qualify for Statutory Adoption Pay or Statutory Paternity Pay. Seek further advice if this applies to you.

Time off for dependents

This is a right to take time off work in order to deal with an emergency, not when a person knows in advance that a problem will arise. This right is available to all employees regardless of length of service. Situations covered by this right include when a child has an accident or when there is a breakdown in care arrangements. There is no statutory right to pay during time off in situations like this.

Flexible working

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. To be eligible you must have worked for the same employer for 26 weeks prior to the application being made. Fathers, as well as mothers, have a right to apply for flexible working, although an employer can refuse the request if there is a business case. Parents with disabled children can make an application at any time until the child's 18th birthday. If you

care for an adult you can also apply for flexible working but only if the person you care for shares your household or is a near relative.

It is important when considering a change in work pattern to also look at the effects on the family's finances. More information about benefits can be found later in this guide.

More information about employment rights

More information about employment rights can be found on DirectGov
Web: <http://tinyurl.com/492o95>
and the Department for Business, Enterprise & Regulatory Reform,
Web: <http://tinyurl.com/2op9yq>

Contact a Family also produce a guide 'Working' which includes details of employment rights and benefits for working parents.

Also, the following organisations can help:

ACAS (Advisory, Conciliation and Arbitration Service)

Helpline: 0845 747 4747
Textphone: 0845 606 1600,
Web: <http://www.acas.org.uk>
Offers a free confidential advice service to employers and employees.

Labour Relations Agency

Tel: 028 9032 1442
Web: <http://www.lra.org.uk>
Offers an impartial and confidential advice service to employers and employees in Northern Ireland.

Benefits, tax credits and other money matters

As the father of a disabled child you may have a whole host of information needs. Making sure you claim all the benefits you are entitled to can help ease some of the other pressures on family life. We have outlined below three of the main benefits families can claim. For detailed advice on the full range of benefits you should phone our free helpline on Tel: 0808 808 3555. We employ welfare rights specialists who can advise on any aspect of claiming benefits and tax credits. We also produce a free guide, 'Benefits, tax credits and other financial help'.

Disability Living Allowance (DLA)

DLA is the main benefit for disabled children. A claim can be made for each disabled child in your family. It is not means tested, so you can claim regardless of 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 of these components or to both. 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 is for children who need help getting around. It is paid at one of two rates. The lower rate is for

children who can walk but who need someone to supervise or guide them out of doors. The earliest this can be paid is from five years of age.

The higher rate is for those who are either unable to walk or who have great difficulties in walking. It can also be paid to children getting the high rate care component and who have a severe mental impairment as well as severe behavioural problems. The earliest that this can be paid is from three years of age.

Claiming DLA

You can get a DLA claim pack (DLA1 child) by calling the Benefits Enquiry Line, Tel: 0800 88 22 00 (Northern Ireland, Tel: 0800 22 06 74). To maximize your chances of being awarded DLA it is usually best to get help with the form from a local Citizen's Advice Bureau (CAB) or disability advice project since it is long and complex. Our free guide, 'Claiming Disability Living Allowance for children' is also available from the our helpline.

Carer's Allowance (CA)

If your child gets the middle or highest rate of DLA care component, 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

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- over 16 years of age
- not in full-time education (that is, a course involving 21 hours or more supervised study)
- if you work you must earn no more than an earnings threshold. This is currently £95 a week (after taking off certain childcare costs and other expenses) but it may increase – contact the helpline for the up-to-date figure.

If neither of you are able to claim CA – perhaps because you both work and earn too much - someone else who helps care for your child may be able to claim instead.

Claiming CA

CA cannot be paid at the same time as Incapacity Benefit, Maternity Allowance, Bereavement Benefits, contribution-based Jobseeker's Allowance or the State Retirement Pension. But a claim for CA may still be worthwhile even if it cannot be paid, since it can help you to qualify

for some means tested benefits. Contact our helpline for more information.

CA is claimed on form DS700, available from the Benefits Enquiry Line (see page 25) or local Benefits Office. You should put in a claim for CA even if your child has not received a decision on their DLA application. This should help protect your right to any backdating.

Benefits if you are out of work

If neither you or your partner work, or if you work less than 16 hours and have very low earnings you may be able to claim Income Support, income-based Jobseeker's Allowance or certain other benefits. You may also need advice on protecting your National Insurance record. Call our helpline for further information.

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 child with a disability. CTC is paid to the main carer, which will usually be your partner if you have one.

