



Fathers

Introduction

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.

This guide will help you learn more about practical information you may need and help you understand how other fathers have experienced having a disabled child.

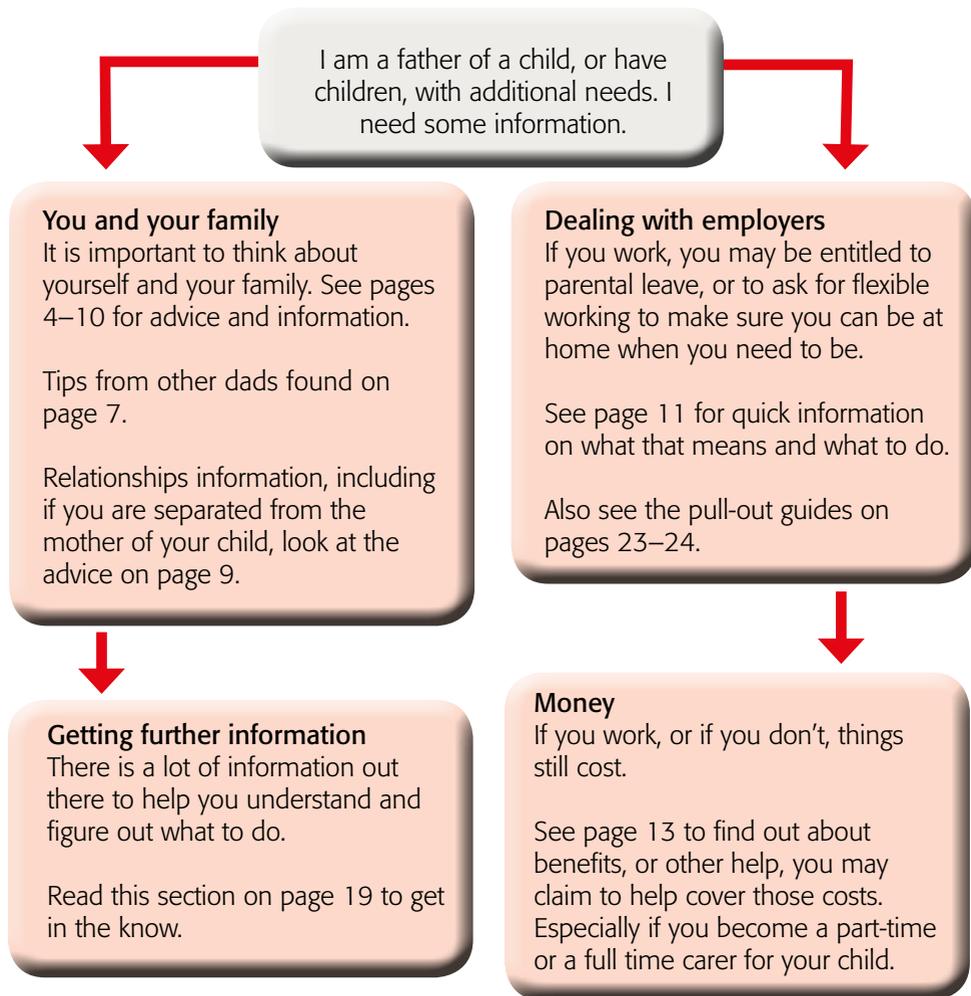
In the development of this guide we met a number of fathers and talked to them about their experiences and their advice for others. We hope it helps you.

This guide will provide you information on the following issues:

- Practical information
- Tips from other dads
- Signpost to benefits
- Overview of some legal issues
- Give you further places to go for information, advice and support.

What do you need to know about?

This flowchart is a quick guide for you to find out what things you need to know about. Use it to get a brief overview of what is involved or what you may be entitled to if you are a new father, an experienced one, and whether your child has a diagnosis or not.



"We always try to be happy and live for today, and at the same time fighting like hell so there's a tomorrow... my children remind me every day that strength comes in many surprising ways!"

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

Your role

The dads we met 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. This often led to them being absent from meetings or from carrying out much of the day-to-day care of their 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.

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.

One of the main concerns dads shared was the management of services available for disabled children and professionals who are designing those services – fathers who cannot attend meetings are sometimes presumed to be not doing anything.

Fathers often see their role as one of providing strength and stability – maintaining normality during a period of uncertainty, 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.



