



Time together - Time apart

carers talk about respite



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Carers Victoria Respite Connections

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Foreword

These stories are deceptive. Ten stories, 13 carers. Conversations around the kitchen table, chats over a coffee and a tape recorder. Mostly relaxed, mostly good humoured and even wryly amusing. While it is the carers' voices we hear, we also feel the presence of the people being cared for. There are some happy memories and some satisfaction about a job being done well and without fuss.

But these stories will creep up on you. You will find yourself thinking about some of the things these carers have said: a respite house is judged as good simply because nothing bad has happened there yet; a carer believes that the system has been deliberately made complex so that carers will give up and *'then they don't have to put you on the case list'*; the mother of a very sick child is advised to *'turn the machines off – it is not worth it'* but refuses, fiercely proud of her little miracle daughter.

We hear some very private things: a mother asks her 16 year old son *'what did you tell your mates you were doing?'* as he puts her to bed. A husband is irritated about having to fetch and carry. A mother battles for months with her guilt for a single evening alone at the movies. An elderly couple struggle with their guilt about years of overlooking their able bodied child in the maelstrom of care for their daughter. A mother reflects on the fact that if she were only able to pay for the services herself, she would at least feel in control of them. A father worries about discussing feminine products with his daughters. As three older mothers share a cup of tea, we hear about stress, deep sadness, lost friends and rejection by family.

We also hear some bold assessments about the system that is only partly propping up their families. *'Take my advice!'* we are told, and we do listen. These carers know.

So we hope you enjoy these stories, but be warned: it is not all cups of tea and a chat. In the words of one of the carers, *'brace your heart'*.

Janet Shaw
Manager
Carers Victoria Respite Connections

The history

Time Together Time Apart – Carers talk about respite is a collection of carer respite stories that has been a long planned for and much awaited important project for the Disability Team at Carer Links West.

It grew from the knowledge that all Carers had stories to tell and experiences they wanted to share. We know that sometimes the best and most salient information is often by word of mouth, often from real and raw experiences.

To all the carers who participated so generously of their time, their experiences, and their hospitality to allow us a small window into their world, I would like to say thank you, it is not always easy to publicly put your personal life out there for others to read about.

I know that this booklet will provide an intense and true account of what it is like to deal with the long term commitment of caring for someone – sometimes light-hearted sometimes quite involved and complex, but often done with grace and dignity.

It has been a privilege to be involved, to read the first raw transcripts and to assist in shaping the stories, we clearly wanted to be true to the ‘voice’ of each person and we hope that we have achieved this.

To all those who worked on this project, from the initial brainstorming of the questions, to the interviewing, the transcriptions, the rewrites, the editing and layout a heartfelt thanks for all your enthusiastic work.

Kathy Karaolis
Project Manager

Carer interviews

I was lucky enough to be given the task of interviewing the carers who agreed to tell their story for this project.

I travelled to ten homes in different parts of Melbourne's West, always a little nervous that my tape recorder would not work. The sheer diversity of this group of carers was surprising. I met older people still caring for children who are themselves now middle-aged. At the other end of the life cycle there were young parents caring for children with disabilities. Some were caring for husbands or wives while trying to sustain a loving, equal relationship.

Despite their differences I found that, of course, these carers had many experiences in common. They all spoke of the often humiliating need to ask, ask, ask – for help, for time, for extra money. The need to tell your story over and over again. Well-meaning social workers asking the same questions over and over again. Personal care workers constantly in and out of the house: helpful and necessary yes, but an invasion of privacy nevertheless. One recurring theme was the need to make endless phone calls – often when you are not quite sure what mysterious organisation might pick up the phone. It became clear to me that the challenges of caring develop resilience, perseverance and strategic thinking.

Like most people I have always thought of carers as compassionate and unselfish, but as the interviews unfolded I also came to admire their range of practical skills. Carers need to become masters of efficiency. They liaise with doctors, organise medical services and supervise medication. They co-ordinate timetables for care workers, activity groups and transport under difficult circumstances. They are also astute financial managers, making few resources stretch a very long way.

I visited ten households where carers were brave and generous enough to allow me to probe into some of their most painful experiences – all the anger, frustration and grief that can be part of a carer's life. But I took away a lasting impression of strengths and joys as well – the passionate love people feel for the person they care for and the pride in their achievements. And I also want to stress how much I enjoyed doing these interviews. Even in the most difficult situations carers tend to see the

funny side of things – in fact I often had to switch the tape off because we were laughing so much.

To all the carers who welcomed me into their homes, gave me tea and biscuits, and sat patiently while I experimented with the tape recorder – my sincere thanks.

Di Russell

Thanks

Particular thanks go to the carers who contributed to these stories:

Amber

Anthony

Dorothy, Marianne and Betty

Chi

Claudine

Helen and William

Liz

Pieter

Robyn

Sally

We value their generosity, their time and their openness in sharing part of their lives and their family's experiences.

This booklet has been published by Carers Victoria and we are grateful to all the staff involved, especially Kathy Karaolis for the overall project management, Di Russell for the interviewing and writing, and Jenny Craig for typing the transcripts of the interviews.

This project was undertaken by the Commonwealth Carer Respite and Carelink Centre / Carer Links West. By the time this booklet goes to print Carer Links West will have changed its name to Respite Connections. The references to Carer Links West throughout the book have not been changed.



Dorothy, Marianne, Betty

Dorothy, Marianne and Betty are widows in their seventies. They are primary carers for their children, now aged in their fifties. They participated in an interview together over morning tea. The three women are close friends – they all attend the Older Carers Group at Carer Links West regularly each month, and Betty supports Dorothy by driving her to appointments whenever she can.

Betty:

I have four sons and I live in Melton with John, my third son, who has an intellectual disability. We get along quite well. Two sons live in Bacchus Marsh and the other boy lives in Maidstone.

Dorothy:

I live with my handicapped son, also John. I have been here about twelve years now. We were in West Footscray before, and we came here to have John nearer to his elder brother Alan who lives just one court away from us. My husband passed away in 2004 and since then I have been alone with John, but we manage quite well with the help of my family who are just around the corner.

Marianne:

I live outside Melton on a sort of farm next to my other daughter. My handicapped daughter, Margaret, lives with me and she is fifty-six years old. My husband passed away sixteen years ago and I have been looking after Margaret ever since.

Betty:

John is easy to look after because he speaks quite well and he knows what goes on. We don't have a lot of visitors and I don't know if that is because of John. His brothers treat him quite well but it could be better, and as far as any other relations I don't have any support, we manage on our own. I've found that you lose your friends, you don't go out very often. You get stressed, you get very stressed. You have just got to look after them, you have got to deal with it and look after them.

**'You get stressed, you get very stressed.
You have just got to look after them...'**

Dorothy:

My John is a bit hard to look after at times. When I had his father with us he did most things for John.

Right from when I first had John I felt quite isolated by the family, and was even told by a family member that they couldn't handle *'that type of thing'* and so they wouldn't see much of me from there on. This seemed to apply to most of the other family. Then when my husband died — well I never thought I could cope with John — but you learn somehow to go on, knowing that while you keep going they keep going. Alan my other son is pretty good and comes around quite often. But I was very isolated. And then I met my friend Betty — she drives and I don't. Betty has been a wonderful help to me, I wouldn't be without her.

Marianne:

I am in the same situation. Margaret and I get on very well, and I have got my other daughter next door. She helps, but then you can't expect too much because they have got their own family. She has six children and grandchildren. If I need help she is there. I don't get many visitors and I take Margaret out as much as I can.

There are days when you are down in the dumps but what else can you do? Especially I think when there are birthdays and weddings, you know, you go without your partner. The same at Christmas, they always invite me but you don't feel...everybody has got their partners and sit there and you just feel sad.

Betty:

I don't have any council help, I don't really need it just at the moment, we just manage on our own, until I'm unable to do it. John goes to

Merrimu four and a half days. It's very good. I don't really know what I would do without them.

Dorothy:

John attends Merrimu also and I find that is great. He also goes into residential respite on occasion, but that didn't start until I became ill in 2002. I was very reluctant to try it at first because John had never been away from home in the thirty-seven years up until then. The first time he went I was very worried about it, worried for the staff and John, but it seemed to work out all right. We got over that weekend and since then I have let him go every so often. He is a bit more difficult to look after at times and they have said that he has autistic tendencies. But I do have council help since my husband passed away, I have someone come in and do the floors and things for me, and a couple of times a week I get meals for us. John now has a case manager and goes out with someone after school. He goes to watch the bowling, he doesn't play himself. But without these supports I think I would be quitting.

Marianne:

I don't have any council supports at all. Margaret goes one day to Merrimu, one day she goes to a program activity group and the other days I take her out. She used to go full-time but she got very sick and had to stay home for more than three months.

Betty:

I don't use facility-based respite services now. John used to go to respite, but he wasn't very happy. I don't really know the reason why he stopped going. I don't know if it was that he liked his own bed or that he didn't like the clients he was with because sometimes they weren't really compatible, but he just refused to go. Before that he went for about three or four years – he used to go about every three months on a regular basis. Now I just rely on Carer Links West and People Outdoors. Also we have a group up here called CALM through Melbacc, and they take them out.

We are going away again through Carer Links West at the end of April. They organise this with People Outdoors – last time we went to Sunnystone, a school camp in Bacchus Marsh. I go with John, and they have paid workers to look after them while you do what you want to do yourself. You have nothing to do with them – you are free as a bird. They take them out one day and we stay back at the camp, and then

the next day we go out somewhere and the kids stay back at the camp. They do crafts and it is very good, very good, it is as good as a holiday. We just relaxed, we had no worries, just doodling around the shops while they were looked after.

Sunnystone was very nice. It was a big old brick building, and they had lots of girls and mothers there, and bunk beds. It was very nice and clean and had television. Your breakfast and meals were all lined up and you just helped yourself. It was all there for you, and no dishes to be done either.

In April we are going away with the CALM program. It is a house in Portarlington and I haven't been there before, but I hope we get the same deal. There are two weekends – the first weekend the carer goes with the child and the second weekend the carers are supposed to be going on their own, but I can't.