Working Tax Credit (WTC) can be claimed by families in work on relatively low incomes. It is normally paid to the main earner in the family. In order to claim either you or your partner must be working for at least 16 hours a week. WTC can sometimes include help with certain approved childcare costs.

Although tax credits are means tested you can have a taxable income of up to £58,000 (£66,000 if you have a baby under one year old) and still get something. In some circumstances – for example if you have more than one child on DLA and have substantial eligible childcare costs - you may get some tax credits even if your income is above these figures. Our free 'Tax credits guide', which includes a ready reckoner to help assess tax credit entitlement, is available from our helpline.

Claiming tax credits

Both tax credits are claimed on the same form - TC600. This is available from the Tax Credits Helpline, Tel: 0845 300 3900 (Northern Ireland, Tel: 0845 603 2000). If you have a partner then you must make a joint claim. Please note that claiming tax credits can

affect the amount of help you get from certain means tested benefits.

Struggling with debt?

Sometimes the additional costs involved in looking after a disabled child can contribute to financial problems. The National Debt Helpline offers specialised money advice if you are struggling to manage.

Tel: 0808 808 4000

Web: <http://www.nationaldebtline.co.uk>

Contact a Family can also provide details of charitable trusts that may be willing to offer some financial assistance.

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Support for you

As a dad of a disabled child, you may have found it difficult to access support when you felt you needed it most, or it might have come in ways other than those you expected.

Support from professionals

Sometimes there is a key professional who can open the door to lots of information or contacts. This could be a health visitor, occupational therapist or person working for a voluntary organisation. There are a few support groups now for dads of disabled children in the UK. There are also many local Sure Start Children's Centre schemes, which are initiatives to work with parents of children who are under five years of age.

Tips for dads by dads

- "Have confidence not to worry about what others think."
- "Speak up - keep asking questions."
- "Make use of services like Crossroads Care or babysitters. When you get the opportunity for time out, just take it."
- "If you don't look after yourself you will collapse. Lack of sleep causes rows and stress."
- "Challenge what people say to you. They said my girlfriend didn't need an amniocentesis because she was only 19. But our child was born with Down syndrome."
- "It's important to look at the child not the condition. The same condition might mean varying

They are keen to involve all parents and some have specific projects for dads. Ask your doctor or health visitor for more information.

Support in the family

The wider family can be a useful support, although not all parents have found them to be.

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

Contact a Family produces a specific guide, 'Grandparents' - you might find this a useful way of sharing information with your child's grandparents. A free copy is available from our helpline.

disabilities in different children."

- "Hack out a role for yourself."
- "Be prepared to lead."
- "Be positive."
- "You may need to make yourself unpopular."
- "Demand time off."
- "Be strong and resolute for your wife - be a shoulder to cry on."
- "Be proud."
- "Realise the potential of your child."
- "It's hard to tell others about disability and why should we? It's best to let the child explain themselves."
- "Don't brush it [disability] under the carpet."
- "Know your rights with your employer."

Talking to friends

You might find it hard to talk to friends or neighbours about your child's disability.

"There is a stigma for dads associated with having a disabled child. You hear the whispers of other people behind your back. It's hard talking to your work colleagues, friends and neighbours."

You might find your wife or partner has access to other friends and support that are not available to you.

"I only had 20 minutes with the consultant whereas my wife has other people to talk to."

It's important to find someone to talk to if you can and realise that you are not alone in this feeling; other dads feel this way too.

"I just wanted someone to burden it all on to. But you find that people's eyes just glaze over. I just wanted someone to listen. I didn't want people to chip in with advice. People shouldn't feel they have to."

Contact with other dads

You might find it helpful to get information from others who have been in the same situation. A support group or national organisation which specialises in a particular condition might be a good place to start. Call the Contact a Family helpline for details of support groups.

"You need support from people who 'get it' - only parents who are in the same situation can really understand."

As a dad of a disabled child, you may have found it difficult to access support when you felt you needed it most

"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."

"Groups about conditions are very important. The Down Syndrome Association gave us all the basic information we needed. You need one centre where you can get everything from."

"Both mums and dads can join support groups - they can be a real opportunity for dads."

Similarly, support groups don't have to be focused just on sitting and talking. Two dads told us about a football team they have set up for their children. This has a double advantage - the children get access to sport and whilst they are playing, their parents get to talk to each other.

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Counselling services

You might find a professional counselling service a helpful way of unloading some of your thoughts and feelings. Your GP should be able to tell you about any local services. Some employers also have a confidential counselling scheme for employees.