A survey of 500 dads by Netbuddy and Scope found that fathers of disabled children are doing all they can to be involved in their child's life, but face hurdles at most steps along the way [1]. This can leave fathers leaving marginalised and unsupported. The survey found that dads often worry about money, do not often know about their right to request flexible working, and want more support in their relationships with their partners and their children.

This guide is meant to help get you started in finding support and information. For further information, our freephone helpline is always available with the most up to date information for you and your family.

Top Tip: It is crucial at this time to make your position as a father clear to all professionals concerned and ask for written information about decisions made about your child. Then it will be clear for all on how to keep you updated.

"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. When I go to the meetings they think I've come to make trouble!"

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 usually take on the role of 'keyworker', sometimes becoming overwhelmed by a system that 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 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: In these situations it is worth your time getting your knowledge together. In other words, do your homework.

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.

Freephone helpline: 0500 618 140
www.bliss.org.uk

They provide information and advice for parents with children "born too soon, too small or too sick."

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 and possible solutions. 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."

Solutions can be easy to find if you know where to look. Be pleasant, but push for answers and seek out services that are there to signpost you to the most helpful path.

Contact a Family has multiple ways of delivering information, support and advice. Call our freephone helpline on 0800 808 3555 to speak to expert advisors and receive free resources.

We have family workers and offices around the UK to offer face-to-face support. Visit our website www.cafamily.org.uk to see if we work in your area.

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

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 – you will need the right information and know where to go for advice or support. Here are some of the things the dads we met said:

"We did it at different stages – she was busy looking on the net, finding other mothers, talking to professionals – I just wanted to take it all in, in my own time, get my head around it."

"We spent the first few 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."

"My boys have shown me the value of life."



"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."

Top Tip: Tell someone you trust how you are feeling because if you don't it will build up. Talking about it may help you find some solutions and comfort. And remember to be as positive as you can, when you can.

Sound Advice

Most of the dads we met felt their most important need was to be listened to and have someone that would just be a sounding block. Try to make use of all your support networks – this might be your partner, family, friends, neighbours or other dads. You can also call our freephone helpline.

Some key tips:

- Try not to keep your problems or feelings to yourself. Share them with someone you trust
- 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 is okay to ask for help from the people around you.

"As soon as I was able I made her a member of our football club. Now she's a regular mascot – I am so proud!"

Tips from dads for dads

- Adore your child for their individuality and be proud of their achievements.
- There is no such thing as a stupid question – don't walk away until you understand.
- Don't be afraid to negotiate on appointment times. An early or late appointment will give you a much better chance of attending and working too.
- Take some time for yourself – it's not selfish, but essential.
- You need to sleep. Tiredness causes irritability and arguments.
- Make time for your partner too. Even if all you talk about during this time is your child, it is healthy to do this without your child there.
- Talk to other dad's who have disabled children – they are much more likely to understand.
- Always emphasise and rejoice in the things your child can do.
- Investigate what help is available for you and your family. There are people who can advise you on this.
- Groups or organisations specific to your child's disability exist. Use them as both a source of information and someone to talk to. Talking to someone who actually knows what you're going through is priceless.
- Don't be afraid to unload your feelings. Select an appropriate person and allow them to listen.
- Take information from the internet with a large pinch of salt unless you trust the publisher.
- Other people are often embarrassed by disability. This is their problem, not yours.
- Never be embarrassed to explain the disability. Don't assume that others will understand first of all.
- It's normal to feel confused, dazed, angry and annoyed.
- Don't be too proud to accept help – it's part and parcel of the journey.
- Don't be too proud to accept benefits or grants. If you qualify for them, you deserve them and you can use them.

"Always 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."

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

Balancing things

You may, or may not, be the main carer for your child. Either way information needs to be communicated well between you and the mother of your child, especially if one of you attends more appointments than the other. Be sure to communicate well with each other about this and how you can best support your child, attend appointments together or pass information between you.

"It can be a balancing act between keeping your employers sweet, wanting to spend time with your family, trying to keep 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 sole carer for their disabled child.

"At first I felt completely excluded and blamed my son's mother. I knew that leaving was my decision but I missed the kids. Then, when I found my feet, I liked my time with both kids, but at separate times, so it made life easier."

Like any parent, when you find out your child has a disability the first thing you're likely to look for is information. When you are ready, sift through it to see what suits your family and always look for trusted and verifiable medical information. Contact a Family's medical information on our website is a good place to start.