Dorothy:

I don't use the same services as Betty does because John is more difficult away at night – even in respite, he has very restless nights when I have sent him away for the weekend. That's stemming, I think, from the fact that he had to be with strangers.

Marianne:

Break, what break? I haven't used respite for years and years. It was all right for a couple of years but then my daughter got 'change of life' and got very, very sick. I put her there once on a Saturday and they let her walk up to the bowling area by herself, through the traffic lights. Since then finish – no more. It has changed now, the people have changed, but she doesn't want to go. Now I go everywhere with her.

Soon we are going on the camp through Carer Links West with People Outdoors. It will be the first time and I am getting a bit worried. But the staff there have been very nice. Jenny came out last week and interviewed me about what Margaret wanted to do, what she is able to do and what medication she needed. She told me that they have got somebody to make her relax and look after her, because Margaret is very quiet. She even asked what food Margaret liked.

Postscript: Marianne and her daughter went on the camp and enjoyed themselves thoroughly. Her daughter said she was really looking forward to going to the next camp on her own. She went along to this second camp with friends from Merrimu and had a wonderful time.



Betty:

The staff at the camp are all organised. When we went the first time they had games for the children to play and their craft was all ready – it was very good, I was very pleased. They also prepared a little book of what we did at Sunnystone camp. There is a nice photo of John feeding a lamb, which was very exciting. Each of the workers who was there has written a little piece on what we did and there is actually a photo of myself in the back.

In the very early days when John went to respite I felt very nervous about him going – whether he would be looked after or dressed properly – all those sorts of things to worry about. My husband had passed away and Michelle came around here one day and she said, ‘*John should go into respite to give you a break*’, and that’s how John came to go. But otherwise I probably wouldn’t even have realised there was anything like that around. You don’t realise those things are around until somebody comes and tells you that it is there.

‘In the very early days when John went to respite I felt very nervous about him going – whether he would be looked after or dressed properly – all those sorts of things...’

Dorothy:

I don’t take my son on those sorts of respite holidays at camps. That is because John had a traumatic experience in hospital. He had a skin cancer on his mouth and because they wanted to stop him pulling out the stitches they restrained him to the bed for some time. Now the doctors and I feel that because of that experience John is very reluctant to settle in another bed. I don’t want to put other clients, parents who are there to enjoy a long weekend, through a night that might be disrupted continually, so I stick to just going to the facility-based weekend respites away for John. I was reluctant with that at first but they have reassured me now, and I cope much better with it since they told me that whatever situation came to bear they would have people who could deal with it. So now I’m more able to let go.

I tell myself now that people are there to handle John even better than I can, and that I should take the opportunity to renew myself a bit so that when he comes home I can cope again, and cope until the next time. So now I’ve gotten quite used to it, and marking clothes and sending him off, and I do it routinely. We haven’t had any issues with the respite so far. They have just said, ‘*He behaved okay*’ or ‘*We were expecting*

some trouble in this way regarding the nights', but they have never said that it has become a real big issue. They have never said anything like, 'Oh he can't come again' or 'He must go in with people who are the same' – no they haven't done that.

I have been happy with the care he has received and my respite bookings have gone fairly smoothly. I like to send John once every couple of months or three months, but I have been told I could get a little bit extra should something come up like a wedding I would want to go to, but that is not very often. I don't send John overly much, but without it I would find the going very difficult. John is big and strong and I have to do all the things now that my husband did for him – shower him and shave him. I didn't think I would cope, but you learn to cope, and according to my other son I'm doing it fairly well.

I also have a lady from the council who comes while I go off on a Friday to a combined pensioners' social day. We play bingo there and at the present the council bus is taking me and bringing me home. John comes home at lunchtime on Friday and the lady comes in and stays with him until I get home. That gives me three or four hours on a Friday. That has been going for the best part of a year now.

'It has been wonderful because other than Alan, my other son and his family, I never had any other support. I didn't know all this existed.'

It's the same paid worker from the council every time. But I have been told recently that they will bring in another one because then if one worker needs to go off I won't miss out on my Friday afternoon outing. The worker gets on well with John. They brought her at first a couple of times and John met her and he really coped well with that. He knows her now, and she just sits there more or less minding him. He doesn't cause any trouble, he goes on with whatever he is doing, listening to his music or drawing things. Then he goes out to watch the bowling after school finishes at the centre at Merrimu on Thursday and he comes home about six o'clock. That's all helpful because before I got ill I didn't know of any of these services much. Then of course through the doctor and council I got the case manager for John. This was set up and everything slotted into place and ran very well from there. It has been wonderful because other than Alan, my other son and his family, I never had any other support. I didn't know all this existed.

Betty:

I haven't got any complaints either because the services are all very good. The only thing was when John was going into respite, some of the clients weren't compatible with one another. But otherwise everything else and the paid workers were all very good. I am in a different situation than Dorothy. I can leave John here and go to the shops and he just settles and does his own thing – he is very good. Where I go he goes, I can take him wherever I go.

If I was giving advice to someone considering respite, I would say, *'Look, I know what you are feeling',* and believe me I do. *'I was terribly reluctant because I thought this is my job and I shouldn't fob it off onto anyone else, it is something that I feel I can only do myself. But if I could really tell you to just let go that little bit and give it a try I really think not very far down the track you would be glad you did, because that's exactly what I feel and I do know what you are feeling.'*

Dorothy:

I think respite benefits us both because I know that some day John will probably have to go somewhere alone. I thought, I must do this for him and me because he is going to have to leave me one day and I've got to let him go. And the more he can get used to it the better it will be for him – mainly for him. I'll be gone, but John will become used to other people instead of just Mum, Mum all the time. Reluctantly I let him go, but I'm glad I did.

Betty:

I've got the same advice as what Dorothy has. You just get a bit emotional when you think that one day they are going to be left on their own, and you have just got to let go and let them go to respite. There they will meet other people and be used to being on their own. John has made progress through this in dealing with other people. He is a quiet person, but he will come out now and have a conversation. John can come home and tell me exactly what happens and what he does so I am very lucky there, very lucky there. Just let them go – you can't hold them, you have just got to let them go.

'You just get a bit emotional when you think that one day they are going to be left on their own, and you have just got to let go and let them go to respite...'

Chi — *not her real name*

Chi is Vietnamese. She has three children: two boys and a girl. Her 9-year-old son David has autism. Chi is a busy mother who works part-time. Her husband has a very demanding job, which takes him away from home much of the time.

David is a lovely boy. He is very quiet. Now he can talk but not that much, he just asks for what he wants, like a drink of water or to go to the toilet.

I have to feed him or prompt him to eat. He doesn't know when he is hungry – he might just cry if he is really hungry if I haven't got the time to feed him. Otherwise I just check the time and feed him at breakfast, lunch and dinner.

When David was about one and a half they hadn't diagnosed him yet.

I was feeling tired because he was small and I was pregnant again, so I was really, really stressed at that time. I took him to the health nurse and he was diagnosed as being slow – very, very slow. Someone introduced me to 'early intervention' and I took him in but it was a rough time. I wanted to give up. I was holding Alex with one hand, and David was always wanting me to be at his side because he was a pretty small boy, very young. I couldn't cope because at early intervention the teachers wanted the mums to sit around and help the kids, but I couldn't do it because I was so tired. Then he was diagnosed as having autism, which was pretty sad. We had prepared ourselves already because my husband and I had been on the Internet and had recognised a few signs already, so we said, 'David has it.' Luckily we were very strong and we moved on.

From the day I was pregnant with Cindy until now, I have been tired, very tired. Even now, everywhere I go I have to look after him still, like feeding and bathing him. Although he is nine now he is still a handful, like a one year old. Even now, everywhere I go I have to come back – if I leave him at my sister's place I have to come back or ring, so it is still there. For example, if we go to a restaurant and he gets upset, we go 'We have to do something quick', because we don't want people to look at us and look funny. Sometimes he embarrasses us, but other times he is quite good because I take him out a lot so he can get used to it.

My eldest son understands him, but sometimes he is big brother and sometimes he is little. If I say, 'David doesn't understand and he needs

your help' then he will help him. Or if we cross the road and I say, *'Let's take David's hand'*, he is the one who will come and take his hand. But sometimes he complains, *'Why do you give David that, why do you feed him and not feed me?'*

I first used respite about 3 ½ years ago, so it is a long time, before I moved here. The first time half of me wanted to and half of me didn't because I didn't know the person. Because I am so tired and I'm always asking for help, if I know somewhere that they provide a service I will give it a try. But the first feeling I had was, *'Should I?'*

'They come into your private home and you don't know the people – what will they do, can I trust them? But then I thought twice and said, "There is nothing to lose, I'm tired."'

They come into your private home and you don't know the people – what will they do, can I trust them? But then I thought twice and said, *'There is nothing to lose, I'm tired.'* Sometimes when I asked the family to look after the kids I had to take them there and after I came home I had to take them back – it was inconvenient. But here I said, *'Give it a try one time and see how it works.'* Even though it was new people they are police-checked and they get paid, and if anything happened the agency would chase after them. But because I am very open to trying new experiences, I'll give it a try and if it doesn't work out the first time then I stop. But then it worked out good. I had two workers who came from an agency. They came and it was hard because you have to explain about your kids. The first time it is hard and I was nervous at the same time, because to me they are new.

With me seven days a week with the kids it was flat out, and then cooking, and do this, do that. I just wished an angel would come down and help me sometimes because I didn't have spare time, space. I didn't have space for myself.

So when I heard that there was someone who would come and look after the kids I grabbed the chance straight away. I was on a waiting list actually, but when the council called and said, *'Your name is up and they are coming, are you happy to do that?'* I said, *'Yeah, why not?'* Hallelujah, I was so happy at that time.

I didn't discuss it with my husband because sometimes when you think negative and talk to someone who is negative they will say, *'Forget it.'* I

didn't want that to happen because that was my chance. With him he just worked, he didn't look after the kids, but with me this was my chance of going out. So it was only me who decided. I couldn't talk to him – I could talk to someone else but not to him because if he was negative then I am gone.