Setting up a dads' group

If you are thinking of starting your own group for fathers or are trying to make an existing group more accessible to dads, Contact a Family produce a Group Action

Pack with information about setting up a support group. It also has a section called 'Reaching out to fathers' which contains ideas on how to include fathers in local and national support groups. You can download it from our website or request it for free from the helpline.

Getting going

If you are interested in setting up a fathers group then consider holding a family day with lots of activities. Let fathers know that you are thinking about starting a dads' group and ask them what they

What can services do to include fathers?

A lot of the dads we spoke to feel that services do not meet their needs as fathers - some feel quite excluded, for example because meetings are arranged in the daytime.

"Services need to be more flexible; they need to arrange home visits outside the hours of 9am to 5pm."

Things services and professionals can do to include fathers

There are some key messages here for those that work in or provide services – all are taken from what dads told us. Most importantly, future services, meetings and training need to be arranged at a time when both parents might have the opportunity to attend. Fathers may have a different but equally valuable view to offer.

Other key messages:

- in appointments make sure you talk to both parents and avoid focusing your attention on mum alone
- when booking appointments find out if there are times that would make it easier for both parents to attend
- if a dad can't attend an appointment offer to talk to him over the phone and give mum information she can take away for him to read
- encourage dad to ask questions in meetings
- don't assume dad is not involved just because he isn't present at a meeting
- don't assume dad gets a break or a rest because they go to work
- acknowledge dad's caring role in discussions
- offer dad the same training, for example lifting and handling training, that mum has been offered
- if dad isn't at a meeting, make sure he doesn't miss vital information – mum may only remember and pass on the worrying things that have been said about their child's needs.



want. You can ask questions such as:

- would you like the group to run events or activities specifically for fathers?
- what kinds of things stop you from attending a group?
- what would you like to get out of a support group?

It would be a good idea to have already organised an activity day for dads to attend so that you can let them know all about it on a family day. For more information see our Group Action Pack guides.

Living apart

This next section looks specifically at some of the legal and practical issues that dads may face if their relationship has broken down completely and they are now living apart from the children. It includes information around:

- maintaining contact with children
- dealing with disputes and family mediation
- getting advice about the legal ways of ending a relationship, and other legal disputes

- financial issues such as child support and changes in benefit entitlements.

Maintaining contact with children

No longer living under the same roof as your children will inevitably affect the level of contact you have with them and it will usually be necessary to agree contact arrangements with your former partner. Legally, a person with parental responsibility cannot be denied contact with their child without the intervention of the courts. Of course it will usually be best if both parents can discuss and agree appropriate arrangements informally. Perhaps a trial period can be agreed, and the arrangements reconsidered after a fixed period? Where an agreement can't be made, it may be necessary to consider family mediation and getting legal advice.

Parental responsibility

The law presumes married parents both have parental responsibility. Unmarried mothers have parental responsibility but not all unmarried fathers do. Unmarried fathers can acquire parental responsibility, for example by entering into a parental responsibility agreement with the mother. A civil partner or member of a same-sex couple can acquire parental responsibility in a similar 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

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the children of a relationship. 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 under publicly-funded legal services might be available).

The Family Mediation Helpline can provide general information about family mediation and contact details for mediation services in your area.

Family Mediation Helpline

Helpline: 0845 602 6627.

<http://www.familymediationhelpline.co.uk>

Getting advice about legal ways of ending a relationship and other legal disputes

Couples who were cohabiting, or are married but do not wish to formally end the relationship, including civil partners,

might need legal advice if no agreement can be reached on issues concerning children, property and money. There are several ways to end a marriage legally, the most common being divorce. If both parties agree to divorce - meaning it is 'undefended' - a solicitor will not usually be needed and a local citizens' advice bureau CAB should be able to help with the petition.

If a divorce is defended, or there are other issues in dispute concerning children, money or property, then it will be necessary to consult a solicitor. The same applies to civil partners wishing to formally end their relationships (this is sometimes called 'dissolution' rather than 'divorce'). A local CAB should be able to help you locate a solicitor in your area and advise you about any legal aid which might be available to help with the costs.



Child Support

Both parents (biological or adoptive) are legally responsible for a child's financial support. If one of the parents does not have day to day care of the child, they may be liable to pay child support maintenance. There are two main options for arranging child support:

- a private agreement between you and the other parent, or
- an arrangement that is set up by the Child Support Agency (CSA).

The CSA can calculate how much is due and set up arrangements for the collection of payments.

