



DAD & ME

SHINING THE SPOTLIGHT ON
THE ROLE OF FATHERS AS CARERS
2018

1. BACKGROUND

Flamingo Chicks is an inclusive community giving disabled children and those with illnesses the opportunity to enjoy dance alongside their friends. While the children explore movement and develop key skills, parents and carers benefit from a vital peer-to-peer support network.



In four years we have grown from a small community group to an award winning social enterprise, with our ballet school reaching 2,500 families each year and our calls for disabled children's rights being heard from Downing Street to the United Nations in New York.

Our Dad and Me campaign shines a spotlight on Dads of disabled children, a group of 720,000 men who are all too often overlooked and unsupported in their role as carers. For most of these fathers, the major challenge they face is the daunting task of combining work with raising a disabled child. In order to find out more about the scale of the problem, we conducted a comprehensive study to understand the issues that fathers of disabled children faced in juggling their responsibilities as dad and employee.

The following findings emerged from our study:

- Dads experience financial stress, putting them under pressure at work and afraid to ask their employers for support to juggle caring and work responsibilities (bringing up a disabled child is estimated to be 3 times more expensive – see JRF). 72% of dads feel under pressure to maintain a good job in order to provide the care required for their child
- Dads find performing their role of dad and employee well an almost impossible task and have limited support to help them to cope. Indeed, most support is geared towards female carers. 76% of dads consider that female carers are better supported, while 98% would like access to more support
- Dads feel stigmatised and unsupported at work and fear their personal situation will damage their career. Fewer than 10% of dads have told their boss they have a disabled child, 97% do not have jobs that are flexible.

We are calling for employers to implement the Flamingo Chicks Dads Charter of four essential standards to create a supportive working environment for dads of disabled children. These are:

- 1) A culture where dads feel able to open up about their children's disability
- 2) Flexible working solutions so dads can balance work with their responsibilities as a father
- 3) Disability awareness training to create more sympathetic and supportive teams to dads' situations
- 4) Policies in place to enshrine these practices, and resources for their successful implementation.

If every employer implemented the Flamingo Chicks Dads Charter then the lives of hundreds of thousands of fathers would be transformed. Dads would be able to combine caring for their child with their work commitments. As a result, dads will enjoy improved mental and physical wellbeing and be able to provide better support to their children. In return, employers will benefit from more committed staff who are better supported to perform their role in a way that enables them to be most effective.

Fewer than 10% of dads have told their boss they have a disabled child

Disabled Family Friendly Employer

For any company adopting our charter, Flamingo Chicks will provide a collateral pack for all employers that sign up. This will include a Disabled Family Friendly Employer logo, posters for the workplace, information on disability training and a factsheet.

2. THE OVERWHELMING LIVES OF DADS OF DISABLED CHILDREN

770,000 dads in the UK have a disabled child. Since we established Flamingo Chicks four years ago we have met and supported many of these dads as their disabled children participate in our ballet school. As we have got to know our dads, we have come to understand the heavy weight they carry in looking after their child and also how this often differs to the challenges the mothers of disabled children face.

We have heard how the most challenging issue that dads face is juggling their working lives with the additional responsibilities that comes with being a father to a disabled child. This includes day-to-day caring duties, hospital and other disability related appointments and the pressure of feeling like you have to earn more as the cost of raising a disabled child is so much higher.

Most fathers we have met have found combining work with caring for their child overwhelming and exhausting. Dads told us they feel a huge stigma around showing emotion or asking for help. The strain put on fathers can lead to mental health issues, such as anxiety and depression, and the breakdown of family relationships.

The problem is compounded by the poverty and financial issues faced by families of disabled children. Dads feel under enormous pressure to keep their jobs, and so are reluctant to discuss with their employer solutions to balance work and caring responsibilities. Most of the fathers we have spoken to do not even tell their employer that they have a disabled child for fear of losing their job or being ignored for promotion.

The many stories that we've heard during these past few years inspired us to gain a deeper insight into the men who were coping as fathers of disabled children. Therefore, in 2018 we commissioned a study into the emotional and physical impact of caring for a disabled child. This was comprised of an online survey of 250 dads, in-depth interviews with 30 dads and desk research.

