Jack & Jill SOS Family Research part 1 of 3

Below are comments from the 32 (25% or 1 in 4) Jack & Jill families who clearly stated that if their Jack & Jill hours were cut their sick child would end up back in hospital in 2011.

J. P., Clare

I am a single parent with 2 children. J. is very vulnerable and is sick and hospitalised very frequently. These hours give me a break to do shopping, sleep, chores etc. and allow me to relax, recharge, knowing that my son is in very capable and trustworthy hands.

E. S., Cork

Our 12 hours nursing support weekly from Jack & Jill means that I can leave the house to do my weekly household shopping, bring the rest of the children to appointments, school, allow other children and visitors to come to see us. This service is like a life line to us. It saved me from mental illness and kept our daughter from been taken into HSE care.

S. M., Cork

Let you have a child with disability at home and see how it feels to care 24 hours a day 7 days a week! I was very near breaking point until Jack & Jill saved me. I now get to go out by day for a few hours to have a break and just go for food shopping and have a cup of coffee. If you like Minister you can come and visit my home and walk in my shoes for one week. Then you tell me why you cannot properly fund this very vital service.

S. W., Cork

We have 5 children under the age of 8. S. is our fourth child and we will always be indebted to Jack & Jill. Only because of them can we give a sense of normality to the lives of ourselves and our children. To cut our hours will be to decimate the lives of *all* our children.

C. McC., Cork

I would be lost without my 15 hours a week assistance from Jack & Jill. I am a triplet mother trying to look after 3 babies for the past 6 months, 2 of whom have significant extra needs. My daughter C. has a brain injury and her sister K. is fed through a gastrostomy tube and needs regular suctioning. Both babies have way above average needs and there still is a 3rd baby to be looked after. Both my husband and I are exhausted and extremely stressed. The only thing that keeps me sane is knowing that my Jack & Jill carer is coming to help me out.

G. M., Cork

Yes, if my child's hours are cut my child will end up in hospital. The hours from Jack & Jill are vital to me and her Dad because it's my only time in the week I don't have to look after G.. If it's cut it will mean I will have a breakdown because I'll be on constant caring with nobody to talk to regarding G.'s progress.

S. H., Dublin

S. is very sick and she will end up in hospital if we don't have Jack & Jill – please don't cut us – we have only one day a week rest and all we have is the help of Jack & Jill. S. needs 24 hour care 7 days a week and the only rest we get is from Jack & Jill which is the best thing the family has. Please help us not to lose them as S. needs the hours and it keeps myself and my husband ticking over. If the person in charge in the HSE would like to visit S. and see what we deal with on a day to day basis we would be more than happy to let him see why Jack & Jill is so important to us and other families.

MK. Dublin

Jack & Jill means everything to us as MK needs 24 hour nursing care and due to her ailments cannot even get respite. Jack & Jill enables me to get a night's sleep to rejuvenate for her full time care. Without Jack & Jill, MK will end up in hospital or worse still in long term residential care.

J. R., Dublin

Without the support from Jack & Jill, J. would be living in Temple Street. I can't bring J. out because of his very low immune system and other complications. My son, my daughter's and my own quality of life will be seriously affected.

S. O., Dublin

Jack & Jill allows me to get carers in that can stimulate S. and do her vital physio a few hours per week. I have 2 other kids under the age of 5 and I work so it's hard doing her daily physio and speech routine. The help I get from Jack & Jill relieves the pressure. If I didn't have Jack & Jill then my daughter would run into physical and chest problems as I don't have the time to do all the physio alone.

M. G., Dublin

Jack & Jill give relief to us beyond words. Their service ensures we as a family with a seriously sick child can enjoy a day out, while our child is accompanied by a qualified nurse. A cut would mean an end to any social outings for the sick child and no reprieve to the parents.

A. M., Dublin

Jack & Jill have been great support helping me with my little girl, A., who is blind, has very poor muscle tone has to be fed by tube, can't walk, talk or sit up unaided and needs 24 hour care. Jack & Jill are always there to help. They saved my life because I couldn't cope without them.

R. C., Dublin

A cut in our hours will mean a pressure our family will no longer be able to bear and will mean R. will <u>have</u> to go to hospital which in a sense will break up our family and will mean her younger brother will rarely if ever see her.

F. D., Dublin

As our daughter is only 4 months old her illness will be very progressive and we fear for what the future holds and without Jack & Jill support we will lose the help and support we badly need.

I. B., Dublin

If Jack & Jill was not there I would not have survived alone, caring for my special child.

S. H., Dublin

Jack & Jill has allowed our family of 5 to live as normal a life as we could hope. S. requires 24 hour monitoring as he has a tracheal tube and makes very little sounds. He requires constant suctioning. Without Jack & Jill one parent would have to stay up all night which means my husband would have to give up work or S. return to hospital.