Choosing to use the Child Support Agency

Until recently a parent with day to day care of a child had little option but to agree to a CSA assessment if they claimed certain benefits like Income Support. However, since July 2008, parents claiming these benefits have been able to choose between using the CSA or not. A new Child Maintenance Options service has been set up to provide information to parents on the choices available.

Child Maintenance Options

Tel: 0800 988 0988 (Mon-Fri 8am-8pm; Sat 9am-4pm)

Web: <http://www.cmoptions.org>

CSA being replaced

The government is in the process of replacing the CSA with a new body called the Child Maintenance and Enforcement Commission. In the meantime anyone who wishes to set up a statutory

agreement for child support rather than a private arrangement should contact the CSA's national enquiry line. Calls are charged at the local rate and the line is open Monday-Friday 9am-5pm.

Tel: 0845 713 3133 (England, Wales and Scotland)

Tel: 0845 713 9896 (Northern Ireland)

Web: <http://www.csa.gov.uk>

Benefits and tax credits when a relationship has ended

If you are in receipt of benefits or tax credits you may need to 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 like a person leaving the family home will affect entitlement. With tax credits you risk a fine if you do not stop claiming when you stop being part of a couple (note you might be able to claim again as a single claimant).

The benefits and tax credits systems recognises gay and lesbian couples who live together, whether or not they have registered as civil partners.

For more information about benefits and tax credits ring the Contact a Family helpline. The helpline can also put you in touch with a specialist benefits adviser.

Freephone helpline: **0808 808 3555**
Web: **www.cafamily.org.uk**

Dad's stories - Diamond Blackfan anaemia

"When I first discovered my daughter had a rare disorder, Diamond Blackfan anaemia, (DBA) my wife was in utter shock. I, however, felt relieved. For the previous nine months she was very ill, with doctors fobbing us off and me feeling powerless to do anything. Now, I thought, there is a name to it; then there would be a process to follow and some sort of resolution. How wrong I was!

"For the past four years since that day, I have felt utterly useless. Although I have greedily consumed every piece of information there is about DBA, becoming a genetics and haematology expert in the process, I look back and see no progress. Even though I have helped set up a parent support group, registered as a charity and spend hours each week trying to find answers, there is no resolution. Each day my daughter doesn't get any better and each day I chide myself for not doing enough to make it better.

"Two years ago, we had another child, a son. The decision to have another baby was difficult. DBA is genetic, but there are no definitive genetic markers, so no genetic counselling is available. Secondly, with no family history of the condition, the chances of having a second child with DBA were unlikely. All my life I have felt jinxed. But this time, it threw me sideways.

"Henry having DBA is, to me, a chance we took, but with his life as the wager.

"With Alexandra, I feel helpless: with Henry, I feel guilty. My children are an absolute treasure to me. I take nothing for granted. I have no ambition for them, except for them to be happy. That doesn't stop them from being the best in the class, superb artists, or being the best comedians of their time. One day, when this is all over, they'll probably tell me off for taking it all too seriously."

Diamond Blackfan anaemia is a rare disorder. The anaemia is caused by a failure of the bone marrow to produce red blood cells. Many affected children are very short for their age, and may have delayed puberty. Children with DBA otherwise develop normally, and it is unusual for affected children to have learning difficulties.

DBA-UK (Diamond Blackfan Anaemia Support Group)

112 Monkton Road, Minster-in-Thanel, Ramsgate, Kent CT12 4EF
Tel: 0845 094 1548
Web: <http://www.diamondblackfan.org.uk>

"Both my boys have special needs"

"I am a single father with three children. Two boys aged seven and nine, and a girl of five. I had to give up my business about three years ago when I split up with my wife, to look after the children. Both boys have special needs; the younger has Asperger syndrome, Attention Deficit Hyperactivity Disorder (ADHD) and a sleeping disorder. The older one has yet to be diagnosed.

"Being a single father, the problems I run into are numerous as people do not associate fathers as being the lone

Attention Deficit Hyperactivity Disorder (ADHD) is a common condition affecting seven per cent of school age children. ADHD is an impairment of either activity or attention control or both. Asperger syndrome is an autistic spectrum disorder and affects the development of social interaction, communication and imagination.

Attention Deficit Hyperactivity Disorder (ADHD)

There are many groups and organisations providing support and information about ADHD. The Contact a Family Directory has information about support groups,
Web: <http://tinyurl.com/4s5vwl> or call

parents. I did go to a carers group for a while but it was all women who, while they tried to be polite, didn't believe that a single man could look after three kids on his own without any help. So I stopped going, as it didn't help me at all.