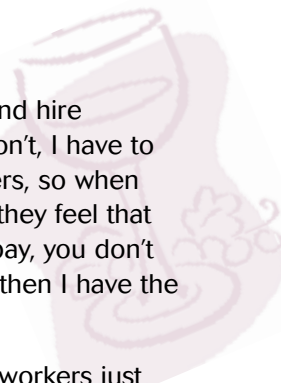
Inside I was nervous, nervous, but it worked out okay. The first day I went out he said, *'Do you think it is okay?'* and I've gone, *'Of course.'* I thought positive. I mean deep inside may be negative things but I go, *'Yeah, why not, there shouldn't be a problem and if there is then we quit, but give it a try.'*

'...and then when you come home you find that your kids are fed, bathed and in bed asleep already, so it is excellent.'

I now have respite from the council every Saturday night for four hours, or I can have it once a month from say 6pm until 12 midnight if I want to choose that. We go to a movie, dinner or catch up with friends. And then when you come home you find that your kids are fed, bathed and in bed asleep already, so it is excellent. I also have a volunteer worker from Extended Families and she takes David out. At the moment I'm asking whether she can take David to swimming.

My parents used to come or I would take them to my mum or my sister nearby, but not any more. I think once a week is enough. Before we had that I had to ask for workers from Carer Links West. Sometimes they would come and sometimes I would take the kids to my sister's and they would sleep over. But now we put everything on a Saturday – we go to the cinema or meet friends – we make the most of it. Sometimes during the week we don't have time to talk because my husband comes home late and then he just zooms to the TV. So we wait until the Saturday thing comes and we talk, talk, talk. Saturday is like the meeting place for us.

It is always been the same people from the council for three years. The first few times we swapped around to find the right ones, but I've never said, *'This one is good, that one is not'*, I just gave it a go. But then somehow it ended up always the same two people. Sometimes if I come home early I let them go, and sometimes I come home a little bit late, but I ring them and tell them that I am running late and they say, *'That's okay'*, but then they put in extra time, so it is all right. Sometimes if I come home 10 or 15 minutes late I don't call them.



For me using the council is different than if I could go out and hire someone. Then I would have the power, but in this case I don't, I have to take their service. I pay little and the council pays the workers, so when they come I feel that I shouldn't ask them for much. Maybe they feel that I have the right to ask, but deep inside, because you don't pay, you don't have that power thing. But if I hire someone, pay someone, then I have the power to do so.

I think there are two kinds of respite. One is when the paid workers just stay with your kid so you can go out. The other is to read to him for five minutes, or teach him writing for five minutes. Sometimes I just wish they would sit with David and read or teach him letters or play ball – do something that I don't have time to do with him just for ten minutes, I would be happy. Sometimes they play with him, but probably with the other children more I think. Even if they don't spend time with David I am happy too because I don't have time.

I think if there is an agency to take David to camp for two days, I would love to give it a try. He can go there and learn new things and then I can have a break because in the morning I have to get up and bath and feed him. It is an everyday thing and sometimes I just want to be me, me. Should I think that because he needs me, why send him away? You know that feeling? But it would be nice. I plan to go overseas soon and I have to leave David behind. At first my husband said to take him along, but then I thought, if I take him along how am I going to cope, because I'm taking the little one with me. We feel bad leaving him behind, but then I think he probably just misses us only a little bit, he wouldn't notice, he just plays on the computer and with books. As long as somebody feeds him he is pretty fine, he is just normal, he is just a lovely boy as long as you feed him.

He is going to stay with my sister, but then I still don't feel good because I have never done it before in my life. My husband said, '*Are you sure?*' and I said, '*Maybe that is a good thing for him.*' We will miss him and I think maybe it is not a good thing to do that. But when you look on the other side, if he comes with us the weather is really hot over there in Vietnam. He might get upset and then you get upset. And if we tour around David can't cope.

'I think that more Vietnamese people should give respite a try. Lots of families have rejected it. They feel that they are not private any more...'

I think that more Vietnamese people should give respite a try. Lots of families have rejected it. They feel that they are not private any more – they can't speak English and new people are coming into their home. Because they think like that they quit before they start. I would say to them: give it a try, it doesn't hurt, it costs little and you find that time to do the things that you want to do, like shopping. Me, I go out with my husband because I treasure that time, but other people can go shopping or go out with a friend and they don't have to worry about their kid.

Vietnamese people might worry that a stranger is coming into their home and what are they going to do. Straight away they think that – even me, I probably thought that at the start. But then I think young girls like me, maybe 50% will give it a try. Older people might rather stay home and the paid worker can play with the kids while they are home. They feel safer. Or sometimes they don't want a worker in their home because they feel uncomfortable, so it depends.

I know many, many families but I think only about two or three are using respite. Even if I say it is good I don't think they would give it a try because at the very first stage when you call and you say you want respite, they find it hard to do that already. And then you have to fill in so many forms, and they go oh my God – to me it is okay because I can ring the council and say, *'I want respite, put me on the waiting list.'* But families out there find that the first step is really hard, too many hurdles. Forms and waiting lists, it is too much.

I feel sad because I know lots of families don't have respite time at all like the husband argues a lot because they don't understand. I've got council home care once a week for an hour, and it is a good feeling. And I have said to other people, *'Instead of having respite to go out, why don't you have home care to help you do this or do that, and then you save that time so you can play with your kid?'* And still it is a no thing, they can't do it.

They can't speak English and getting an interpreter is really hard. I think for example if I said, *'Do you want respite, they will come tomorrow, are you happy with it, all right, done.'* I think maybe they will say, *'Okay, I will give it a try'*, if it was there and ready. But you can't do that, you have to start at the first step, to put your name down, they are going to call you, are you going to be home? The process is too long, too long. Maybe it could be talked about more on SBS radio, the newspaper, the *Vietnamese TV Week*.

Chi – không phải là tên thật của cô

Chi là người Việt nam. Cô có ba đứa con: hai trai và một gái. Đứa con trai lên chín của cô tên David bị chứng tự kỷ. Chi là một bà mẹ bận rộn đang làm việc bán thời. Chồng cô đang có một công việc đòi hỏi nhiều nỗ lực, khiến anh phải thường xuyên vắng nhà.

David là một đứa bé dễ thương. Cháu rất trầm lặng ít nói. Hiện nay cháu có thể nói chuyện nhưng không nhiều, cháu chỉ đòi những gì cháu muốn, như uống nước hay đi cầu.

Tôi phải cho cháu ăn hoặc nhắc nhở cháu ăn. Cháu không biết khi nào cháu đói – cháu chỉ khóc khi cháu thật đói và tôi không có thì giờ cho cháu ăn. Ngoài ra thì tôi chỉ việc xem giờ giấc rồi cho cháu ăn sáng, trưa và tối.

Lúc David được khoảng một tuổi rưỡi thì họ chưa chẩn đoán bệnh cho cháu.

Tôi cảm thấy mệt mỗi bởi vì cháu còn nhỏ mà tôi lại có thai, cho nên lúc đó tôi thật sự rất căng thẳng. Tôi dẫn cháu đến y tá và cháu được chẩn đoán là cháu bị chậm – rất rất chậm. Có người đã giới thiệu tôi về chương trình ‘can thiệp sớm’ và tôi dẫn cháu đến đó nhưng lúc đó là lúc thật gian nan. Tôi muốn bỏ cuộc. Một tay tôi dắt Alex còn David thì luôn luôn đòi tôi ở bên cạnh vì cháu còn bé, rất nhỏ. Tôi không thể đương đầu nổi bởi vì trong chương trình can thiệp sớm, các giáo viên muốn các bà mẹ phải ngồi gần đó để phụ giúp con cái, nhưng tôi thì không thể làm được chuyện đó vì tôi đã quá mệt mỏi. Sau đó cháu được chẩn đoán là cháu bị chứng tự kỷ, thật buồn quá. Chúng tôi đã chuẩn bị trước rồi, vì tôi và chồng tôi có lên internet và chúng tôi đã ghi nhận một □ dấu hiệu rồi, nên chúng tôi đều nói là ‘David bị chứng đó rồi’. May mắn là chúng tôi rất kiên quyết và chúng tôi tiếp tục đi tới.

Từ ngày tôi có thai cháu Cindy đến nay, tôi rất mệt mỏi, rất mệt mỏi. Ngay cả lúc này, bất cứ tôi đi đến nơi nào, tôi vẫn phải trông nom lo cho cháu, như cho cháu ăn và tắm rửa cho cháu. Mặc dù bây giờ cháu đã chín tuổi rồi, nhưng cháu rất nặng lo, giống như một đứa trẻ lên một vậy. Ngay cả hiện nay, dù tôi có đi đâu tôi cũng phải quay về - nếu tôi gọi cháu ở nhà chị tôi, tôi cũng phải trở lại hoặc gọi điện thoại về, cho nên vẫn còn chuyện. Chẳng hạn như, khi chúng tôi đi ăn ở nhà hàng và nếu cháu bực bội quấy rối, chúng tôi ‘phải hành động thật nhanh’, vì chúng tôi không muốn mọi người nhìn chúng tôi với ánh mắt kỳ cục. Đôi khi cháu làm chúng tôi ngỡ ngàng, nhưng còn những lần khác thì cháu rất giỏi vì tôi đã dẫn cháu đi ra ngoài nhiều lần nên cháu quen với việc đó.

Đứa con trai đầu lòng của tôi rất thông cảm với cháu, tuy nhiên thỉnh thoảng cháu hành động như một người anh lớn và đôi khi lại hành động như chú em nhỏ. Nếu tôi bảo cháu, ‘David không hiểu đâu, em cần con giúp em’ thì nó sẽ giúp David. Hoặc khi chúng tôi băng qua đường và tôi bảo cháu ‘Hãy nắm lấy tay của David’ thì cháu là đứa đến nắm lấy tay David. Nhưng đôi khi cháu

than van là ‘Tại sao mẹ lại cho David cái đó, tại sao mẹ lại cho David ăn mà không cho con?’.