C. K., Dublin

Jack & Jill means a lot to us because we can function as a family again. Without their support we would lose our family happiness and wellbeing. Life is hard enough without the added stress of cuts to vital care of our critically sick child.

L. R. H., Kerry

Jack & Jill Foundation are giving us really huge help and support. Because of their nurses we can rest and forget for a while about all our problems. Big support.

K.T., Kildare

I can't express properly in words what having a Jack & Jill nurse come to mind our daughter means for us. I have never been so tired in all my life and it's a never ending tiredness – when K. sleeps – I try to do some washing, tidying before she wakes again. The physical tiredness is so exhausting but it's the emotional tiredness that drains us so much. We worry about her all the time and are upset thinking of what her life is filled with – hospital visits - and what lies ahead for her and us. I'm attending the doctor due to stress and depression but had to come off the tablets as they made me too drowsy. Those few hours a week that the nurse comes for, helps me get a break from some of the feeds etc and gives us reassurance that what we are doing with K. is right. To know that she will have some physio done by the nurse that day means I don't feel guilty if I can't get physio done that day myself.... I wouldn't be able to mind K. if I didn't get this help and it's so reassuring if K. is unwell at home to ask the nurse if we should bring her to hospital or if she is ok. Every day is so hard but the Jack & Jill nurse makes life a bit better. If we didn't have this help either K. or I, or both of us, could end up in hospital unnecessarily. They are invaluable and literally Angels in our lives.

K. C., Kildare

If my hours are cut it will be extremely hard for me to cope as I am a full time carer to my disabled daughter and she will end up back in hospital. She is peg fed and is unable to do anything for herself and I also have three older children who need my attention.

H. H., Laois

Without the help from Jack & Jill we would not be able to function properly. My son H. needs night care from Jack & Jill for many different health issues. We as a family need Jack & Jill to help us with our sick son. He gets the best care even in his own home which means so much for him.

K. F., Laois

Either K. or her mum S. will end up in hospital if Jack & Jill hours are cut. Where is the State support that should be a basic entitlement for my daughter and family? Rhona our liaison nurse and our other Jack & Jill nurse are our lifeline. We simply could not cope without them. Our family care, our friends care, Jack & Jill care. Who else cares?

R. H., Louth

Words cannot describe the level of care R. requires and without Jack & Jill we would not be able to cope. Jack & Jill gives us both nursing time and support, providing us with time to sleep one night a week and to spend some time with our two boys.

E. C., Louth

It's hard to put into words what Jack & Jill means to us. Mainly though, it's a chance for us, in the most abnormal of situations to be a normal family. With caring, professionals to look after E. it gives us a chance to live and it also means E. is at home with us and that means the world to our family.

F. McD., Mayo

Jack & Jill has been a great support to our son and to the whole family, as we have six other children to care for. I'm unable to pass the tubes and often have to ring our Jack & Jill nurse during the day or night to do this. No doubt, our child would end up back in hospital if Jack & Jill hours are cut.

M. O'D., Meath

To us it means everything, we can do regular things like shopping and make arrangements to do things. Most importantly for M. it means that if he is unwell we have the support of fully trained nurses to care for him instead of having to bring him into hospital.

S. McM., Meath

Our little girl is due home from hospital today after a 15 week stay and it's only because the Jack & Jill Foundation have granted us hours that we are able to take her home. Any reduction in hours from Jack & Jill would be catastrophic for both S. and ourselves as she cannot be left unsupervised.

L. H., Roscommon

Not only will L. end up in hospital in 2011 should hours be cut, I would also end up in hospital due to burn out as I would have no support to give me a break from the 24 hour care which L. needs. Jack & Jill's support is crucial for us to have some "normality" even if only for a few hours a week as this is the only support we can rely on.

D. L. B., Roscommon

I get 6 hours a week from Jack & Jill. It is very important as it allows me to do my shopping and messages in town without having to bring D. with me. If D. gets a flu it could turn into pneumonia very quickly which would mean hospitalisation for him and it would mean deterioration in his condition. I cannot deal with a cut in hours. If anything I could do with a few more hours, not less. Jack & Jill is a wonderful service and critical for us as a family.

L. H., Tipperary

The hours I get respite from Jack & Jill are my only respite from the constant demands both physically due to his health and mentally due to him being delayed and therefore I can remain sane and have the energy that is needed on a 24/7 basis to care for my child.