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3. OUR FINDINGS

Our study revealed some extraordinary insights into the lives of fathers of disabled children. These dads find combining parenting of a disabled child and working enormously challenging, and yet most employers do not provide the necessary support to enable them to be both great employees and dads.

OUR STUDY REVEALED THREE KEY INSIGHTS:

1. Dads face financial stress

A significant number of dads of disabled children live in poverty with their family. Four in every ten disabled children in the UK (320,000) are living in poverty¹. Parents of disabled children are significantly more likely to be out of work or earning less than parents of non-disabled children. Disabled children, for example, are twice as likely to live in a home where there is no parent in paid work². This is often attributable to the fact that the additional responsibility of looking after a disabled child can make it difficult for parents to work or force them to work fewer hours.

This is compounded by the significant costs of bringing up a child with a disability. Research has found that the total cost of bringing up a child with a disability is three times higher than for a non-disabled child³. Extra costs incurred by parents include specialist childcare, adaptive clothing, vehicles, sensory toys and mobility devices. For many parents, there is the additional worry of who will provide for their child when mum and dad have passed away, putting pressure on parents to earn more money now in order to make suitable provision.

The financial pressures that these families face puts a huge burden of responsibility on fathers to perform at work, and keep their employer satisfied with their efforts. Our survey revealed that 72% of dads felt under pressure to maintain a good job that pays well in order to look after their child.

“I work so hard for my employer because I know I can't risk losing my job - this actually makes me (and dads like me) a real asset to employers because we have to be so focused and driven.”

Damien, dad to Millie who has Angelman syndrome

While employers benefit from driven, committed employees, dads have to put work first rather than looking after their children in their time of need. We heard from several fathers that the financial pressure they are under means they are

afraid to ask their employers for time off or to work flexibly so that they can better juggle caring and work responsibilities. This means that all too often fathers are forced to miss their children's important hospital appointments.

“Bringing up a disabled child is expensive. We also have to plan to provide for our son for long after we've died rather than until they just are 18, like parents on non-disabled children can do. That puts huge pressure on me to hold down a good job. I am afraid to say too much about our child's needs at work for fear of being overlooked for promotion or my boss and team thinking it'll impact my work. I miss crucial appointments so I don't fully understand his treatment/condition. Whilst my wife also works full-time, she has to bear the burden of juggling everything. It's sad but it's more socially acceptable for her to have time off work for our son than it is for me.”

Greg, dad to Jack who has Global Developmental Delay

The financial pressures faced by fathers also put additional strain on their relationships. 78% of fathers we surveyed reported that their relationship is under pressure as a result of caring for a disabled child, with our interviews confirming financial issues to be a key contributor. Other research supports our findings. For example, Relate found that 39% of parents of children with a learning disability cite money worries as a source of strain. Unsurprisingly, studies have found that couples raising disabled children are more likely to divorce or separate than parents with non-disabled children (e.g. *One Plus One's Growing Together of Drifting Apart* report⁴).

1. *4 in 10 Report*, Children's Society (2011)

2. *Caring more than most*, Contact (2017)

3. *Disability in the United Kingdom 2016*, Papworth Trust (2016)

4. *Growing apart or drifting apart*, OnePlusOne Fiona Glenn (2007)



2. Dads face an almost impossible job with little support

Our study revealed that dads struggle to successfully perform their roles as father and employee. A recurring theme across our interviews was that dads either felt that they were letting down their families or their colleagues. The findings of our survey supported this, with nearly one third of dads reporting that they do not feel confident in their role as a carer to their disabled child.

“The biggest issue I face regularly is trying to meet the demands of my profession and my family. My employer is willing to let me be there for Mary for big events such as operations and annual reviews. However, I choose not to go to all appointments and meetings as I feel guilty that I am letting my employer down.”

Gareth, dad to Mary who has Cerebral Palsy

Despite the huge challenges that they face, dads do not feel supported. A staggering 98% of dads reported that they would like access to more support. A clear gender divide emerged in our findings, with a strong perceived difference between the support received by male and female carers of disabled children. 76% of

surveyed fathers agreed that female carers are better supported, while almost all (96%) agreed that it is deemed more acceptable for female carers to show emotion and ask for help and support than male carers.