Some dads might take on the sole care of their children. If this is what you have done, or plan to do, 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, then there is particular support for stepfamilies – see our list of useful organisations on page 19 of this guide.

"I found out he has most of my interests – cars, lorries, aeroplanes, buses 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. It is important to talk them through and at times you might need to compromise. At times you might need to talk to others about your relationship – that is fine, but remember the main person you need to talk to is your partner.

If you think your relationship is under strain – then do something about it as soon as you can. Dealing with any problems or strains, before they get too much to cope with is the best way to deal with it.

Relate

Tel: 0300 100 1234
www.relate.org.uk

Relate offers advice, relationship counselling, sex therapy, workshops, mediation, consultations and support. This can be done face to face, by phone or through their website.

We have a printed and downloadable *Relationships* guide from the Contact a Family website or available for free through calling our freephone helpline.

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 can sometimes feel a bit uninformed because their partner sees information first.

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

“I’d say to most other fathers – make it your business to read the letters and find out what’s going on.”

“Be part of the planning otherwise you’ll get left behind, everything moves fast and you need to know what’s going on, it’s your business too.”

Your 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 parents 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 information and 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. Talking about how each of you handle situations is important. Remember that all families are unique and each of you might use different methods.

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

Having a break

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

For information around getting a break, ring our freephone helpline. You can also get our guides *Disabled children's services* and *Getting direct payments for your disabled child* from our freephone helpline.

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 just the two of you is important and worth arranging, 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.

"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 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.

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

Some siblings benefit 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 our freephone helpline. You may also find our *Siblings* guide useful, also available free from our freephone helpline and our website.

Top Tip: Plan a time with your sibling children and stick to that. It will be good for them and for you.

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 having a disability.

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.

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

Sometimes people will feel as though they have to offer advice. You can tell them whether you want them to, or if you want to just talk, and for them to listen. Telling people what support you want from them will help you to engage 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.

Dealing with employers

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

It is important to know your rights with your employer so that you can take the time off if you need it. Whether you live with your children, or not, you have a range of employment rights which they can use to have more flexibility. These include:

- 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.

Get information from our freephone helpline about whether you could claim any extra benefits if you are on unpaid leave.

You are entitled to parental leave if you have parental responsibility for your child – check the pull out diagrams on pages 23–24 to help.

Paternity leave

This is leave fathers can take after a child is born, or adoptively placed. To be eligible for paternity leave fathers need to:

- Have worked for the same employer for 26 weeks
- The 26 weeks' work must have



happened before week 25 of the pregnancy.

Paternity leave entitles you:

- to take either one or two weeks together up to eight weeks (the 56th day) after the actual or expected week of the child's birth
- to receive Statutory Paternity Pay. This is paid at £135.45 per week or 90 per cent of earnings, whichever is less. Check your contract of employment to see if you're entitled to more.

Time off for dependents

This is the right to take time off work in order to deal with an emergency, such as your child is suddenly ill, or there is a sudden breakdown in care arrangements. It does not apply when you know about the problem in advance. This right is available to all employees no matter how long you have been in the job for. There is no statutory right to being paid for this.

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



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. 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. To be eligible:

- you must have worked for the same employer for 26 weeks prior to the application being made
- You must have parental responsibility for that child
- Parents with disabled children getting DLA can make an application at any time until the child's eighteenth 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 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

information about benefits can be found on page 13–15 of this guide and specific information can be got through calling our freephone helpline.

"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".

Adoption leave

Those who adopt children are entitled to up to 52 weeks' adoption leave. This is made up of 26 weeks of ordinary adoption leave followed by 26 weeks of additional 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 £135.45 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.

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 (£107 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.

Additional Paternity Leave

If your child was born or adopted after 3 April 2011 you could have the right to claim up to 26 weeks' Additional Paternity Leave. This applies if your partner doesn't use up all their statutory maternity or adoption leave, and goes back to work. You may then be able to take the remainder of their leave to look after the child.

More information about employment rights

More information about employment rights can be found on the website DirectGov, as well as timelines for how to apply for flexible working and how long that should take.

DirectGov can be found online, www.direct.gov.uk and the Department for Business, Innovation and Skills (BIS), www.bis.gov.uk

Contact a Family also produce guides on benefits and employment which you can get free through our website or by calling our freephone helpline on 0800 808 3555.