A. O'N, Wexford

Any cuts in hours to my help will have very severe impact, as my daughter is 24 hour care and is also a twin - so both her and her sister will both suffer. My daughter has such medical needs and problems it's difficult to manage and she will most certainly end up in hospital if hours are cut. Without Jack & Jill help I wouldn't be able to cope from day to day with my situation and the help for my daughter keeps our family at home.

A. D., Wexford

It is a full time job being a mum of a special needs child and with the cuts in funding we are going to be hit and this will disrupt A.'s routine and upset him. They provide me with a few hours a week where I can grab a shower, clean the house and do other jobs I would not be able to do if they weren't there for myself and A.. I don't know how I am going to manage if my Jack & Jill hours are cut. Not only do the Jack & Jill look after our children they are also a support system for the parents and us parents need them when we are going through bad days.

Part 2

Comments from 53 (41%) parents who replied "I don't know" if my child will end up back in hospital in 2011 if our Jack & Jill hours are cut.

L. W., Carlow

A cut in Jack & Jill hours will impact immensely. It gives me independence to go out and do normal things where otherwise I maybe housebound especially when she is ill. It keeps my mental health in good condition knowing I have extra help.

A. A. D., Cavan

The nursing hours provided by Jack & Jill give us peace of mind that A. is being well cared for whilst we get on with the normal day to day tasks. We know that A. is safe while he is with the Jack & Jill nurse and that any medical situation is kept well under control. Without this service family life will be seriously impacted and we will be left to deal with medical situations which we have not been trained for which adds stress and will affect A.'s new little sister and will make it difficult for me to find work again having been made redundant in June 2010.

K. H., Cavan

K. has multiple complex needs and requires 24 hours care. Our Jack & Jill nurse helps us with transport to and from hospital appointments. Gives respite on a weekly basis allowing me to tend to some of my other child's needs. The level of care needed for K. is a lot and we would be lost without our Jack & Jill nurse.

E. T., Cavan

Jack & Jill are a lifeline to me and my family which enable us to live a somewhat normal life. The hours provided are fundamental to our family unit as our baby requires a lot of extra attention and appointments and the help we receive through Jack & Jill allows us to relax about other things which are taken care of by our home help. There are 7 people in this family including a severely brain damaged baby. If funding is cut all our lives are hugely affected, especially the children.

J. M., Cavan

Jack & Jill have provided us with the only respite we have ever had since coming home from hospital and when J. ends up in hospital for weeks on end our carer is there to support us as we have 3 other children. One is on chemotherapy and we would like really to be in hospital - both of us at times. With our carer for J. it makes it possible for one of the parents to be home with our other two daughters sometimes. I don't want to think about how we would be able to spread ourselves between two hospitals and home if our Jack & Jill hours are cut.

T. M. H., Clare

T. is the only baby in Ireland with the severe form of non ketotic hypoglycaemia with 2 other children with mild form. I have a nurse that calls who is lovely and her support means everything to me - just to go away for one simple hour to recharge my batteries or meet a friend for coffee, knowing T. is in the best hands possible. I have no one else that can give T. her feeds through the pump she is on, or give her the Meds she needs so often through the day through the tube. She suffers so many seizures that no one outside of myself or her nurse can handle her. Please please do everything you can and listen to your heart. Let us keep our nurse. I myself am very ill at the moment and with regular hospital visits many weeks I need my nurse more than anything.

D. G., Cork

D. does not have grandparents that we can call on for support. If his hours are cut he will lose his one to one care he needs. His seizures will become stressful for D. and myself as they occur several times a day without a pattern. He will be left in his chair a lot as I am unable to lift him unaided. He will lose out on this baths that he loves, physical stimulation and play time that I cannot always commit to - as I also run a house and care for his 5 year old sister. If D.'s hours are cut this will have a huge impact on me physically and mentally.

A. O'C., Cork

A. has a life expectancy of less than 12 months and we both care for her full time at home. We use our Jack & Jill hours one day per week and this enables us to get through the other 6 days. Cuts will impact on A's quality of life at home and on our family life also with our other son.

M. O'S., Cork

The support we get from our liaison nurse Eilin is incredible. She's always there when we need her. Jack & Jill hours take the pressure off for a while as M. is 24 hour care. A charity everyone should support – especially the HSE!

A. K., Dublin

The end of Jack & Jill hours means we will be back to where we were before we came under the Jack & Jill umbrella - exhausted and with less "normal" time as a family with our two healthy children. Jack & Jill support is a life line particularly for families like ours who have no family support.

E. C., Dublin

I truly depend on my Jack & Jill nurses every week. I'm a single parent with a palliative care, very sick child. My nurses actually save my sanity at times. The impact of my nurses being cut would be terrible and I would not be able to have some form of life and my only option would be to leave E. in hospital for care. Myself and E. depend on Jack & Jill for a better life.