Lần đầu tiên tôi sử dụng việc chăm sóc thay thế tạm cách nay khoảng 3 năm rưỡi, đã lâu rồi, trước khi tôi dọn về đây. Lần đầu tiên, phần nửa con người tôi muốn vậy còn phần nửa kia lại không muốn bởi vì tôi không biết người chăm sóc. Bởi lẽ tôi quá mệt mỏi và tôi luôn luôn cần sự giúp đỡ, nếu tôi biết một nơi nào mà họ cung cấp dịch vụ đó thì tôi sẽ thử sử dụng xem sao. Nhưng cảm tưởng đầu tiên của tôi là ‘Minh có nên không?’

Họ đến tận nhà riêng của bạn và bạn lại không biết họ – họ sẽ làm gì, tôi có thể tin tưởng họ không? Nhưng rồi tôi nghĩ lại một lần nữa và nói ‘Không mất mát gì cả, tôi mệt quá rồi.’

Họ đến tận nhà riêng của bạn và bạn lại không biết họ - họ sẽ làm gì, tôi có thể tin tưởng họ không? Nhưng rồi tôi nghĩ lại một lần nữa và nói ‘Không mất mát gì cả, tôi mệt quá rồi’. Đôi khi khi tôi nhờ gia đình trông chừng mấy đứa nhỏ, tôi phải đưa chúng đến đó và sau khi về nhà, tôi lại phải đến rước chúng về - thật là bất tiện. Nhưng rồi tôi nói, ‘Minh hãy thử một lần xem sao.’ Ngay cả khi họ là người mới, họ đã được cảnh sát kiểm tra lý lịch rồi và họ được trả lương, và nếu có chuyện gì xảy ra thì cơ quan sẽ săn đuổi họ. Nhưng vì lòng tôi thật tình muốn thử những kinh nghiệm mới, tôi sẽ sử dụng thử và nếu lần đầu tiên không tiến triển suông sẽ thì tôi ngưng. Nhưng rồi sự việc đã tiến triển tốt đẹp. Tôi có hai người chăm sóc từ một cơ quan gửi đến. Họ đến và hơi khó là vì bạn phải giải thích về những đứa con của bạn cho họ biết. Lần đầu tiên hơi khó và tôi lo lắng vì đối với tôi, họ mới quá.

Đối với tôi, lo cho đám con một tuần bảy ngày thì quá mệt, rồi nào là nấu nướng, làm chuyện này, chuyện nọ. Tôi chỉ cầu cho có một bà tiên hiện xuống thỉnh thoảng phụ tôi vì tôi không có thời giờ và nơi nào được rỗi rảnh cả. Tôi không có một chỗ nào cho cá nhân tôi.

Do đó khi tôi nghe có người sẽ đến nhà tôi và trông chừng con cái tôi, thì tôi chộp lấy cơ hội này ngay. Thực ra thì tôi đã nằm trong danh sách chờ đợi, nhưng khi hội đồng thành phố gọi tôi và bảo rằng ‘Đã đến phiên tên cô rồi và họ sẽ đến, cô có muốn làm thế không?’ Tôi trả lời ‘Vâng, tại sao không chứ?’ Tạ ơn Chúa, lúc đó tôi rất vui mừng.

Tôi đã không thảo luận việc này với chồng tôi bởi vì thỉnh thoảng khi bạn nghĩ tiêu cực và nói chuyện với một người tiêu cực thì họ sẽ nói ‘Bỏ qua chuyện đó đi’. Tôi không muốn chuyện đó xảy ra vì đó là cơ hội cho tôi. Đối với chồng tôi, thì anh chỉ làm việc, anh không trông nom con cái, nhưng đối với tôi thì đó là một cơ hội để được đi ra ngoài. Do đó, việc này chỉ có tôi mới quyết định. Tôi không thể nói việc này với chồng tôi – Tôi có thể nói với một người nào khác nhưng không phải chồng tôi bởi vì nếu anh ấy tiêu cực thì tôi cùng đường.

Tận đáy lòng, tôi luôn băng khoăn, lo lắng, nhưng việc này tiến triển tốt đẹp. Ngày đầu tiên tôi đi ra ngoài, chồng tôi hỏi, ‘Em có nghĩ là việc này tiến triển

tốt đẹp không?’ và tôi đã trả lời, ‘Dĩ nhiên rồi’, tôi nghĩ một cách tích cực. Thực sự ra thì tận đáy lòng tôi có thể có những chuyện tiêu cực, nhưng tôi nói, ‘Vâng, sao lại không, không có vấn đề gì đâu và nếu có thì chúng mình ngưng thôi, nhưng phải thử mới được.’

‘...và rồi khi bạn về nhà, bạn thấy con mình đã được cho ăn, tắm rửa và lên giường ngủ rồi, thế thì tuyệt quá.’

Giờ thì tôi sử dụng việc chăm sóc thay thế tạm của hội đồng thành phố mỗi tối Thứ Bảy trong bốn tiếng đồng hồ, hoặc tôi có thể sử dụng dịch vụ này mỗi tháng một lần chẳng hạn như từ 6 giờ chiều đến 12 giờ khuya nếu tôi muốn chọn như thế. Chúng tôi đi xem chiếu bóng, đi ăn tối hoặc gặp gỡ bạn bè. Và rồi khi bạn về nhà, bạn thấy con mình đã được cho ăn, tắm rửa và lên giường ngủ rồi, thế thì tuyệt quá. Tôi cũng có một cô làm thiện nguyện từ cơ quan Những Gia đình Nới rộng (Extended Families) và cô dẫn David đi chơi bên ngoài. Hiện nay tôi đang hỏi xem cô có thể dẫn David đi bơi lội được không.

Ba mẹ tôi thường đến nhà tôi hoặc tôi dẫn con cái tới mẹ tôi hoặc chị tôi ở gần đó, nhưng tôi không làm như vậy nữa. Tôi nghĩ một lần mỗi tuần cũng đủ rồi. Trước khi chúng tôi sử dụng dịch vụ này, tôi có xin nhân viên từ cơ quan Liên Kết Người Chăm Sóc Phía Tây (Carer Links West). Thỉnh thoảng họ có đến nhà và đôi khi tôi dẫn con cái đến nhà chị tôi và chúng ngủ lại ở đó. Nhưng bây giờ thì chúng tôi sắp xếp mọi chuyện vào ngày Thứ Bảy – chúng tôi đi xem chiếu bóng hoặc gặp gỡ bạn bè – chúng tôi tận dụng tối đa thời gian này. Thỉnh thoảng trong tuần chúng tôi không có thì giờ nói chuyện với nhau bởi vì chồng tôi về nhà trễ và rồi anh chỉ dí mắt vào TV. Cho nên chúng tôi chờ cho đến ngày Thứ Bảy và chúng tôi nói chuyện, nói và nói. Thứ Bảy cũng giống như ngày hội họp của chúng tôi.

Hội đồng thành phố luôn gọi cùng người chăm sóc đến trong ba năm. Trong vài lần lúc đầu, chúng tôi đổi vòng vòng để tìm cho đúng người mình muốn, nhưng tôi không bao giờ nói rằng, ‘Người này tốt, người kia không tốt’. Tôi cứ để tự nhiên. Nhưng rồi không hiểu sao cuối cùng cũng vẫn là cùng hai người. Thỉnh thoảng nếu tôi về nhà sớm thì tôi cho họ đi về và đôi khi tôi về nhà hơi trễ một chút, nhưng tôi gọi điện thoại và báo cho họ biết là tôi bị trễ thì họ nói ‘Không sao đâu’, và họ ghi thêm giờ và như thế cũng được. Thỉnh thoảng nếu tôi về nhà trễ 10 hoặc 15 phút thì tôi không gọi cho họ.

Đối với tôi việc sử dụng dịch vụ của hội đồng thành phố có khác hơn là nếu tôi đi tìm mượn người nào khác. Rồi tôi có quyền hạn, nhưng trong trường hợp này thì tôi không có, tôi phải sử dụng dịch vụ của họ. Tôi trả ít tiền và hội đồng thành phố trả lương cho người chăm sóc, cho nên khi họ đến, tôi cảm thấy là tôi không nên đòi hỏi ở họ nhiều quá. Có thể họ cảm nhận rằng tôi có quyền được yêu cầu, nhưng tận đáy lòng tôi, bởi vì bạn không trả tiền, bạn

không có cái quyền hạn đó. Nhưng nếu tôi mượn một người nào khác, trả tiền cho họ thì tôi có quyền hạn được làm như thế.

Tôi nghĩ rằng có hai loại chăm sóc thay thế tạm. Một loại là khi những nhân viên có lương chỉ ở với con bạn để bạn có thể đi ra ngoài. Một loại khác là họ đọc sách cho cháu nghe trong năm phút, hoặc dạy cho cháu viết trong năm phút. Đôi khi tôi chỉ muốn họ ngồi với David và đọc cho cháu nghe hoặc dạy cho cháu những chữ cái hoặc chơi bóng với cháu – làm một việc gì đó mà tôi không có thì giờ để chơi với cháu chỉ trong mười phút là tôi mừng rồi. Thỉnh thoảng họ chơi với cháu, nhưng có thể chơi với những đứa trẻ khác nhiều hơn, tôi nghĩ thế. Ngay cả nếu họ không bỏ thì giờ chơi với David thì tôi cũng vui bởi vì tôi không có thì giờ.