Equality Act 2010

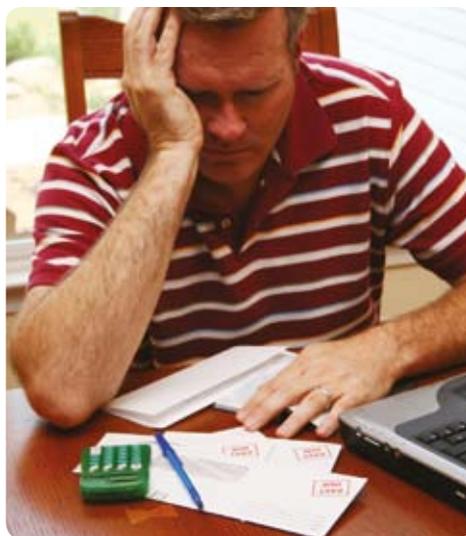
The Act makes it unlawful to discriminate on the grounds of gender, age, marital status, race, religion and belief, and disability. The Act also makes it unlawful for people to be discriminated against or harassed because they have an association with a disabled person. This can apply to a carer or parent of a disabled person. Information and advice is accessible from the Equality and Human Rights Commission's website www.equalityhumanrights.com

Money

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 on the next page three of the main benefits families can claim.

For detailed advice on the full range of benefits you should phone our free helpline on 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* with more detail and more information about benefits.



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

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.

Claiming DLA

Call our freephone helpline or download a copy from our website of the *Claiming DLA for children* guide for all the details on how to do this and what you might be entitled to.

To maximise 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 one of our family workers, since it is long and complex.



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
- 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 currently £100 per week (after taking off certain childcare costs and other expenses).

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 Carer's Allowance

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.

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.

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.

Working Tax Credit (WTC) can be claimed by families in work on relatively low incomes. Contact our freephone helpline for an up-to-date description.

Debt

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

National Debt Helpline

Freephone: 0808 808 4000
www.nationaldebtline.co.uk

Depending on where you live our freephone helpline may also be able to refer you to a local debt project for face to face advice. Contact a Family can also provide details of charitable trusts that may be willing to offer some financial assistance.

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

Support and advice 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.

Contact a Family has trained and experienced family workers, helpline advisors and volunteer parent representatives who can help. Call our freephone helpline 0800 808 3555 to get put in touch with the right information and people for you and your family.

Support in the family

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

Your extended family can be a massive help, and if they are already helping that's great for you and your children. Whether they are involved or not, extended family relationships can be helpful or stressful. It's okay to seek advice from others about managing that, as well as pointing your family in the right direction for them to seek support in caring and being there for your child.

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

Contact a Family produces specific guides such as *Grandparents* and *Siblings* – you might find these useful and helpful with your other family members. Free copies are available from our freephone helpline, or download them from our website.

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 our freephone 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."

"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's 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.

Talking and advice 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 – use it if you have one. It may be a quick chat on the phone at lunchtime, but it could help you lots more than you think.

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 our freephone helpline.

You can also get help and support to set up a fathers support group from our dedicated officer and get linked in with our Local Groups Network. Contact details for this officer can be found at www.cafamily.org.uk

As a dad of a disabled child, you may have found it difficult to access support when you felt you needed it most. Contact a Family provides good quality advice, support and information. We can signpost you to a support group and help you get connected to other parents.



When you don't live with your children

This next section looks specifically at some of the legal and practical issues that dads may face if they live apart from their children. It includes information around:

- maintaining contact with your children
- dealing with disputes and family mediation
- getting legal advice about the ways of ending a relationship, and other disputes
- financial issues such as child support and changes in benefit entitlements.

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 be agreed to try out arrangements before settling on something more permanent. Where an agreement can't be made, it may be necessary to consider family mediation and getting 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 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. 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 Helpline

Helpline: 0845 602 6627
www.familymediationhelpline.co.uk

The Family Mediation Helpline can provide general information as well as contact details for mediation services in your area.

Freephone helpline: 0808 808 3555
www.cafamily.org.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, such as 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 (although you might be able to claim again as a single claimant).

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 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
www.mpssociety.co.uk

You can find support groups for specific disabilities and rare conditions on our online Directory. Each condition also has useful, reliable and verified medical information which you can access for free.