R. B., Dublin

My daughter has global developmental delay and intractable seizures. She cannot walk, talk or eat and is fed by peg tube. She needs full time nursing care and is medically very unwell a lot of the time. The only real support we receive is from Jack & Jill. The nursing hours from them are a lifeline for us and mean we can have a break from her care for 8 to 10 hours a week. Without this support it would make our already difficult lives very difficult indeed.

T. M., Dublin

Jack & Jill support is very very important for us to survive as my wife's health is already not good and Jack & Jill care is very helpful. If Jack & Jill's support was not there then we all would have been in deep trouble health-wise.

V. C., Dublin

Jack & Jill support is a big physical and mental relief for me from 24 hours care around my daughter V.

L. McG., Dublin

The Jack & Jill support is a great help to our family as L. needs constant care and with 3 older children up to 5 years of age it means we can spend a bit more time with them. A specialist nurse is the only babysitter we can get for L. as she would know how to react in an emergency situation.

T. W., Dublin

The Jack & Jill support arrived on my doorstep 3 ½ years ago at which stage my son T. was really ill. I could not drop my other child to school or go for a bottle of milk if I didn't have this support. The simplest thing could not have been done without it. Our whole lives have changed dramatically but we learned to cope through the aid of Jack & Jill. So to sum it up, "the Jack & Jill Foundation was my Guardian Angel" and I would not have survived without it. It gave me courage and strength to care for my son with good support.

A. K. R., Dublin

I said Jack & Jill is a big big support for me especially to my daughter who's been diagnosed with unusual syndrome. Don't know what to do without this Foundation. Really really want to say a million thanks for the support.

G. K., Dublin – I don't know if my child will end up back in hospital in 2011.

B. M., Dublin

I am a lone parent and sole carer of B. who sustained Hydrocephalus at birth as a direct result of a forceps delivery. I have no support from my ex partner. My parents are both dead and my family don't help me at all. Jack & Jill give me an allowance which enables me to get out one night and one day a week. Certainly would not be able to cope mentally without this time off which keeps me sane.

B. B., Dublin

My Jack & Jill hours are so important - it's hard to explain. I can't leave B. with anyone else really who is qualified. It is crucial for our sanity and peace of mind. This organisation is a vital part of our lives and has given us more support, advice and help than the HSE.

M. B. Galway

Jack & Jill Foundation is a great support to me. My son needs specialist help and I can't leave him with anybody for a few hours. I really need the hours I have.

T. M., Galway

It is an invaluable support. Without our few hours it will be extremely difficult for us as parents to cope mentally and physically with T.'s daily demands, as we also rely on it heavily for our time as a couple to cope with the loss of his twin brother.

L. M., Galway

Our daughter L. has a brittle bone condition that means her bones are so fragile she could break them if she were lifted incorrectly. Apart from my husband and I, there are a handful of people trained in L.'s care. Without our Jack & Jill funding I cannot imagine how we could manage to avoid hospital stays for L. should my husband and I require respite. The only assistance with L.'s home care that we have received since her birth has been from the Jack & Jill Foundation. We have not received one hour from the HSE. When L. has a fracture, thanks to assistance from Jack & Jill, we have been able to nurse her at home. I have home based oxygen concentrates for L. and all the equipment necessary for splinting her limbs when she breaks them. Without financial support to pay nurses and carers to help us with L.'s care, the entire burden would fall on my husband and me. Because of Jack & Jill, we have managed to continue to do some "normal" things in the past few years, such as getting to family weddings or out for a meal on occasion. It is these things that keep you going when you are responsible for the care of a hugely dependent and vulnerable child.

A. L., Kerry

Jack & Jill is an invaluable respite service for our family. A. needs a lot of care and services and I need a few respite hours to recharge my batteries. She has upcoming operations on her hips and we need a lot of after care. We also have to modify our house which takes a lot of planning.

E. O'C., Kerry

We are currently receiving 20 hours Jack& Jill a week which we feel is essential to E.'s care. E. requires 24 hour ventilation and supervision and any cut would have a huge impact on us all. The Foundation has been amazing and we couldn't continue without it.

T. L., Kerry

T. spent his first six months in hospital (Tralee & Crumlin) and without Jack & Jill's help he would have spent a further year in hospital. We are so grateful to Jonathan and all in Jack & Jill. They help us cope through the tough times.

M. N., Kildare

The Jack & Jill support is a very valued assistance to our family. This gives us a break from the everyday stress and worry that comes with a child with special needs. Unless you are in the position of a parent/sibling no one has any concept of the enormity of the challenge of raising a sick child with severe development needs.