Tôi nghĩ nếu có một cơ quan nào dẫn David đi cắm trại trong hai ngày, thì tôi rất thích gởi cho cháu đi. Cháu có thể đi đến đó và học hỏi những điều mới lạ và rồi tôi có được thời gian nghỉ ngơi bởi vì buổi sáng thì tôi phải thức dậy tắm cho cháu và cho cháu ăn. Đó là công việc hằng ngày của tôi và nhiều khi tôi chỉ muốn là tôi, tôi thôi. Tôi có nên suy nghĩ như thế không bởi vì cháu cần tôi, tại sao tôi lại gởi cháu đi? Bạn có hiểu được cảm giác đó không? Nhưng điều đó rất hay. Tôi định chẳng bao lâu nữa tôi sẽ đi nước ngoài và tôi phải để David ở lại. Lúc đầu chồng tôi nói rằng phải đem cháu theo, nhưng rồi tôi nghĩ, nếu đem cháu theo thì làm sao tôi có thể đảm đương cho nổi, bởi vì tôi dẫn theo đứa út. Chúng tôi cảm thấy áy náy và khó chịu khi phải bỏ cháu ở lại, nhưng rồi tôi nghĩ cháu có thể chỉ nhớ chúng tôi chút ít, cháu sẽ không để ý, cháu chỉ việc chơi đùa với máy vi tính và sách vở. Miễn là có người nào cho cháu ăn là được rồi, cháu chỉ là một chú bé bình thường, dễ thương miễn là bạn cho cháu ăn.

Cháu sẽ ở lại với chị tôi, nhưng rồi tôi vẫn cảm thấy không yên ổn hài lòng bởi vì tôi chưa bao giờ làm như thế trước đây trong đời. Chồng tôi nói, ‘Em chắc không?’ và tôi trả lời, ‘Có thể đó là điều tốt cho nó.’ Chúng tôi sẽ nhớ cháu và tôi nghĩ làm như thế có thể không hay. Nhưng khi bạn nhìn ở một khía cạnh khác, nếu cháu cùng đi với chúng tôi lúc thời tiết thật nóng bức ở bên Việt nam. Cháu có thể bực bội và rồi bạn sẽ bực bội. Và nếu chúng tôi đi tour du lịch thì David không thể nào chịu đựng nổi.

‘Tôi nghĩ rằng nhiều người Việt nam nên thử sử dụng việc chăm sóc thay thế tạm. Rất nhiều gia đình đã từ chối không chịu sử dụng. Họ cảm thấy rằng họ không được riêng tư nữa...’

Tôi nghĩ rằng nhiều người Việt nam nên thử sử dụng việc chăm sóc thay thế tạm. Rất nhiều gia đình đã từ chối không chịu sử dụng. Họ cảm thấy rằng họ không được riêng tư nữa – họ không nói được tiếng Anh và người chăm sóc mới đến tận nhà họ. Bởi vì họ nghĩ như thế nên họ bỏ qua không chịu bắt

đầu. Tôi phải nói với họ là: cứ thử đi, không hại gì đâu, chỉ tốn ít tiền và bạn sẽ dùng thời gian đó để làm những chuyện mà bạn muốn làm, như đi mua sắm chẳng hạn. Còn tôi, tôi đi chơi với chồng tôi bởi vì tôi quý trọng thời gian đó, nhưng đối với những người khác, thì họ có thể đi mua sắm hoặc đi chơi với bạn bè và họ không phải bận tâm gì đến con cái.

Người Việt nam có thể lo rằng có một người lạ đến nhà mình và họ sẽ làm gì. Họ nghĩ ngay đến chuyện này – ngay cả tôi, tôi cũng đã có phần nghĩ như thế lúc bắt đầu. Nhưng rồi tôi nghĩ rằng những phụ nữ trẻ như tôi, có thể 50% sẽ sử dụng thử. Những người lớn tuổi hơn có thể muốn ở nhà và người chăm sóc có lương có thể chơi đùa với con cái họ trong khi họ vẫn ở tại nhà. Họ cảm thấy an toàn hơn. Hoặc đôi khi họ không muốn người chăm sóc ở trong nhà họ bởi vì họ cảm thấy không thoải mái tự nhiên, do đó còn tu□.

Tôi biết có nhiều, rất nhiều gia đình nhưng tôi chỉ nghĩ đến hai hoặc ba gia đình đang sử dụng dịch vụ chăm sóc thay thế tạm. Ngay cả nếu tôi nói là dịch vụ này tốt, tôi không nghĩ là họ muốn sử dụng thử bởi vì vào giai đoạn ban đầu khi bạn gọi đến và bạn nói rằng bạn muốn có dịch vụ chăm sóc thay thế tạm, họ đã cảm thấy khó làm việc đó rồi. Và rồi bạn phải điền rất nhiều mẫu đơn, và họ sẽ kêu lên Trời ơi – đối với tôi, thì việc đó cũng bình thường thôi bởi vì tôi có thể gọi điện thoại cho hội đồng thành phố và nói rằng, ‘Tôi muốn sử dụng dịch vụ chăm sóc thay thế tạm, xin ghi tên tôi vào danh sách chờ đợi.’ Nhưng những gia đình ở đó thấy giai đoạn đầu tiên thực sự khó khăn, có quá nhiều chuyện phải vượt qua. Mẫu đơn và danh sách chờ đợi, nhiều thứ quá.

Tôi cảm thấy buồn vì tôi biết rất nhiều gia đình không có thời gian nghỉ ngơi gì cả như người chồng tranh cãi rất nhiều bởi vì họ không hiểu. Tôi sử dụng việc chăm sóc tại gia của hội đồng thành phố mỗi tuần một tiếng đồng hồ, và đây là một việc hay. Và tôi đã nói với người khác là ‘Thay vì sử dụng dịch vụ thay thế tạm để đi ra ngoài, tại sao bạn lại không sử dụng dịch vụ chăm sóc tại gia để giúp bạn làm chuyện này hay chuyện nọ, và rồi bạn dùng thời giờ đó để bạn có thể chơi đùa với con bạn?’ Và vẫn không được, họ không thể làm được chuyện đó.

Họ không nói được tiếng Anh và xin một người thông ngôn thì thực là khó. Tôi nghĩ thí dụ như nếu tôi nói, ‘Bạn có muốn sử dụng dịch vụ chăm sóc thay thế tạm, họ sẽ đến nhà ngày mai, bạn có muốn như thế không, được rồi, xong.’ Tôi nghĩ có thể họ sẽ nói, ‘Được rồi, tôi sẽ thử’, nếu ở đó có sẵn. Nhưng bạn không thể làm như vậy, bạn phải bắt đầu ở giai đoạn đầu tiên là ghi tên mình vào danh sách chờ đợi, họ sẽ gọi điện thoại cho bạn, bạn sẽ ở nhà phải không? Diễn tiến còn dài, rất dài. Có thể điều này nên nói nhiều hơn trên đài phát thanh SBS, báo chí, TV Tuần san.



Anthony

Anthony is a single father of four children. Emma, 13, started high school this year. Vanessa is eleven and has an intellectual disability. Nine-year-old Bianca and seven-year-old Jerome both go to Altona Primary School.

Vanessa was diagnosed with global development delay at a very young age. When she was five she was assessed for going to school and diagnosed with an intellectual disability. She is very happy going to Rosamond Special School – she is very popular and she is very good at making friends. She catches the bus at 7.30 in the morning and gets dropped off about 4.15pm, so she spends nearly 3 hours a day on the bus, an hour and a half each way.

My kids are all good friends with each other. Bianca, the nine-year-old, has got a very good friendship with Vanessa – they share a bedroom, and because her mother is not in the house Bianca takes on the mother role with Vanessa. She cares for her and shows her how to put on bandaids and does her shoelaces up for her and tries to teach her how to write her name. So it is really good.

Vanessa is sometimes easier to look after than the other three. They are so demanding and they want so much, all the latest jeans and runners, whereas Vanessa is not very fussed about what you dress her in. Her needs and wants are just a lot simpler. But then again you have got other responsibilities, like when you go to a shopping centre Vanessa can easily just go into a shop and not tell you that she is walking off on her own from

the family circle. There are other dangers as well, I mean she can take off from the house and go outside and harm the dog for example, or she can go outside and play with the dog. So you are doing something and always watching her at the same time.

'I felt very, very – not scared – but very cautious about having somebody that I didn't know in my house for five to six hours and leaving my children with them.'

I first started using respite when Vanessa was about five and she is eleven now, so it is a good six years. I felt very, very – not scared – but very cautious about having somebody that I didn't know in my house for five to six hours and leaving my children with them. But then as time went on I got to know the workers that were coming in and I felt very comfortable. I trust them completely now. At the time when we were first getting respite there was a lot of commotion going on in the house and things were not right, so it was a time when we really needed some respite. It took me a good four months, maybe five, until I really got settled about someone coming in and staying in my house while I was away and leaving my children with them.

Basically the ongoing support I get now is through the council, which is respite. I used to have six hours a week and then they dropped that down to five. Because our family set-up changed it was reduced, which made it even harder because that was when I needed it most. There was a big battle going on because they were trying to get it down to two hours a week, which was very very difficult. The principal of Vanessa's school helped me a lot by sending letters and making phone calls.

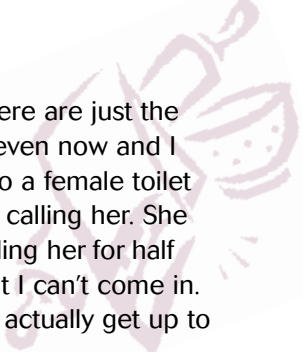
Being a carer is harder than working full-time. It would be so easy for me just to go to a factory and work for a boss and not have all these responsibilities. It is sort of like running a small hotel because you are catering for the children. We need at least three hours respite, and they go very quick. I get respite every Friday, and I plan my week around that. It is normally from 4pm until 7pm. The kids say to me, '*Dad can we do this and that*', and I'll say, '*Okay Friday you have got respite*', so it is automatically in the back of my head that Friday is a good day to do things. It gives me peace of mind knowing that Friday I have got that time allocated and free.

The respite workers who come in are really good – they help with tidying up and going through the children’s rooms – and having another adult in the house that I can talk to is great. Talking to children is fine but there are certain things you can only talk about with an adult. Also I get advice from the ladies like, *‘Do you reckon this laundry detergent is good, or what do you reckon I should clean this with?’* They know because they just do. As a male carer I just don’t have the knowledge, I haven’t grown up with all the training that girls do. There hasn’t been a need to know and now there is – it is like you are looking for something that isn’t there, so it is all a learning experience. There are times when I think, *‘Oh it is Wednesday, so I can ask Heather on Friday what do you reckon about this?’* Vanessa still wets the bed, and I was forever washing and changing sheets, then the worker said to me, *‘There are plastic sheets that you can buy that cover the mattress.’* I didn’t even know about it. It’s all knowledge, their knowledge that they are passing on to me.