Useful organisations

For fathers

BLISS

Freephone helpline: 0500 618 140
www.bliss.org.uk

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.

Family Lives

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

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

Netbuddy

www.netbuddy.org.uk

Online information and support forums. Specific forum for male carers called 'Dads talk'.

The Foundation for People with Learning Disabilities

Tel: 020 7803 1100
www.learningdisabilities.org.uk

Has resources and information for fathers and professionals working with them.

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

Working Families

Freephone helpline: 0800 013 0313
Text: 07800 00 4722 (Text your query to 'Edads')
www.workingfamilies.org.uk

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

Home Dad UK

Tel: 01938 810 626
<http://homedad.org.uk>

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

Disabled Parents Network (DPN)

Tel: 0300 3300 639
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. Information and resources available.

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: 0300 0300 363
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

Freephone helpline: 0808 802 0925
www.gingerbread.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

Freephone helpline: 0808 801 0366
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
www.fatherhoodinstitute.org

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

General resources

Department for Work and Pensions

www.dwp.gov.uk

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

National debtline

Tel: 0808 808 4000

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: 0844 477 2020 (Wales)

Tel: 0844 411 1444 (England)

www.citizensadvice.org.uk

A 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

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

Freephone helpline: 0800 882 200

Textphone: 0800 243 355

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

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

£13.99

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

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.

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

Uncommon Fathers: Reflections on Raising a Child with a Disability

Edited by Donald J Meyer

Published by Woodbine House (1995)

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)

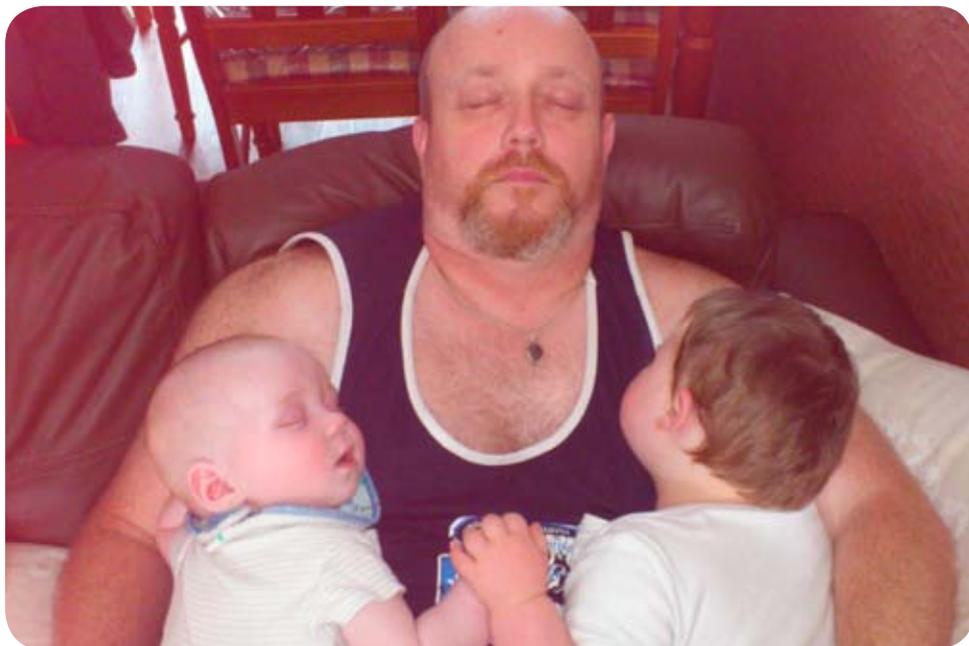
www.handseltrust.org/shadow.htm

Research paper with father's views. Available free to download from their website.