R. J. K., Kildare

As R. is now 4 she no longer receives any hours from Jack & Jill. This has had a huge effect on us because R. really enjoys spending time with Michelle (carer) and I enjoyed doing things on my own as R.'s Dad spends most of the time away working so I don't get much time to myself. I need to do housework and shopping that can't be done while I have R.

S. W., Kilkenny

The Jack & Jill support means a great deal to our family. If the hours hadn't been available to us it would have meant S. attending hospital for regular stays when he got sick.

E. M. L., Kilkenny

By Jack & Jill getting cut it will impact me because it won't give me the few hours a week to get my education.

L. R., Laois

Quite simply Jack & Jill has changed my life. Before Jack & Jill I rarely got out of the house, especially if the weather was bad because L. couldn't go out. L.'s twin brother S. now benefits too because he gets to spend some quality time with me – time that he doesn't get when I'm looking after L. The nursing and respite that we get means everything to us and the advice and comfort we get from our liaison nurse is invaluable and lets us know we're not alone.

T. F., Limerick

We have just started to receive support from Jack & Jill and already we have noticed a major impact on all our lives in this house. The highly stressed / pressure we feel as a result of T.'s ongoing needs, the full time assistance that she requires is eased some little bit purely by the period of time each week we are more relaxed and our lives have "normalised" a little bit, particularly in respect of our other daughter. The hours that Jack & Jill give us allow us to give a little (well deserved) attention to our other daughter.

P. D., Louth

Jack & Jill provide great support, care and respite. It gives us the opportunity to concentrate on our other children knowing that P. is well cared for by a trained professional.

R. F., Louth

Jack & Jill support means we can cope with very little sleep and little time for our 3 and 5 year olds during the week because we're not on our own. Our nurses come in and we can catch up on sleep, life with C. and A., housework, work and normality knowing that R. is being loved and cared for at home. Reduced hours will impact on our mental, physical and emotional health. Having Jack & Jill support gets us through the really dark tough hours, days and weeks. Without them it could be hard not to get swallowed up by exhaustion, grief and depression.

R. K., Louth

If our help from Jack & Jill is cut to me it will be less time for my older son and a lack of time to live daily, such as visit the doctor, the pharmacy etc. My daughter R. requires much special care which also means that there will be no time for any rest.

M. W., Mayo

Baby M. is a Down Syndrome baby and has heart and bowel problems etc. She can't drink herself and ever since she was born we're up and down to hospital. Never stops. Even when she is home we're often at the GP. I'm a single Chinese mum and I have no family members or friends help. I really need the help and support from Jack & Jill.

A. R., Meath

Jack & Jill's support has given me the means to have a shower, do shopping and spend a few hours with my other children. It is a lifeline to me and to lose it would be devastating to my family. Thank you Jack & Jill.

E. A. H., Monaghan

Jack & Jill mean the world to us. We only have one other person that can look after E. that's her granny and she works a five day job. So it's not fair to rely on her. Plus we're expecting a new baby.

B. B., Roscommon

Having B. turned our family life upside down. We were so lost until we met them. Jack & Jill gave us back some normality in our lives. People forget how a special needs child affects their siblings' lives so thanks to Jack & Jill we can do normal things i.e. cycling, cinema, shopping with our daughter.

L. D., Sligo

Jack & Jill are the support that defined taking my son out of hospital to go home where he belongs. The do not only provide hours but they provide advice and are able to answer a lot from experience. Without Jack & Jill the big weight on my family and my shoulders would be a lot more unbearable. Without Jack & Jill the stress would definitely rise and would in turn decrease the quality of care we would give L. and to ourselves.

L. J. M., Tipperary

L. is a very complicated case. He remains on the profound to severe end of the scale and is a 24 hour job. He still has not been diagnosed as his condition baffles doctors, without the support of Jack & Jill we would be lost.

N. Mcl., Tipperary

N.'s needs are multiple and she requires 24 hours supervision. This is provided by ourselves supported by HSE night nurses, Enable Ireland and Jack & Jill. Our Jack & Jill are indispensible.

K. F. B., Waterford

My nurses are my life line. Some days I count down the seconds until they arrive. As K. is getting older it's getting harder to take care of her and without Jack & Jill I don't know how I will cope.

K. B., Waterford

Our son was diagnosed with a terminal illness in June. Jack & Jill have been a tremendous support to us in helping us cope with this diagnosis and also providing for baby K's needs. Two weeks ago K. was in Waterford Regional hospital but thanks to Jack & Jill we were able to take him home from hospital after a week and are now looking after him at home with their help.

M. H., Waterford

M. needs care 24/7 and the support the Jack & Jill provide to our family is without question very much needed. M. is at risk without the help of Jack & Jill full stop.