‘...people look at me like, ‘Oh he is a father, he doesn’t really know what to do, it can only be a mother’s job to do certain things.’

I actually would feel more confident asking the paid workers certain questions such as when the girls are going to get their period rather than family. The workers have helped me out a lot with things. There are a lot of issues with being a single father. On top of the list is that my girls are growing up now and there are certain things that I find very hard to explain to them like feminine products and things. What I also find hard is that in the public’s eye people look at me like, *‘Oh he is a father, he doesn’t really know what to do, it can only be a mother’s job to do certain things.’*

I don’t find that with everybody, but when I talk to the older generation, like my aunties, they are pretty confident that I’m not doing it right. At the end of the day I just do my best and that’s all I can do. But I do find it a little bit difficult even going shopping – you go in and say, *‘My daughter wants underwear, can you direct us to this size?’* and people look at you like, *‘Why are you taking your daughter and buying underwear?’* Or if you go without your children and you want to buy for example a bra or something they look at you like, *‘Well why are you doing this, is there something wrong with you?’* These are the things that you find are a little bit more difficult.



When Vanessa needs to go to the toilet in public and there are just the two of us, we have to go into a disabled toilet. She is eleven now and I can't take her into the male toilets. If I let Vanessa go into a female toilet by herself she would be in there playing and I would be calling her. She might be just pulling off the toilet roll, but I could be calling her for half an hour and she just won't come out and she knows that I can't come in. These are little things that you take for granted until you actually get up to them.

I don't really go away much, although I have recently just come back from a holiday.

A friend of mine got married in Vanuatu and I was best man at his wedding. When he first told me I said, *'Look I can't afford to do that'* and he said, *'We have already thought of that and we have paid for your tickets so you are going'*, so I had no choice. But I am paying him back slowly which is really really good. So that was a really good holiday. I can't remember the last time I was in an aeroplane – it was about eighteen years ago, and the children had never been in a plane.

Vanessa didn't come with us. I was actually going to take the four of them but a lady down the road, a friend of mine, was having holidays around that time and she asked me to leave Vanessa with her. A council worker came from 4pm until 7am and looked after Vanessa each night at home. Then Maria would pick her up at 7am and send her off to school in the morning, so she didn't miss out on school or anything like that. This was all arranged through Carer Links West. The council said originally they could do it and then they turned around and said we haven't got enough funding, so it put me in a spot because we were ready to leave. Carer Links put me onto another organisation and they came through for me.

'The counselling through Carer Links West came at a good time because I really needed someone to talk to so it was fantastic...'

Carer Links West are like a back-up – when something is going wrong I ring them and see what they can do for me. They usually let me know that there are certain events going on, including workshops and luncheons. They helped me with the holiday program and they paid for Vanessa's fees and that helps me a lot – it gives me a break. Also they guide me down avenues of other organisations that help me. The counselling through

Carer Links West came at a good time because I really needed someone to talk to so it was fantastic, and I've got the opportunity to go back at any time. I just felt so good speaking to someone professional rather than speaking to friends and family where they are just too busy and can't really listen. I also go to the workshops and on a couple of occasions I was the only male. They have a session where they do back rubs and stuff and I am always at the front of the line, so I'm the one who is getting the back rub rather than giving it. They seem to accept that I'm there and they really listen to my story when I say '*I'm a single father with four children.*' I do stand out though! On a couple of occasions there were some other gentlemen and that was good.

As far as the council respite goes I am happy with the way things are. The only thing I am unhappy about obviously are my hours being pulled straight out from under my feet. And the way that the person in charge of organising the hours came here and tried to make me feel that I was lucky to get two hours. That is the only thing that I was really disappointed about. I could also try and get some extra respite through some other organisations but I don't want to have different people coming here and the children having to deal with different people. With the council I always get the same person. The children don't like it – they have made it quite clear to me that they don't like staying with people they don't know, they are just not used to it. Children don't know how to really deal with a different person, they can't just go up and say, '*Can we play X-box now*' or something like that.

I would love a representative of the agencies that give respite to come over and see what actually goes on here and judge for themselves, rather than me telling them what I think I need. Maybe somebody coming over between 4.00 and 5.30 pm, just for an hour and a half, and see the mayhem when the kids come home from school. To see how things get pulled out of drawers and the attention I need to give the children with homework and cooking and all that. There is nothing like reality, seeing it for yourself. I can ring up an agency and say, '*Look I'm a single father, this, that and the other*' and they will be painting a picture in their mind what they think is happening but not what actually is.

To families who are new to respite I would say: try and look at your needs. For example, what day do I really need respite? Do I need to break it up? If I have a two-hour block or a three-hour block am I going to take it all at

once? What is a good time for paid workers to come in and help? When the kids are at school I can relax – well not so much relax, but I can go around and I can do my washing and hang it out and do the dishes. But if the children were here I'd be getting called '*Dad, Dad, Dad, Dad*' from four different corners of the house. Having respite when all my children are here is ideal for me, so if someone is in the same boat, obviously take respite when it is the busiest time in the household.

I was nervous when I first started using respite, and I really think that people should just give it a trial run for a month and then assess it again. The staff have been taught how to look after children and work in people's houses, so I've learned now that they are professional and they do their job well. It is in the interest of the workers to come out and do the right thing because they don't want to lose their job.

So I rely on my friends and I rely on respite from the council and I rely basically on Carer Links West. I have good support from my friends but they can only help as much as they can. At the end of the day this is my thing that I am dealing with, and I don't want to be asking for help all the time.





Liz

Liz is primary carer for her son Joel who has autism and an intellectual disability. Liz has made creative changes to her living area at home to make a space for Joel where he is not shut away and can safely be a part of family activities.

I have four children and I am divorced but I only have two of the children at home. My son Joel is now nineteen – he has the mentality of a two-year-old. My younger daughter has juvenile diabetes, so basically I am looking after her and there is not a lot of support that I do have. My two eldest girls don't live locally; one is in Prahran and the other in Indented Heads. They have their own lives – one has got a family – so they can't provide a lot of support for me anyway.

Joel's father lives in Adelaide and comes down occasionally – maybe twice a year – and takes him for about a week to give me some sort of break. Generally it means that he moves into this house and I have to move out. I go home to my parents but that is not necessarily a rest because I probably clean up the house for them. I love them dearly, I don't mind it, but this is what happens. In the last few years really I haven't had much of a holiday. My case-worker actually managed to get me a week's holiday. I was able to take it because my ex-husband came down and minded Joel for that week and the agency was able to give me the funding for the accommodation. That was absolutely fantastic. I came back a different woman. It was the first time I have had 'me time' for a long time.

I'm pretty much on the go from 7 o'clock in the morning until after 8 o'clock at night and that's seven days a week, so basically I'm exhausted. I also have arthritis, I've had breast cancer, I've had heaps of medical issues that impact on it, so that means that I end up fairly sick. I get run down fairly quickly. I want to try and get fit – I've started trying to go swimming on Tuesday nights which is just adding a longer burden to my day, it means that I now finish at 10 o'clock. But it is important for me to try and give that to get my body into order. It is wonderful – it is such a relaxation for me.

The council have been the best thing in the world for me because they are the only ones that have helped. They basically come in and bath Joel every morning because my arthritis is really bad in the morning, and that is a godsend for me. Weekends it is still hard because they are not there. It has taken me a long time to get to this point. I have been in Melton probably three and a half years, and it has only just been put into place. They were giving me three hours of a night-time, and really I suppose I could have thought about it and made it like this before but I didn't realise the benefits.

I don't have a package. I have been trying for three and a half years to get a 'Support and Choice' package. I had to wait three years to get a caseworker. It's been just short-term intermediate little bits and pieces here and there to save my sanity – it hasn't been anywhere near enough. I mean there have been times when I was absolutely losing it because I just couldn't cope any more and those three years were very traumatic. I've been sent around in circles – you go around, around and around and you end up at the same department under a different name. You don't even know who you have called any more. The system is made so that you can't understand it, you don't know who is what and you just go crazy. Those three years of being on the phone, ringing and ringing – I am sure that it is designed so that you just give up. A lot of people do just give up, and that means they don't have to put you on the case list.

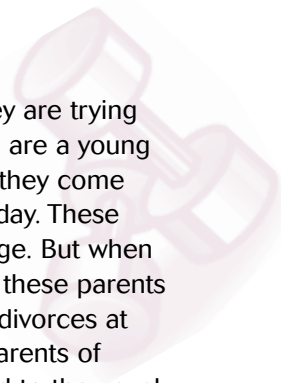
Nobody should go through three years like that, no one. That was the most heartbreaking and traumatic time I have been through. Even when you have the help put into place it doesn't come through, they let you down all the time. You finally get respite, it's on the books, you are entitled to it, you are supposed to have it, and then they ring up and say, 'Sorry, we haven't got him booked in here, sorry I forgot to book a worker, sorry

you know that worker has become sick, sorry your son is sick he can't go in, sorry, sorry, sorry. It is too late now, we have already given all the time to everybody else, you will have to wait three months until the next one.' And this is the type of thing that you are up against all the time. The amount of times that people have let me down when I was supposed to have respite is just incredible.

The first time I used respite was when Joel got to about 10 years old. There was a lot more available then, and we had been asked many times to put our child into facility-based respite. We decided not to because we could cope with him and I am not a person who believes in wasting the government's money or facilities when they are not needed – that is just stupid. When he was old enough and ready to go into respite we organised it. We had a choice of two respite houses, so we worked out which one suited. It was fabulous, it just gave us a whole new lease of life. We could go out, we could do things, we had a world. I was married at the time and that was great. We had respite every second weekend then, but now it is one weekend out of twelve. Basically now that my husband has left and my child is older and more difficult all the services are even less and less and I am not getting the support I need.

