

Relationships

All normal relationships experience a range of demands and stresses. Having a child with a disability brings additional emotional and physical demands to a relationship.

A couple that have been planning their family may feel that their dreams have been shattered. This was not the baby experience that they were expecting. The grief around the loss of this “family dream” can be great.

Either partner may withdraw emotionally and be less available to the other partner as they struggle with their grief. These losses may be compounded by the loss of social opportunities, friends, careers and jobs in order to provide the necessary support to one’s child. Financial demands increase to cover costs of medical intervention, therapy and equipment.

For some couples, the ultimate outcome is an end to their relationship as they struggle to deal with their own emotions and to provide their child with the needed services and supports.

For other couples the emotional and practical challenges bind and strengthen their relationship as they embark on this difficult journey together. Couples who feel that they are able to face these challenges together express the importance of close communication and time-out, both as a couple and individually.

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There is a whole more stress in your life. Everyone has stresses but it is an extra one. You can't have the family you wanted or do the things you wanted. You don't do things that other people do or things you thought you would have done. There is a lot of financial strain. No one has a charmed life and who knows what other stresses would have happened? You deal with your life as you can.

My husband makes sure I have time-out and I make sure he has too. We do get a bit of time together, but not as much as we would have done. I play golf a little bit and bridge, whereas I would have been working if I did not have a son with cerebral palsy. I would like to work a bit. I never wanted to work full time as a mother, but I do think I would have worked a bit.

With my husband, it has both strengthened the relationship as well as weakened. Strengthened only because you have to. Weakened because all conversations are around our son, or interrupted by him. Most fights are over him, and most of the spare time is spent with him. It always comes back to him. It's hard, because when you do have time together you are so tired and in a zombie-like mode. We argue like most normal couples, but over different things. It's important to have time-out - make sure that you each have time to relax and breathe.

It was like we were punished, but it didn't happen to me. It happened to all of us - the family.

At first my husband and I didn't deal with it together. We had our own ways of dealing with it. It probably brought us closer.

My husband takes the back-burner a bit. Sometimes he says, 'Oh, you know... what about me?' He tried to be stronger than me. He was sort of, 'Oh, don't worry', you know. But I know deep down... it's a hard thing. Very hard.

Every book I read says that a majority of marriages end in divorce. Our daughter is a great kid but she is very time consuming. Other kids her age will dress themselves or brush their teeth but we are doing all those things for her. She is a very messy eater but very determined to do it herself - so there are all those issues of how you deal with that. Taking her out for dinner, she can become very loud at a restaurant or anywhere really. Then you start dealing with other peoples' reactions to her.

Apart from that, it's the time involved. It takes time away from your partner. With a normal kid you always have the main issues on how you discipline your child. With our daughter, it is completely different issues. You and your partner will have very different ideas, so you're always dealing with that.

I was working at the time, but I found after a while it was too much for my partner to bear on her own. So I made the decision that we spent pretty much the next three and a half to four years with him everyday doing what we needed to do. That was our decision, but I think that it did take its toll on our relationship because we're not together now. We still have a very, very close relationship. It's still pretty much the same priorities there, but we are not together as a couple.

As far as family relationships, it's gone either way in my experience. Sure, all the family are very loving towards my son, but with grandparents... you know the love is sort of there but the acceptance in some respects?... They can't have their grandson come over, jump in the car, go to the movies. It just makes life hard... [With Aunts and Uncles] there is no sort of, 'Why don't you come over and play with your cousins'. We've sort of become the unmentioned.

It is so different to what I have experienced with other families that have children without any particular problems. The relationship is there, the love is there, but there is a lot of misunderstanding of how difficult 24 hour supervision is They are just unaware of the responsibility and not normally prepared to take it.

It hasn't made any difference to our relationships really because she just fits in. Friends come around after school. Just the fact that she goes to the local school is great. She has sisters a year older and in the year above, so all their friends know her and they are all really nice to her. She is such a little mush bucket. She'll go, 'Oh hello. I love you', and they'll go, 'Oh, I love you too'.

There was a lack of understanding and sympathy from my child's father (my husband). We are now separated.

I think it made us stronger. We wanted to do things together. My husband never told me, 'It's your fault'. He's different to me. He doesn't say much but he will go along [with what I want to do].

We were married very young and our son was born when I was 22. My husband has always backed any decision I have made about our son. If anything, it has made us stronger. We both need each other's support.

We have nearly lost our son twice, so we greatly appreciate the good times. We understand that we both feel overwhelmed, devastated and grieve for what could have been.

There was sort of a bit of frustration in the beginning because we both didn't know what to do and how to go about it. But I think communication is so important. Once you talk it through and compromise... It's up to the stage where it is just great. We work as a team and that is how it should be. But also the fact that we were never in denial from the beginning. That's also very important. It took a while for my husband to accept it. But not long. After that it was fine.

It's interesting, because when the paediatrician told us the situation with our son the day after I gave birth, my husband collapsed in a heap. I had never seen him that way before. He was quite upset. Understandably so, but for some reason I held it together. I thought I've got to do this for our son. I suppose that's why I suddenly fell ill soon after.

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Tips for relationships:

- Set aside some time to be together as a couple and also time to pursue your individual interests.
- Accept that you will have differing viewpoints and different ways of handling situations at times.
- Recognise and acknowledge each other's contributions to the family.
- Listen to one another – whether the communication is spoken or unspoken.