E. D., Westmeath

The few hours every week mean a lot to our family. As we are so busy with appointments for E. - up to four a week - we don't get much time to spend with our 2 ½ year old or to just have a break or to go to bed for a rest. It's such a rollercoaster of emotions when your child is not well and a little break every week could be the thing that keeps you sane.

R. Q., Westmeath

I am a single mother who works part time to support my child. Jack & Jill has given me a "life boat". Otherwise, I would have drowned. Jack & Jill has been a huge support for me because it has given me a break from my daughter and made me feel human again.

C. McC., Westmeath

Jack & Jill's nurse has meant everything to our family. It has kept us "sane". The last 2 weeks the nurse has not been able to come due to very bad snow and I am lost without her, feeling depressed and very down and cannot leave the house. It has made me realise how our life is made so much easier by Jack & Jill and I don't think we would cope as well without her.

J. P., Wexford

J. is not receiving critical care but we lost a daughter last year and the liaison nurse was an absolutely incredible support to us throughout that. She became aware of J.'s special needs through that and has done her best to provide us with any help/support she can. Jack & Jill are the only emotional support we've had at all. They are invaluable.

C. C., Wexford

Without Jack & Jill's help and support I'm not sure C. would be back in hospital, but I'm almost certain that I would be. Jack & Jill's help is invaluable.

A. K., Wexford

Without Jack & Jill's support and help to my family I do not know how we would have coped. A. was born 11 weeks premature and is one of twins. She was diagnosed with Cerebral Palsy 2 years ago and cannot even stand. It is so upsetting and disheartening to think of all the money that is squandered in this country and Jack & Jill cannot get the support it needs.

C. H., Wexford

I use the Jack & Jill money to pay someone to do essential physio with C. Without this money he will miss out on hours of physio and I cannot afford to pay for it.

M. G./O'G., Wicklow

I will not be able to work part time to pay our bills and we are already in financial difficult times. We must stay healthy for our baby as he requires 24 hour care. If our Jack & Jill hours are cut I'm terrified M. will end up in hospital.

<u>Part 3 - Comments from the 44 parents (34%) who replied "No" if their Jack & Jill hours were cut their sick child would not end up back in hospital in 2011.</u>

Z. D., Carlow

Until Jack & Jill started supporting us we were hitting rock bottom. My husband and I never had any time together. We never had a full conversation after Z. was born, unless it was about Z. We were stressed, tired, frustrated and even our other 2 children suffered as we didn't have time for them either. Since Jack & Jill started supporting us our family life has improved so much and even Z. is better as we are more relaxed to deal with him. Thank you so much to Jack & Jill for everything.

K. H., Cavan

The money that is kindly funded for K. has helped us as a family, with myself getting a break and being able to spend more one to one time with K.'s one year old brother, time that he doesn't get with K.'s special attention that he needs. The money funded for K. has also brought him on with the one to one he has been getting. As a single mother and with K.'s needs it sometimes gets hard, and your help has made me feel more recharged in myself. My aunty who minds K. has brought him on in areas such as his speech and that quality time away from Mummy does him the world of good, with him being very much a child who is shy and sometimes withdrawn. I can't thank you enough for what you have done for us as a family.

I. K., Cork

I. is extremely medically complicated. He gets sick a lot and ends up in hospital extremely often, regardless of Jack & Jill care. I want to stress how important Jack & Jill is to families like ours. My husband and I take care of I. 24 hours a day. I. can't be alone for a minute. More often than not we are up all night too. I am lucky in that my husband's job up to now has allowed him to work from home. Jack & Jill have been a blessing that words can't express. The nurses have supported us through times that no family could cope with without support.

A. O'M.. Cork

Jack & Jill has been our lifeline since we received your help. A cut in hours will lessen time spent doing household chores, shopping & time spent with other children. However, we fully understand the current funding situation & will accept any reduction in hours that may happen.

C. G., Dublin

C. is blind and isn't able to do anything for herself. I also have a 4 and 5 year old at home and it's very hard to make time for the others, with all C.'s needs. So we depend on Jack & Jill hours for some time for the other kids.

B. P., Dublin

Jack & Jill provide a service to families with special needs that provides the help and time for not just the sick child but the entire family, ranging from care provided by funding and also the help of the liaison nurse that is so crucial that words can't express the help they provide.

H. R. M., Dublin

Jack & Jill mean so much to us, without them life would be so much harder. It allows us to have some special time with our other children, to feel normal for a while and do the simple things like shopping and paying the bills. It means so much to have these few hours a month. Without them I don't know what we would do.