In interviews dads revealed that they felt excluded from most support groups for parents of disabled children, as they tend to be focused on mums. We also heard from several fathers how the focus of health services on the mother left them feeling ignored. Our survey found that 56% of dads say they often feel excluded because of their sex.

“Even in these ‘enlightened times’, when you’re a father it can be hard to be recognised as a hands-on parent.”

Steve, Dad to Alex who has genetic mutation of the DDX3X gene

Despite the lack of support available, there was real appetite for it from the dads we interviewed. Encouragingly, dads understood the benefits of receiving support and appeared willing to access it if it was available. For example, 98% of fathers reported that they would like greater access to support groups for them and their child, particularly ones that operate outside of typical working hours.

3. Dads feel stigmatised & unsupported at work

Our study found that employers do not consistently provide the necessary support to help fathers to effectively combine caring for a disabled child with their work. Despite their legal right to request flexible working, an astonishing 97% of dads said that their jobs were not flexible. Similarly, 96% of fathers said that they felt there was no emotional support at work.

Unsurprisingly, almost all dads (97%) would like the option of flexible working to be available to them so that they can better combine their caring and work responsibilities.

Astonishingly, our study found that many dads kept their disabled child a secret from their employer. Although 80% of fathers confided in their colleagues about having a disabled child, less than 10% of respondents had told their manager, mostly from fear of it affecting their career prospects.

We also heard several depressing stories from dads about the attitudes of their employer. One father, for example, spoke of the verbal abuse he received from his manager about the support his family was receiving for their disabled child, accusing him of abusing the benefit support system.

However, we also heard positive stories. A small number of dads told us about the huge difference that their employers had made to their lives through supporting them to be able to balance their work with their parental responsibilities. Several commented on how dads of disabled children are a vital asset to companies, with the financial pressure creating highly motivated employees willing to go the extra mile for their employer and – in many cases – extremely loyal to companies that had done all they could to make a difficult situation more manageable for the fathers they employ.

9%

have told their boss they have a disabled child for fear of impacting their career

32%

do not feel confident in their role as a carer to a disabled child

56%

say they often feel excluded because of their gender

72%

feel under pressure to maintain a good job that pays well to look after a child with a disability

76%

believe that female carers are better supported

96%

feel it's more acceptable for female carers to show emotion or ask for help

96%

feel there is no emotional and mental support at work

98%

say they would like access to more support for them and their child

97%

said their jobs are not flexible

4. DADS' STORIES

Here we share four different stories of dads to highlight the issues fathers of disabled children face in combining caring and work responsibilities, and the solutions they have found – or would like to see happen – to enable them to become both great dads and employees.



Nick's Story

Nick, aged 50, knows only too well just how unsupportive employers can be to the fathers of disabled children. In 1995 his son Joe, now 22 and diagnosed with spastic quadriplegic cerebral palsy, was born and immediately taken to intensive care. In order to be by his son's side, Nick took two weeks off from his job as a supervisor in a tile warehouse. However, when he returned to work he found his employers were less than supportive.

He explained: "On going back into work, I was immediately called into the office and given a lecture about how taking time out for my family shouldn't be my priority, work should be. They were also asking about whether I'd be likely to need any more time off because of my son's condition."

However, it was to get worse. Because Nick had worked at the factory for less than two years, he had very few employment rights. His employers simply sacked him on the grounds that he had not given sufficient notice that he was taking time off after his son's birth.

For Nick, this was to signal the beginning of a very dark period in his life in which he became both full time carer to his son and tried to support his wife, who began suffering mental health problems after Joe's birth. He explained: "We became very isolated as a family, which wasn't good for us or Joe and ultimately contributed to the breakdown of our marriage. If I had been able to work around my caring commitments I think it would have helped, but at the time it just wasn't possible. And so our whole world became smaller."