"The benefit system has been a nightmare, as I didn't know anything about it. I could find no one to help me with it so I have found that getting the correct benefits is still difficult. I find that the local housing department can help fill in forms and I have used them on several occasions lately and they have helped greatly.

our helpline.

Asperger syndrome

Many groups support children with Asperger syndrome, among them:

The National Autistic Society
393 City Road, London EC1V 1NG
Helpline: 0845 070 4004 (Mon-Fri, 10am-4pm)
Tel: 0845 070 4003 minicom
Web: <http://www.autism.org.uk>

The Contact a Family Directory has information on our website,
Web: <http://tinyurl.com/48arau> or call our helpline.

Freephone helpline: **0808 808 3555**
Web: **www.cafamily.org.uk**

"I have no family except a brother whom, for his own reasons, cannot help me very much with the kids. Social services have completely ignored all requests for help and advice, both from me and other professional bodies. Getting the proper education for my kids is also frustrating as I have had to take the education authority to a tribunal to get a special school specified for my son. They ordered a special school but I find that every one in the area is full. So I am still fighting education to get him a suitable school.

"When I take the kids out to places like Alton Towers, it is impossible to go on any rides the oldest one wants to, as there is no one to watch the other kids. So I spend the day trying to get the kids on rides one or two at a time and with a child with ADHD that is not easy.

"I can't have a social life as I can't go out without the kids. The local people took a long time to understand that my boys were not naughty but don't understand that what they do is wrong. But now my neighbours understand and accept them. I struggle to keep the house in order but I do it. I hope this gives you an insight into problems of being a single father of children with special needs."

"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 that '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.

Morquio disease is part of a group of rare disorders called Mucopolysaccharide diseases, each caused by a different enzyme deficiency. In most children growth is restricted and some diseases cause progressive mental as well as physical disability.

The Society for Mucopolysaccharide Diseases
MPS House, Repton Place, White Lion Road, Amersham HP7 9LP
Tel: 0845 389 9901
Web: <http://www.mpssociety.co.uk>

"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."

"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"

Freephone helpline: **0808 808 3555**
Web: **www.cafamily.org.uk**

Useful organisations

For fathers

BLISS

Free helpline: 0500 618140

Web: <http://www.bliss.org.uk>

Charity for babies born too soon, too small or too sick. Information and advice with a fathers section offering dads advice on how to deal with the stresses and practical difficulties of having a premature or sick baby.

The Foundation for People with Learning Disabilities

Tel: 020 7803 1100

Web: <http://tinyurl.com/3f6ex3>

Runs a project called 'Recognising Fathers.' Has resources and information for fathers and professionals working with them.

Parentline Plus

Helpline: 0808 800 2222 (24 hours)

Web: <http://www.parentlineplus.org.uk>

Focuses on parents and children and offers support for stepfamilies, with tips on family life, parenting and helping teenagers.

Working Families

Helpline: 0800 013 0313

Text: 07800 00 4722 (Text your query to 'Edads')

Web: <http://www.workingfamilies.org.uk>

Offers information and advice to working parents. The 'Waving not Drowning' project is for parents of disabled children who want to work. Also have a 'Fathers' page and a text advice service, 'Edads'.

Home Dad UK

Tel: 0775 254 9085

Web: <http://homedad.org.uk>

UK support for stay-at-home dads, with an online forum.

Disabled Parents Network (DPN)

Tel: 0300 3300 639

<http://www.disabledparentsnetwork.org.uk>

National organisation of and for disabled people who are parents or who hope to become parents, and their families, friends and supporters, with information and resources.

Living apart/lone parents

Both Parents Forever

Helpline: 01689 854 343

Helps all parents, grandparents and children understand their rights following divorce/separation, care proceedings or child abduction.

Families Need Fathers

Helpline: 08707 607 496 (6pm-10pm, mon-fri)

Web: <http://www.fnf.org.uk>

Provides information on shared parenting issues arising from family breakdown and support to divorced and separated parents, irrespective of gender or marital status.

Gingerbread/One Parent Families

Tel: 0800 018 5026. (Mon-Fri 9am-5pm, Weds 9am-8pm)

Web: <http://www.oneparentfamilies.org.uk>

Provides lone parents with personalised advice and puts people in touch with local support and self-help groups. Has a free downloadable 'Lone fathers' handbook'.