J.P.G., Dublin

Jack & Jill provide excellent support and the quality of care is brilliant indeed. We really worry when the Government won't support an organisation like Jack & Jill and we can't imagine why Jack & Jill should be forced to cut their support through lack of funding.

G. B., Dublin

I get good support from Jack & Jill and I can afford a child minder for 5 hours weekly only because of Jack & Jill.

J. L., Dublin

Our baby has severe brain damage with a very short life expectancy. It is likely that J.'s care may become more demanding and our future is very uncertain.

N. D., Dublin

My son is diagnosed with Charge Syndrome with long term medical needs. He has significant developmental delay and feeding difficulties. He is attending Enable Ireland. I also have a 2 month old baby, so I mostly rely on Jack & Jill hours to manage him along with my other boy, especially when he is not settled in outside respite services, where he refuses to take his feed. Child minders giving similar service are very expensive and we cannot afford that. So from my son's, and as well as our point of view, he is more happy and settled with Jack& Jill care nurses and we are very grateful and thank you for all your support.

C. McK., Dublin

The 2 nurses allocated to us have been life savers in terms of giving me – C.'s mum - some much needed reprieve from PEG tube feeds, changing colostomy bags and post surgery care (8 operations in his first 16 months, with a further 3 planned in 2011).

M. McD., Dublin

Jack & Jill Foundation provided us with the answer when we found out that our child was severely disabled and that the State would not provide any solution in regard to childcare. If Jack & Jill had not been there I would probably have got depressed and needed extensive medical leave. If they are not able to support other families, I fear that we will have many more broken families of people on carer allowance when they actually want to work.

A. M., Dublin

The Jack & Jill support has been a huge financial help in allowing us have more one to one care for A. which has meant more essential therapy which is crucial for his physical progress.

M. F., Dublin

M. was in hospital for the first 18 months of her life. Jack & Jill were the first to let us have her home. We can't tell you how we felt the very first time we had her overnight at home. We will be forever grateful. Jack & Jill support means everything to us.

K. O'B., Dublin

Jack & Jill's support allows us to have a carer that we would otherwise struggle to have, and allows us the peace of mind that K. is being well cared for during her very bad episodes. This is something that a hospital could never provide for her as she needs constant care when in acute episodes.

K. C., Galway

To have a child with special needs gives you very little time to yourself. A cut in Jack & Jill takes away that simple luxury – time to yourself. There are a lot of families who don't have a good network of support from family or friends and I believe having the Jack & Jill Foundation as part of that support has helped a lot of parents from spiralling into depression.

J. W., Galway

The support of Jack & Jill has allowed us to take much needed and invaluable time away to recharge our batteries and spend time together, knowing J. is in good hands. Not having family living close by means we lose our only support if Jack & Jill is cut.

C. P., Kildare

We have lost all our Jack & Jill support. This means we have no chance of any respite. So myself, my husband and other 2 children (1 of whom also has special needs) continue to try to cope as best we can with no sign of a break any time soon. When we had Jack & Jill support there was a chance for myself and my husband to have a break ourselves and also to spend some time with our daughter A. and our other son A.. Now we just stumble from one day to the next, and one night to the next.

E. H., Kilkenny

Jack & Jill are my lifeline. I'm the only person in my family who can use the machine to feed E. She doesn't travel well in a car on her machine. I went to a funeral last Saturday in Dublin and I would not have been able to go without Jack & Jill. They help us to have a normal family life.

J. B., Kilkenny

Jack & Jill are the best thing to happen to us, especially when J. was very very sick. We are able to pay someone to mind her (professional) which is great peace of mind. I am a lone parent as I cannot work with J. Losing Jack & Jill will mean I will have no help as I could not afford to pay it myself.

L. K., Kilkenny

Jack & Jill provide the support which all families need with a sick child who needs qualified medical attention. Family and friends can't support you. The chance to sleep or take our other child off for a few hours is essential.

R. M., Kilkenny

Jack & Jill support has been a lifeline for us since R. was born. Without it, I have absolutely no doubt that we would have been unable to cope. It has helped to keep our family together during very difficult times especially our boys who know that for a few hours every week they get a little bit of normality with Mam and Dad.

B. C., Laois

Jack & Jill is a life line in what can be a difficult life with a special needs child. It's a chance to get out of the house for a break and a bit of normality, because of the nature of his problems e.g. feeding and because he is floppy etc you can't leave him with most people.

K. D., Longford

I very much appreciate the help I get from Jack & Jill. Even though K. is not a sick child, I am very saddened to read how the government is treating you and if my hours need to be given to a child less fortunate, that's no problem. Thanks for everything.

H. B., Limerick

Jack & Jill nurses have been a massive support to both H. and us his parents during a very difficult period of his life. They brought such a standard of care for H. and allowed some normality into our lives for those precious hours.