This wasn't helped by the way he was treated at some parenting classes. He explained: "One health visitor asked me to start turning up at the

end of the class because other parents were finding Joe's disabilities 'upsetting'. Needless to say, I didn't attend that class again. The isolation was like a snowball. I lost confidence and ended up taking Joe out less and less."

When his son turned 18 Nick re-entered employment, first as a carer and then as a school caretaker, a job he still does now. With flexible hours that allow Nick and his second wife to manage Joe's needs, this job works for him, but he feels much more could be done to help the fathers of disabled children.

"We face so many more challenges than your average parent and deserve better support."

And one area Nick thinks needs looking into is employment law; "Obviously certain protected characteristics make it more difficult for employers to dismiss you without two years of service, but at the moment caring responsibilities aren't taken into account. This puts parents like me at a disadvantage. We face so many more challenges than your average parent and deserve better support."

Fewer than 10% of dads have told their boss they have a disabled child

Tom's Story

One father Tom (not his real name) we spoke to as part of the campaign only felt able to speak to us if he could remain anonymous. Working in the property industry and dad to Phoebe aged 9 who has mitochondrial disease, his experiences in the workplace have so far been less than positive.

For Tom, increased flexibility from his company would make both his working and personal life easier, but because of the 'presenteeism' culture at his workplace, it is not something he feels he can ask for. He explained: "A more flexible way of working would really help me, but I don't feel able to broach the subject with my boss. Because of the competitive environment I work in, I think it would come across as 'weakness' and affect his perception of my performance. I don't think he would understand and it would affect our working relationship."

Tom's reluctance to 'rock the boat' is understandable given his experiences with his previous employer, who refused flexible working on the grounds that then 'everyone would ask

for it'. And yet, even though his past and current employers have not been supportive of his circumstances, he actually feels that being the father of a disabled child makes him more, not less, of an asset in the workplace. He explained:

"I feel hugely under pressure to provide financially for my family due to the additional pressures of our situation. We don't know what the future will hold for our daughter, but we do know it will be expensive. This means my job is very important to me, so I do all I can to impress my boss and make sure I keep it. I regularly work evenings and weekends – unpaid – in order to go over and above. In fact, I think the loyalty and hard work I give is worth that of two employees!"