Joel seems to accept respite, he hasn't been hurt, there haven't been any real problems with him. Sometimes they are not as careful as they could be with his diet. It is just so difficult – sometimes the staff get very offended if you ask them any questions. You might not be negative to them, you just want to know what happened, you know – *'why did he come home with diarrhoea? Can we work through this so that it doesn't happen again?'* They get upset with you, so it is very hard to be critical. But generally all in all it is something that is needed and mostly they are good.

There are some lovely respite places out there that really do care for the kids and there are some that don't, you have just got to be lucky to get the ones that do. Some of the workers are not that interested – it is just a job – and then you come across workers that have got such a big heart and this makes it all worthwhile. There are a lot of people working in the field who are absolutely wonderful, beautiful people who will put themselves out as far as they can for you. They are up against a brick wall because they don't have the funding, they don't have the facilities to work with.



Where the government is heading at the moment is that they are trying to persuade people to take in-home respite. Now when you are a young mum and your kids are young in-home respite is not bad – they come around, they will take your child out for six hours on a Saturday. These young mums think that this is very good, and it is at that stage. But when the kids get over 10 or 12 and they are starting to get older these parents are getting worn out. There are probably going to be more divorces at that time, the children are getting older, the fathers leave. Parents of handicapped children have a divorce rate of 85% compared to the usual divorce rate of 50%, so that is an extra 35% because your child has disabilities. That means that after a while these mothers are left on their own with these children, and all of a sudden the facility-based respite that they have been talked out of doesn't exist any more for them because they have been talked into having in-home support. Eventually I believe the government is going to shut the respite homes, and where once you were getting six hours on a Saturday and then six hours on a Sunday they will be saying, *'I'm sorry but we can only give you six hours on a Saturday.'* They are putting the respite back on the parents and the parents cannot cope.

In my opinion, if you are starting out, whatever you do don't accept in-home because you are going to want facility-based respite later on. If you give in and take in-home now, when you want the facility-based it won't be there because they are shutting them down. I know this for a fact, it has been leaked out – that that is their plan. Another thing is that if you want facility-based or you want help don't give up. They count on you giving up, and the point is that if you give up you are lost. They don't want you using stuff, they want you to manage it on your own. This is what the government is doing, they are trying to put it back onto the people. My message is fight for your rights and keep fighting and keep fighting and keep fighting.

'As somebody once said to me, "The thing I hate most about having a child with disabilities is the poverty..."'

One of the problems is just getting Joel to the facilities – one of them is a three quarter of an hour drive away. So that is an hour and a half over there and back, and it means petrol money. You have got to pay for the time that they are in respite, \$15 to \$25 a night. I don't have a package so it has got to come out of my pension money, and that means that I don't

have any money left for food because I am paying respite. But if I don't have respite then I collapse, so I have to have respite. It becomes an issue of finances. As somebody once said to me, *'The thing I hate most about having a child with disabilities is the poverty. If it wasn't for the poverty I could cope because I could then buy whatever help I needed, but because of the poverty you are up shit creek and back again.'*

I have had to go out and look for a job. I had a job assessment at Centrelink today because I haven't got enough money to live on. I have a Carers Pension but it doesn't give me enough money to support Joel and myself so I have had to go out and look for work. I have been through a job assessment today to see if they can get me anything, which is not an easy chore because you have got to find an employer who has got flexible hours so if my daughter gets sick I can leave. If Joel has a curriculum day, if he is sick, or during the holidays, I am going to have to have someone look after him.

It would be nice to know that every fortnight you would get respite so that you could plan your life, you could see your other children. My children and my grandchild have missed out in their life a lot because of me. When they have been sick, when my brother-in-law died, when people get married, I can't always go, and that is not fair on anyone.

I am 53 and medical studies have shown that most people who have a child with disabilities are ten years older physically than their age because of the wear and tear on their body. So I am not going to be able to do this forever. I mean – what happens to him if something happens to me? There is nothing in place, you can get emergency respite for maybe 12 hours, but it so hard to get anything into place even to go to hospital. We can't afford to be sick, we can't afford to die. There is a guy who is 94 who said, *'I can't die, I have my child to look after, he is 70.'* This is so wrong! There are people who are killing their children or themselves because they cannot cope. There are people who are dropping their children off at respite homes and not picking them up because it is the only way to get community residential housing. I have had to think about that, but it would destroy me – I could not do that to him. So I guess if we go down we go down together and that is how it is going to be. I don't know how much longer I can go on or what I can do.

I think that to have a child with disabilities and to not have the respite that you need means you end up trapped. I have always been the type

of person that if anything is wrong in my world I find an answer, but in these circumstances it is very hard to find that answer. It means that you don't have a life. You have a normal child and when they are eighteen or nineteen they are starting to become independent. But my future now is seventeen years – I've got to wait maybe seventeen years to get him a home because there are none out there. That means that I will be seventy before I get a life, and that is a prison sentence. I mean, I am going to have no money and no life and then I am just going to die and that is how it is.

What I need for Joel is a community residential home. I would put him in it on weekends, from Friday to Monday, and then I would have him home so that gradually he would get used to his new home. I would get used to him not being here all the time, until he is happy and I am happy and he is in there full-time in his own place.

The one thing I didn't mention because I've been talking about respite and I would hate anybody to have the wrong idea, is that I love my son passionately – I think that he is the most beautiful boy in the whole world. I wouldn't change him for the world, I don't want to change him, I love him, I just want help with him, okay. Don't ever think that I don't love him.



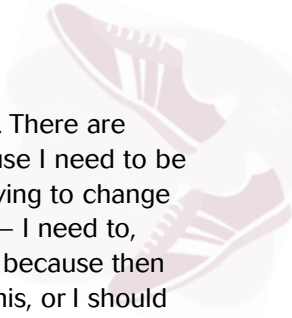


Robyn

Robyn lives in a blended family with her husband Darryl, her fourteen-year-old daughter and his three children aged eight, seven and five. She is primary carer for Darryl who has an acquired brain injury. The couple were childhood sweethearts when they were fifteen, but they lost touch. They met again and married after his accident.

Darryl was injured when he fell from the fifth floor of a building. He's now paralysed on his right side. He's had nineteen operations, and still has pins in his pelvis and a plate in his arm. He can't use the arm, but he can get around without a stick now. He has epilepsy because of the brain injury but he is on medication to monitor it – he hasn't had a fit now for over two years. He has short-term memory problems. It has an emotional side because it is frustrating for him, but it doesn't stop him from still trying. He has had to re-learn simple things like how to open a jar. I remember him first making himself coffee – that was a milestone! He just recently got his driver's license back.

I am always worrying, constant worry, anticipating his moods, always worrying – worrying about if he is going to feel okay on this medicine at the moment because it could cause epilepsy. He gets nauseous, he gets cold symptoms. I constantly worry about him, which affects my sleep, I don't get a good sleep because I feel him tossing and turning. We just recently got a new medical alarm put in so I don't have to stress when he is at home – he sleeps with it on.



I have to consider everybody else's needs before my own. There are things that I would love to go out and do but I can't because I need to be here for him or I need to be there for the kids. But I am trying to change those ideas. Recently I have lost 10 kilos. I am exercising – I need to, health-wise I have to look after myself, which can be hard because then you feel the guilt and then you feel, I shouldn't be doing this, or I should be doing that. So I just think no, I need to focus on this today.

His family doesn't understand the situation, and it doesn't matter how much I tell them and talk to them about what Darryl is and what he is about – they don't understand. Recently they wanted us to go over to meet his sister but he was feeling sick so we didn't go. They got really cross at us. They know the old Darryl who was probably a nice person before his accident but we are talking about a different person now.

When we first moved here I was at my wits end because he was constantly at my side and I was feeling very, very, suffocated. The children used to go away and visit so at least I could take off with my daughter, even just for the day, and he would be at home. He would be upset when the kids weren't here so that was another thing that I would have to deal with. I don't get a break from the kids and I don't get a break away from him. Sometimes I feel like, '*Go away, go sleep somewhere else.*' I was just going, what can I do, how am I going to alleviate this feeling? It felt like I was drowning.

The first place we found was *Outlooks*, which was really for mental illness, but they accepted him to go to the day centre. They came to pick him up so that was one less thing I had to do. He also got dropped off so it was great, because I had to pick up kids at the same time he was getting dropped off. At that place they would do activities, just talking, getting him to talk, because I had listened to the same story over and over again, and it was just like, I've heard this. He would play table tennis and pool, but mostly I think he wanted to talk and be heard because I guess he didn't feel like he was being heard. That was great because it allowed me to sit down and not worry and not have to run after someone, I could go to the shops, just try and do the things that I wasn't doing.

That was great initially, and then I think I ended up calling *Carer Links West*, which was my first contact with them. They got me onto *Lead West* which was then *Isis Primary Care* as well, which was all sort of linked in together, so that helped him with his car and stuff like that. But then it also

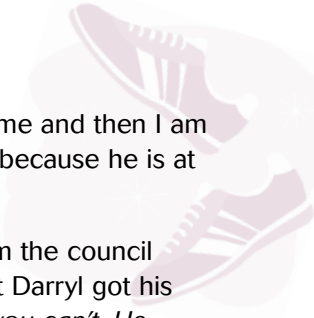
got him involved with an ABI group they had just started at that time. This Monday night group means the kids and I can relax and just go about our business in the evening. He also goes out every second Thursday for a dinner group so that just alleviates a little bit there. He does like the people that go and he has made friendships. That is what it is all about, making them feel good about themselves and being more independent, teaching them how to get back into the community. He won't go to the shops, but now he will go to places where he is comfortable – he will go to work, he will go to the groups, because he is around people that he knows and who are in a similar situation.

Sometimes the staff at the groups can get quite stroppy with them. I guess because they are only out once a week they just want to hang out and talk until the time allocated to them. Sometimes the staff rush them and it just puts that added burden on them. They don't want that. I'm sure they get enough of that at home with their wives so they just want to go and chill.

Darryl is working three mornings a week packing things at *Melton Regional Industries*. I go to carers' groups that are on when he is at work so we fight over the car. I say to him, '*I need the car today*', and that makes him a bit cross because it is like, '*Why didn't you tell me?*' The thing with telling him beforehand is that he tends to forget, so then I am repeating myself. I need to coordinate our diaries or something.