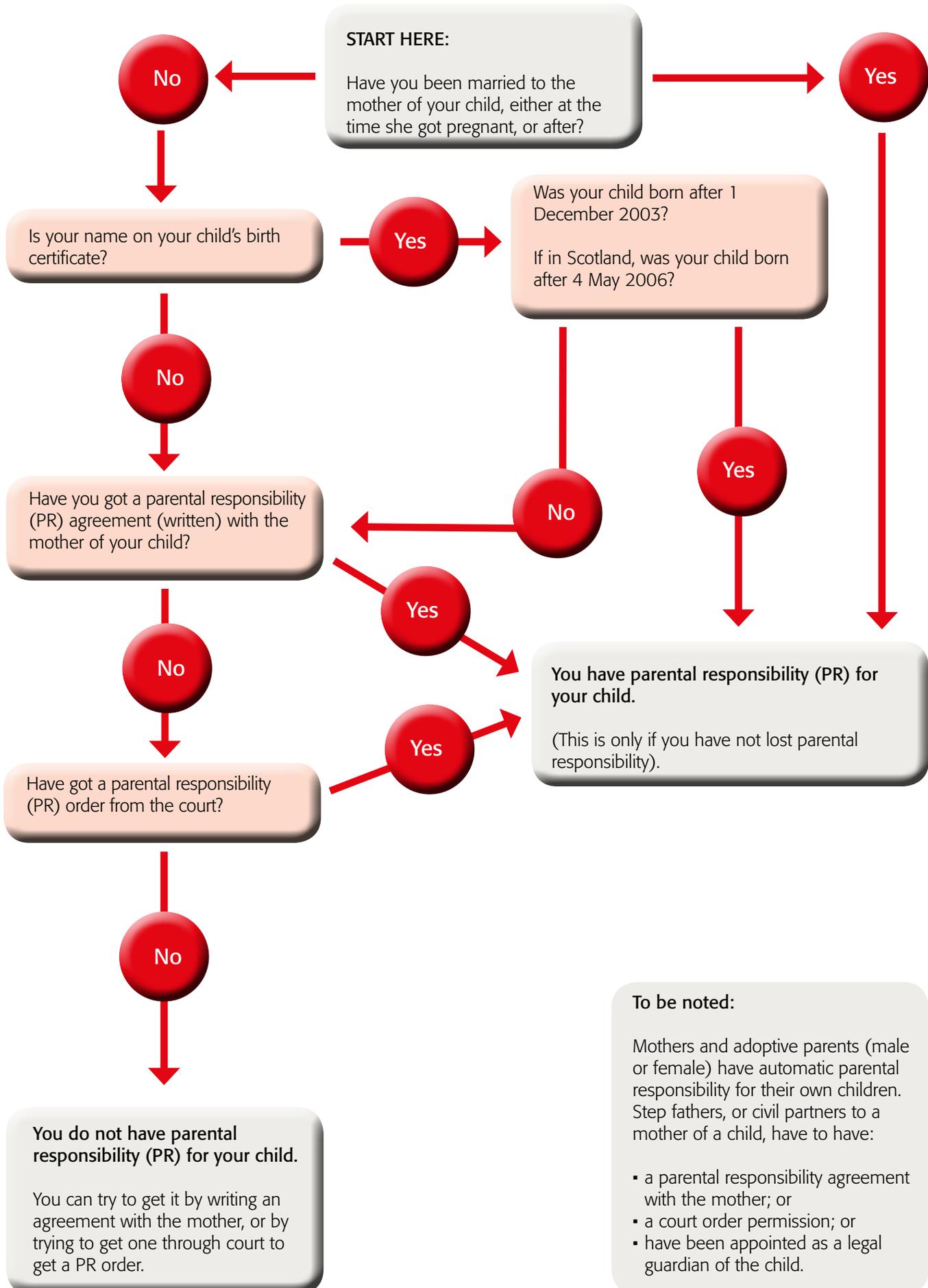
References

¹ Netbuddy and Scope (2012)
Dad and me: a survey of 500 fathers of children with disabilities
www.netbuddy.org.uk/newsletter/dad-and-me

Survey results of 500 dads of disabled children, along with campaign information.