Alastair's Story

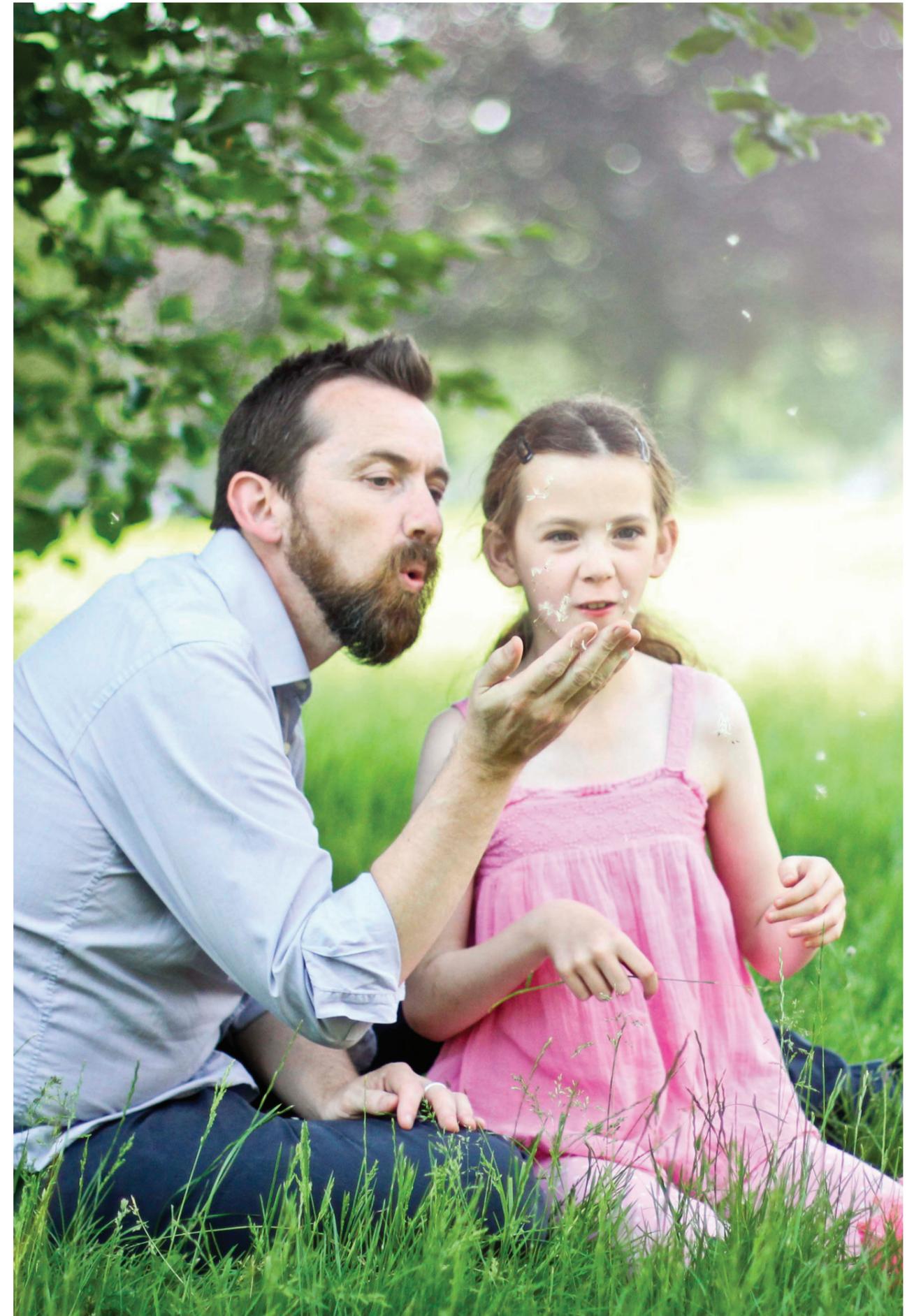
Alastair, aged 48, a neurologist in the NHS is father to 11-year-old Josie, who, as a result of a brain injury at birth, has severe epilepsy and requires full-time care. Because Alastair's role is relatively autonomous, he is able to work his schedule around his daughter's needs, something that has made a great deal of difference to him and his family.

He explained: "Because of the nature of my work, my employer allows me to make my own schedule, and this makes all the difference to me as the parent of a disabled child, meaning that I can be there for all of her appointments. It benefits me and my family and has no negative impacts on my employer. In fact, I think my experiences have actually helped me become a better doctor."

And while his own experiences of managing his duties as an employee and being the father of a disabled child have been positive, he is very aware that this is not the case for everyone and feels that employers need to do more to support

parents who have children with disabilities and not just pay lip service to the issues involved. He explained:

"All too often things get written on charters and employers look like they'll be helpful but in the event, they are not. More workplaces need to not just do things like equality and diversity training but actually think about how they can implement practical measures to support the diversity within their workforce – including the fathers of disabled children."



Steve's Story

Steve, aged 49, is an engineering project manager for manufacturing firm Rotork. He's also dad to Zara, who is almost three and has Global Development Delay, as well as Alastair (11) and Holly (8). For Steve, having a supportive employer who allows him to take time out for Zara's appointments and simply make the time up later has made the world of difference in helping him support Zara and wife Catherine, and has helped him develop a deep loyalty to his employer.

He explained: "Having a child with a disability puts a great deal of pressure on you. There are so many appointments, investigations, MRI scans – some weeks we will have two or three appointments. I want to attend as many of these as possible – to support both Zara and my wife – and the fact that my employer is supportive makes all the difference to us as a family."

"It means we can both be there to reassure Zara during sometimes invasive procedures and support each other too. It also enables us to make decisions about her treatment on the spot rather than one of us having to relay information to the other at home, meaning she can get the care she needs faster.

"I also feel like being able to attend appointments helps me to understand my daughter's condition better. I can be there to talk to the medical professionals myself. It would be so much harder if Catherine had to relay all the information back to me, and if I wasn't able to ask questions or get clarifications myself. The

fact that my company enables me to do this really makes a difference."

