

Dads play an important role in the upbringing of their child but in reality they can feel marginalised by a lack of support.

Netbuddy and Scope surveyed 500 dads to find out the reality of their situation.

Dads are battling against many misconceptions and challenges when trying to juggle work and caring.

Are you a dad? How do you feel about the support you receive and the challenges you face as a father of a child with additional needs? A new survey of UK dad carers by Netbuddy and Scope provides a dramatic insight into their experiences of looking after disabled children.

It illustrates the shocking truth that fathers aren't getting the support they need and are left feeling marginalised. Are these your experiences?

Dads are battling against many misconceptions and challenges when trying to juggle work and caring. The survey shows that dads are doing all they can to be involved but face hurdles every step of the way. In short, they want their voices to be heard, to be given more consideration in terms of support and to be acknowledged as having an important role as a parent.

What dads said they feel

- Greater financial pressure as carers the vast majority worry about money and many feel they are seen only as the breadwinner.
- They are not getting support from colleagues or bosses 15% say their workplace does not even know they have a disabled child.
- Unaware of their right to request flexible working four in ten do not know this is an option.
- They do fully understand their child's condition four in ten do not fully understand their child's disability and a third are not confident in caring for their child.
- Suffering relationship problems two-thirds say their relationship is suffering.
- They want more support as fathers eight in ten feel alone but only about four in ten get help from support groups or professionals.



♦ Work and Money

The survey asked fathers about their employment and financial situation.

- 84% say they are under more financial pressure as a result of caring for a disabled child.
- 38% in employment did not realise they have the right to request flexible working.
- 15% of dads in employment say neither their employer nor their colleagues know they have a disabled child.
- 74% of those in employment whose employers know about their child's condition say that they are accommodating to their needs.
- 50% are in full-time employment and 20% are selfemployed, with many saying this gives them greater flexibility for looking after their child.

Some dads have given up work to become a full-time carer. One dad who has done this to focus on his son's transition to adult services says whilst he felt it was essential, he often feels he is being judged for not working.

'It seems that unless men are providing financially for their families, they are considered second-class citizens in the eyes of others. I would like to see a change to this longheld belief,' he comments.

Their Child

When it comes to their child:

- Four in ten (37%) dads surveyed say they do not fully understand their child's impairment or condition.
- 32% do not always feel confident caring for their child.
- The average number of hours spent providing care over a week is 30 to 40, nearly the equivalent of a full-time job.

Despite doing all they can to learn about their child's condition and take advice from professionals, dads still struggle.

flexible 'Medical appointments are usually in the day pressure and I cannot always get time off work to attend,' one dad ccommodabing explains. 'This leaves me with less first-hand knowledge of what my daughter's autism inadequate means and makes me feel inadequate. If I have not been there to find out about a

different medication or technique I cannot confidently change how I care for her.'

Relationships

Having a child with a disability can put a strain on relationships.

 Seven in ten (72%) say caring for a disabled son or daughter has affected their relationship with the partner.
 Many cite stress, tiredness and not having time together as the main causes of relationship problems or breakdowns.

Relationship problems are incredibly common among those caring for a disabled child and the breakdown of a relationship puts added stress on the family.

Dads say they have no quality time with their partner and, even if they do snatch a moment, they are often too tired to make that time special.

One dad explains, 'The stress of coping with our son's needs has put considerable strain on our marriage. Lack of sleep, constant worry, the demands of caring for him is exhausting. This has often led to disagreements and losing our tempers. We never have any time at all to be "just us". My wife and I both feel very pressurised and anxious.'

Support

A lack of support can leave dads lonely and isolated.

- 84% say they often feel uncomfortable or excluded at events or activities for parents, such as coffee mornings, support groups, social clubs, play sessions or at the school gates.
- While 79% say they turn to their partner for support, only 20% got help from specialist support groups, and 22% from professionals.
- 63% say they cannot easily talk to others when they are having a rough time.
- 80% feel sadness or loneliness as a result of caring for a disabled child.
- 22% say they do not think it is acceptable for men to communicate emotion.

The lack of support for dads and their feelings of isolation or exclusion are major factors. Often, they feel that groups or activities are targeted towards women and they feel uncomfortable if they are the only man there.

'Where the women talk in groups and invite one another to their houses for coffee etc this never happens to the man and you can become isolated,' one dad states. 'You lose most of your friends as most men won't want to talk about disabilities and feel awkward around you and you stop getting invited to the pub.'

What needs to happen?

The survey also asked dads about how the situation could be improved and what could be changed to ensure they have the support they need.

Appointments outside working hours

Meetings, medical appointments, courses and support sessions are often held during the working week and dads in employment find it difficult to get time off. If more of these could be held at evenings and weekends, dads could have more involvement. This also applies to things such as coffee mornings, social clubs or play sessions to allow dads to interact with other families.

Forums for dads

Help and advice on day-to-day issues targeted at dads, perhaps in a forum or on a one-to-one basis. In particular, dads want suggestions that are based on their situation, not hard and fast rules that might not work for them.

'Sometimes having someone to look at your situation in a pragmatic way and offer advice could be really helpful especially when your head is not in a place to be thinking rationally,' one dad points out.

Respite care

Children, mums and dads all need a break, but many fathers simply cannot find short break services to give them some valuable time to themselves.

Employer awareness

Many dads are afraid to tell employers about having a disabled child or asking for time off for fear of jeopardising job security and being overlooked for promotion. Employer awareness and understanding would help this.

Greater community integration

Dads realise the need to balance their child's specialist care with quality time within the wider community. They want more opportunities for their sons and daughters to integrate with others in their age group in 'everyday' social situations.

'Mainstream clubs and activity groups could do more to welcome children with special needs. I feel this can sometimes hold my son back,' one dad explains.

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About the research

Netbuddy and Scope, two national charities working to give carers and families the support they need for looking after disabled sons and daughters, joined forces on the research project. Entitled *Dad & Me*, the aim is to raise awareness of the issues facing dads who

are looking after disabled children and show that much of what they are doing is hidden from view.

They questioned 500 father carers during April 2012 and asked what they think about the support systems in place for them and how they are coping. They talked to dads with children of all ages, from young fathers with babies to older dads with grown-up children.

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For practical support and to talk to other parents and carers about parenting a child with special needs, visit www.netbuddy.org.uk. Netbuddy has also set up a forum especially for dads www.netbuddy.org.uk/forums...

Do you agree with this survey? Have you found this to be the case? Please let us know via: editor@mychildandmemagazine.co.uk, www.twitter.com/mychildandme, www.facebook.com/mychildandme.