**Do you have parental responsibility for your child?
Use this diagram to find out.**

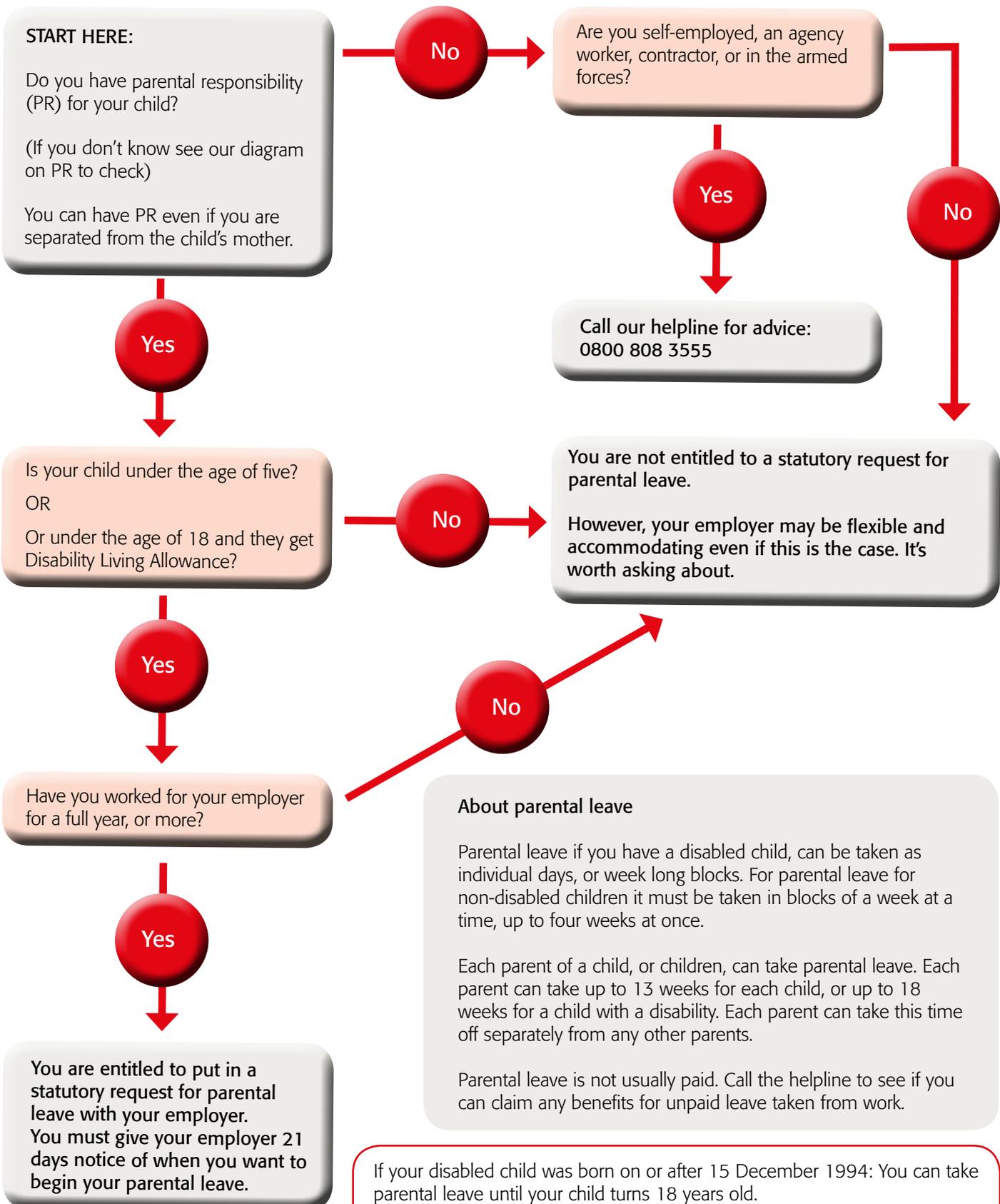


To be noted:

Mothers and adoptive parents (male or female) have automatic parental responsibility for their own children. Step fathers, or civil partners to a mother of a child, have to have:

- a parental responsibility agreement with the mother; or
- a court order permission; or
- have been appointed as a legal guardian of the child.

Parental leave: use this diagram to find out if you are entitled to a statutory request with your employer.



Social networking

Contact a Family is on Facebook and Twitter. Join us at:

Facebook

[www.facebook.com/
contactafamily](http://www.facebook.com/contactafamily)

Twitter

www.twitter.com/contactafamily

Podcasts

You can download podcasts from our website:

www.cafamily.org.uk

Videos

You can watch videos on our YouTube channel at:

www.youtube.com/cafamily

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

Getting in contact with us

Free helpline for parents and families
0808 808 3555

Open Mon–Fri, 9.30am–5pm
Access to over 170 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. Other guides include:

- Understanding your child's behaviour (UK)
- Relationships and caring for a disabled child (UK)
- A guide to claiming Disability Living Allowance for children (UK)
- Special educational needs - England (England)
- Benefits, tax credits and other financial help (UK)
- Holidays, play and leisure (UK)

A full list of Contact a Family publications is available on request or can be downloaded from our website www.cafamily.org.uk

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