"I also feel like being able to attend appointments helps me to understand my daughter's condition better. I can be there to talk to the medical professionals myself."

At work, it is not just his boss who is supportive, but the whole company. After writing a short piece about his daughter in the company newsletter, his colleagues fundraised to buy her a special tricycle to support her development. "I was blown away," said Steve.

Because of this, and the flexibility he enjoys from his employers, he simply wouldn't want to work anywhere else. He explained: "I have a bit of commute to this job - and Zara's nursery is in the other direction - so it could be argued that getting a more local job would be sensible, but I simply wouldn't want to work anywhere else."

"The fact that my employer is so supportive means I wouldn't want to work anywhere else."



5. OUR RECOMMENDATIONS

Flamingo Chicks calls for all employers to create a supportive working environment that enables fathers of disabled children to flourish as both employees and dads. To create this, we are urging all employers to sign up to and implement our Flamingo Chicks Dads Charter of four essential standards.



1. A culture where dads feel able to open up about their children's disability without fear of losing their job or inhibiting career progression. Employers working towards breaking the silence will:

- Set the tone from the top, ensuring senior advocacy and vocal support from leadership
- Encourage dads of disabled children to share their personal circumstances so that they can develop working practices that work for both employee and employer (ideally developing existing formal review processes to include a section around personal circumstances for all employees)
- Proactively offer flexible working solutions to dads, rather than waiting to be asked
- Start general conversations within the business around disability and the role of carers to create a safe space for dads to come forward and ask for the support they deserve
- Equip managers with the confidence, knowledge and skills to support dads of disabled children
- Create a group of individuals in the workplace who can champion a supportive working environment for dads of disabled children.

2. Flexible working solutions so dads of disabled children can balance work with their responsibilities as a father. Companies doing this well will:

- Offer dads the opportunity to work flexible hours to attend medical appointments
- Recognise that medical appointments can happen at short notice
- Acknowledge that dads will not always have evidence for medical appointments before they happen.

3. Disability awareness training for managers and co-workers. This will deepen employers' understanding of what it is like to look after a disabled child, creating a more sympathetic and supportive team.

4. Enshrine these practices in equal opportunities and other appropriate policies, and invest in their successful implementation.

Those employers who conform to the standards will be able to promote themselves as a Disabled Family Friendly Employer and Flamingo Chicks will provide a logo they can use.

“Much more needs to be done to promote the value of flexible working to support family relationships and family finances. Employers have a real opportunity to make a big difference to the lives of families caring for a disabled child. Dads in particular are all too often overlooked in this area and by supporting fathers it has a knock-on effect, better supporting mums too. The stigma around asking for flexible working is a real barrier so if we can get people talking, opening up about the huge challenges these families face and employers offering more understanding, it will make an enormous difference. Plus – the commercial benefits are there for employers too – as the case studies show, offering empathy and understanding typically results in some of the most loyal and hardworking employees.”

Katherine Sparkes, Founder of Flamingo Chicks

If companies introduce our Flamingo Chicks Dads Charter this will create several positive changes:

- Dads will be able to better combine caring for their child with work commitments, improving their wellbeing
- Disabled children will have better support from their dads at critical moments in their lives
- Families will benefit from improved relationships as pressure reduces
- Companies will benefit from loyal, motivated employees, well-equipped to do their jobs in the most effective way. They could also increase staff retention.

6. OUR COMMITMENT

TO SUPPORTING COMPANIES TO ADOPT THE CHARTER

1. A resource pack provided to all employers who join the charter. Providing materials to raise awareness of the charter within the workplace and factsheets and useful information including use of a Disabled Family Friendly Employer logo.
2. Access to / signposting to disability awareness training.
3. A review meeting with the nominated champion for the charter 3 or 6 months after they adopt the charter.

**Disabled
Family
Friendly
Employer**

7. SUPPORTERS

We have been approaching companies to share our findings and support them to introduce a supportive working environment for dads of disabled children.

“I urge all companies to create a supportive working environment so that they can be the best possible employees and dads.”

Darren Jones MP





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