Family Rights Group

Helpline: 0800 731 1696 (10am-3:30pm

Mon-Fri)

Web: <http://www.frg.org.uk>

Charity in England and Wales that advises parents and other family members whose children are involved with or require social care services. They also have a 'Fathers Matter' discussion board for dads.

For professionals

Fatherhood Institute

Tel: 0845 634 1328

Web: <http://www.fatherhoodinstitute.org>

A research, campaigning and training organisation with resources for professionals working with fathers.

General resources

Department for Work and Pensions

Web: <http://www.dwp.gov.uk>

Information on employment and benefits, with a disability and carers section.

National debtline

Tel: 0808 808 4000

Web: <http://www.nationaldebtline.co.uk>

Free confidential and independent advice. Offers information packs, a personal budget section, sample letters and debt advice.

Citizens Advice Bureau

Tel: 020 7833 2181 (admin)

Web: <http://www.citizensadvice.org.uk>

A UK network of independent advice centres, giving advice about your rights and entitlements. Use the website to find your local centre. Also has online advice on all aspects of your rights.

Direct Gov

Web: <http://www.direct.gov.uk>

A government website that brings together official information and advice plus information and rights about caring for a disabled child.

Benefit Enquiry Line

Tel: 0800 88 22 00 (Northern Ireland,

Tel: 0800 22 06 74)

Confidential advice and information about social security benefits and how to claim for people with disabilities, their carers and representatives.

Freephone helpline: **0808 808 3555**
Web: **www.cafamily.org.uk**

Useful reading

'Different Dads - Fathers' Stories of Parenting Disabled Children'

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

ISBN: 978-1-84310-454-4
£12.99

Web: <http://tinyurl.com/4hlrco>

Draws together stories of fathers' experiences in bringing up disabled children.

'Recognising fathers – Understanding the issues faced by fathers of children with a learning disability'

Christine Towers et al

Published by the Foundation for People with Learning Disabilities (2006)

ISBN 978-1-903645-90-1

Web: <http://tinyurl.com/47424x>

Tel: 020 7803 1100

Booklet and a report with recommendations to help employers, practitioners and service commissioners understand the issues fathers face.

Available free to download from their website.

'Uncommon Fathers: Reflections on Raising a Child with a Disability'

Edited by Donald J Meyer

Published by Woodbine House (1995)

ISBN 0-933149-68-9

Web: <http://tinyurl.com/3rgryb>

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



'Just a Shadow - a review of support for fathers of children with disabilities'

Sheila West

Published by the Handsel Trust (2000)

ISBN 1 903745 00 4

Tel/Fax: 01497 831550

<http://www.handseltrust.org/shadow.htm>

Research paper with father's views.

Available free to download from their website.

References

¹ The Experiences of Fathers of Children with Disabilities, Ruth Soult, Advocacy West Lancs, 1998.

² Just a Shadow: A review of support for the fathers of children with disabilities, Sheila West, The Handsel Trust, 2000.

³ Fathers in Context, edited by Barry Carpenter, David Fulton Publishers, 1997.

Contact a Family is now on Facebook, MySpace, Bebo and YouTube. We also have an office in Second Life.

Join us at:

MySpace

www.myspace.com/contactafamily

Bebo

www.bebo.com/contactafamily

Facebook

www.facebook.com

and search for 'Contact a Family'

YouTube

www.youtube.com/user/cafamily

Second Life

You can find our Contact a Family virtual advice office in Second Life on Aloft Island 19.40.22 (PG) or visit <http://tiny.cc/P9A5l> to teleport there directly

Freephone helpline: **0808 808 3555**
Web: **www.cafamily.org.uk**

Getting in contact with us

Free helpline for parents and families

0808 808 3555

Textphone

0808 808 3556

Open Mon–Fri, 10am–4pm;

Mon, 5.30–7.30pm

Access to over 100 languages

www.cafamily.org.uk
www.makingcontact.org

Contact a Family Head Office:

209-211 City Road, London EC1V 1JN

Tel **020 7608 8700**

Fax **020 7608 8701**

Email **info@cafamily.org.uk**

Web **www.cafamily.org.uk**



Language Line
services

Other information booklets available

This guide is one of a series produced for parents and groups concerned with the care of disabled children. A full list of Contact a Family publications is available on request or can be downloaded from our website www.cafamily.org.uk

- Siblings (UK)
- Relationships and caring for a disabled child (UK)
- Grandparents (UK)
- Special educational needs - England (England)
- Working (UK)
- Benefits, tax credits and other financial help (UK)
- Holidays, play and leisure (UK)
- Understanding your child's behaviour (UK)

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