C. G., Mayo

If the Jack & Jill hours are cut it means myself and my husband would get no free time as the girl I have through Jack & Jill is very flexible and tries to accommodate our needs to the best of her ability. We would be lost without her as C. has a sister with needs as well and the girl that comes is brilliant with her too.

C. B., Mayo

None of my family knows how to do C.'s physio. My nurse knows how to practice physio, OT and SLT. This is so important as C. is really low toned. He also needs to be lifted very carefully. Jack & Jill hours mean I can get some things done around the house and spend time with C.'s older brother. Without my respite hours I would be under huge pressure and strain.

M. C., Mayo

Jack & Jill support means a lot to me because I can have a few hours to myself. M. needs a lot of attention and the only relief I get are the hours I get from Jack & Jill.

C. T. M., Meath

Jack & Jill has helped me and my family to have a small break from our very hard and busy life looking after our son C. who has a severe and rare syndrome and needs full time care as he will never be independent. Thank you Jack & Jill. I wish there was more I could do for you.

P. B., Monaghan

Although P. isn't a dangerously sick child, as some of the Jack & Jill children are, he still requires 24 hour care, as his physical disabilities mean that he has no ability to do anything for himself at all. The respite care from the Jack & Jill funded nurses has been an absolute lifeline to us, to know that P. is being well cared for, with all his feeding and medication needs being met by a competent and trained professional. This gives us great peace of mind and a short period of much needed respite. We do not know how we would have coped without Jack & Jill.

S. McD., Offaly

The Jack & Jill means a lot to me and only for them I would no longer be able to spend time with my daughter A. The nurse looks after S. twice a week so that's the impact on me.

A. McD., Roscommon

Jack & Jill has been a new life line for me, giving me back my life for the first time in 3 years. Having a few hours to myself during the day means I sleep at night. I have a better quality of life as does A.

K. M., Tipperary

I get 5 hours per week which allows me to go to the Post Office, bank etc. Had waited 6 months to get to a dentist appointment as I had nobody to mind my daughter and my husband could not take any more time off work.

H. C., Tipperary

My son has Cerebal Palsy and he needs special care. Having Jack & Jill support helps so much just to give us some respite. Having hours cut will mean less help for us as parents.

D. D., Waterford

Jack & Jill are a wonderful charity and without them we would have no break at all. They give us the chance to have time to ourselves or the chance to catch up on housework or normal everyday chores/activities. For example our child can't sit unaided so it would be impossible to do the grocery shopping with him as he is too big for the baby seats in the trolley, but could not sit upright in the normal trolleys. Having Jack & Jill allows us to do a simple task – like shopping.

R. M., Waterford – Just ticked the No box.

I. D., Waterford

I can have a break having time for me to recharge my batteries. I've learnt to let others help.

M. R. O'C., Waterford

Our daughter is 4 in January 2011 and we will no longer be taking Jack & Jill support. Our daughter's illness is no longer as much in need as your other children. We wish to thank you sincerely for your invaluable support and we would not be this far without you!

I. K.. Wexford

The Jack & Jill hours we get allow us to spend quality time with our other children and know I. is being looked after well.

L. F., Wexford – Just ticked the No box.

C.G., Wexford

Jack & Jill has been an invaluable service to us since April 2010. This followed the birth of our third son Cr. Our second son Ce. has Down Syndrome and has significant medical problems meaning he is sick a lot. Given how busy life became in April Jack & Jill ensured that Ce. got to attend all his appointments which are hard to come by and was given opportunities to learn and practise new skills which help him to reach his potential which is the least Ce. deserves. It also meant that Cr. got a chance to have his basic care needs (as harsh and that sounds) met. There is no doubt that without the support of Jack & Jill, Ce. would have been left unstimulated and unable to attend appointments and Cr. would have seen very little of Mummy not withstanding the significant stress his Mother would have endured. Thank you Jack & Jill, we are indebted to you.

S. M., Wexford

My son no longer has acute medical needs thankfully. However he requires adult supervision/care 24 hours because of global developmental delay due to his condition. His behaviour can be extremely challenging and Jack & Jill support has been invaluable and the only additional / outside service we have received. The HSE have offered us a service 1 day per month in Wexford town which is 30 miles away. It appears to be a drop in type service at a facility which caters for all ages of child and I would be concerned about putting S. in such a facility. I also believe the modest amount it would take to subsidise a few hours care here in our own home would be far better.

J. McC. (B.), Wicklow

Having Jack & Jill helping us means we get to spend time with our children. Looking after a child with a disability is a full time job. Spending the first year of my daughter's life in hospital meant I was away from my family.