Yooralla in the city provide support, which is respite for me and that also helps him with domestic things around the house. They set up goals that he wants to do. He has learnt how to hang out the washing, vacuuming, domestic things, cooking. I can't teach him things because he gets frustrated at me and at the moment he's getting frustrated with the worker, so it is okay have a break. He just likes to figure it out himself – even if it is the hard way he still wants to be manly about it.

Everyone has been watching over us – the social workers. Explaining everything really gets tiring, you can't just go and do something. If you want to do anything you have to then get funding from somewhere, so then you have to explain why and then you feel like you are not deserving of it – but when you do get it, it makes it so much better. We are still waiting on a *Home First* package through *DHS*. We first applied back when we started living together, so that's about three and a half years ago. And that is for little things like taking Darryl to the shops, to appointments, helping out with family outings. We are very isolated because we don't



go out much, and if we do go out either Darryl stays home and then I am out there by myself with the kids, so then we rush back because he is at home and we don't want to exclude him.

Council help is very limited. The only thing that I get from the council is transport to the doctors. But when they found out that Darryl got his license they wanted to pull the plug on that. I said, *'No you can't. He knows how to get to his work and back because he has been going for two and a half years. But he doesn't know how to get to the other side of town to his neuro doctor who is in Caulfield. By the time he gets there he will be so exhausted, how is he going to drive home? I don't fancy him getting lost if I can't go.'* I won on that, I wouldn't fold! If you get a closed door you just need to find one that is open. One phone call will not get the answer – you have to find someone you know who can help, and just keep on trying.

'When he goes in the car with someone to the doctors I hate it because I am not there to advocate for him.'

It is hard, trusting someone else to care for him. When he goes in the car with someone to the doctors I hate it because I am not there to advocate for him. One time he came back and he didn't have his blood tests, and I'm like, *'Why did you bring this home – you were meant to have your blood tests?'* so I had to run around and get blood tests. So it alleviates that running around. I wouldn't be able to do that because I have to pick kids up; I would have to put them in care so that I could take him.

I need to have that couple of hours a day just to sit down – I can't even sit down – just to think of something else. I can easily go and have a sleep through the day and not feel guilty about it. I mean it still sticks in my mind that I should be doing housework or I should be doing this or that, but I fight that and just go to bed anyway, and go, *'nope I'm not getting up yet'*.

We got some funding to go on holiday. We only went to Ballarat but I figured I didn't want to go too far just in case Darryl felt a bit anxious. We were able to have a paid worker come with us every day. We'd start the day at nine and finish at three when the worker went home. I wouldn't finish my day until eleven o'clock at night because I was planning for the next, planning to see how much money I had, how much food we had. We packed our lunch every day so that we didn't have to pay for lunch out. A park is the best, it is free, and a picnic.

I think a night away would be great but I guess I am reluctant for that one and so is he, he wants to be home. *Isis Primary Care* are going to plan a camp for the blokes and that would be fantastic. He is excited by that because he knows the people. So I guess if they can get into groups and they can form these friendships they are not going to be reluctant to do other things with them. I call it planting a seed – you suggest something and at first you don't get a good response – it's like, '*Nah nah nah I don't want to do that.*' So it is initially saying, '*You could do this,*' not telling them to do it. Then they come back and say, '*I should do this*' and it is their idea, and you just sit back and go, '*That's good, you can do that.*'

Doing these new things is never easy, you do have to take it slowly. There are always anxieties, there is the unknown: what am I going to get into? It is even more so for people with ABI because they can't control the way they feel, they don't understand the way they feel, you have to hold their hand for everything. I remember going to physio every single day, sitting there and watching him do his physio. It got to the point where I was there telling him to do it and the physios were off doing other stuff. Then I thought, '*this isn't my job,*' so then I had to wean myself away and make him comfortable with someone there.

'The respite and going to those groups really helped me – I no longer had to be there 24/7, just a couple of hours a day.'

I hear ladies say their husbands don't want to go to the groups because they feel they are being dumped. You are their only safe haven and they trust you. I used to sit at *Outlooks* and chat to the other ladies and the workers, and I couldn't get anything done. So it was like, '*Okay I am going to leave you now, I'm going to get Ben to drive you home,*' and it was '*Oh, okay, see you later*' and he would be happy. You just have to stay with them until you see they are comfortable with their friends, then you can leave knowing that they are safe and happy. The respite and going to those groups really helped me – I no longer had to be there 24/7, just a couple of hours a day.

I wasn't around when Darryl first had his accident and I didn't have those initial meetings with doctors and stuff like that, so I didn't know what I was in for – I thought everything was normal. Even when I became a carer I didn't think of myself as a carer, I was in denial for a very long time, and then I was like – I am.



Claudine

Claudine came to Australia from France forty years ago. She has a daughter, 37, and a son, 35, from her first marriage. Her 18-year-old son Tyson is the only child from her second marriage. Claudine works as a community volunteer: she takes elderly people out to lunch and gives talks on falls prevention at her local community health centre.

My son Tyson was born a lovely little baby but around three years old he started with attention deficit disorder and a bit of autism. He was very hard to manage. I was trying to run a business and it was very hard, managing my son, the business and a bad marriage at the time. So I was very very stressed and when my marriage broke down I almost committed suicide. I couldn't see the light at the end of the tunnel – it was absolutely shocking. My case manager found a place in emergency accommodation for my son and he stayed there for three years while I worked on my inner self and became strong. I used to go and pick him up every Thursday for dinner and he spent weekends at home. He was there for three years. Then eighteen months ago I decided after a back operation to take my son home with me. He is doing very well. I made him very independent – he goes to school on his own, he takes a bus and everything.

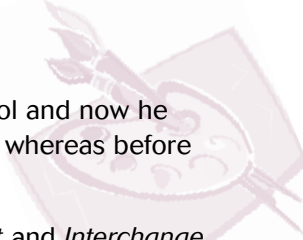
It is hard when my son is around me because he runs my life. He is constantly asking questions as soon as he comes home from school, his bag still on his back, 'What did you do today? What did you read?' But once he goes to sleep or he is at school I don't think about all that – that is what I know, I am a different person from what I was. So now I enjoy

myself, I enjoy my home, I go out and I do a lot of volunteer work and I enjoy that. When he comes back I tackle the situation and then I move on.

After Tyson came back to me I didn't have any support at all for three months and it was so hard. I had a lot of pain in my back, very very bad, and he was all over the place. He wouldn't go to sleep, so it was a battle, a battle. Since he turned eighteen I am getting more support. He goes to Curlew Avenue in Altona on a Friday around 5 o'clock and then he comes back on Sunday. Then there is *Pindari*, which is with *Annecto*, but the rest are with *DHS*. There is also *Scope*, so the mothers can get one day during the week, where the child can go after school and come back the afternoon after, and that is a great break. I use each place once every two months, so it might be a couple of weekends a month altogether, and there are camps as well. *Melbourne City Mission* runs a camp, and *People Outdoors*. On Sundays I go to a spiritual church so the paid worker comes and picks up my son from the church. She stays with him from 5.00pm until 9.30pm. They teach him how to handle money because he has a problem with that; there is also mowing to do and they supervise him.

I remember when Tyson was little and he went into care for the first time. It was absolutely shocking. He clung to me and I was a mess: *'What am I doing, I'm leaving him'*. He went to *East Avenue* in Glenroy (it used to be *Peacock Street* then) and once a month he would have a weekend there. He was six, seven then. He said to the worker there, *'Please ring Mum, please ring Mum, I want to talk to Mum'* and that went on all weekend. But when I got on the phone he didn't want to talk: *'Are you all right, are you all right?'* and nothing. But we went back a second time. You don't give up. For your own sanity you need that weekend, that weekend off, you look forward to that. It took him three or four times to accept it. I said, *'You are going to East Avenue, yeah, yeah, you know it is, good.'* Because they go out and meet different people which is why he doesn't have any problem going anywhere now. His bag is all packed for tonight, he is going to *Curlew Avenue*.

I make plans for my respite weekends when he is away. Like tonight I am going to the movies – there are a few movies I might see. When I go I see three movies, I just stay there for hours, I love it, and then I am all recharged. Or going to dinners – I have got my sister-in-law, we are great friends, so probably once a month we might go and have dinner together. I am starting embroidery work now that my son is more independent. I



don't have to be home when he comes home from school and now he knows that he has to get some food and a glass of juice, whereas before he wouldn't.

I have been on a couple of retreats with *Carer Links West* and *Interchange*. My son was looked after in respite during that time. I am very happy, very happy with the way things are organised. I have met quite a few of the staff from the respite houses because I go first and look at the house and meet the staff. I am his manager you could say, I do everything for him. I am the one who rang when he turned eighteen. I rang everywhere: *'I have got my son who is turning eighteen, what can you offer?'* So I advocate a lot for him, I do go out of my way and go and visit everywhere and if I am not happy, no, no, he doesn't go in.

One thing I am unhappy about is the issue of cancellation of bookings because homeless people are taking up the respite beds. (*Ed Note: 'homeless people' are people with disabilities waiting for permanent accommodation.*) The government has closed respite houses and I know that for a fact, so (they) can only give my son a place maybe once every three months because of the homeless people. If there are only two beds, how can they cater for all the disabled? There's a respite house he has never been to, and we were booked in January, February and March, and then they cancelled. That has been happening a lot, a lot. I plan my weekend but then I get a call on the Thursday and they don't even talk to me – if I am out they just leave a message on the answering machine, *'Oh sorry we can't have your son this weekend, we have to cancel.'*

'You just tell them, "It is only for two nights, and then you will be back here and you will make so many friends there that you will meet again next time you go".'

If you are putting your loved one into respite for the first time, brace your heart because this is something that you have to do, probably for the rest of his life so that you can become a person yourself. It is sad but what can you do, you need to go through with that. If the first time doesn't go well, try again and talk to your child about the positive situation of meeting a peer group and making friends and all and it is just beautiful. You just tell them, *'It is only for two nights, and then you will be back here and you will make so many friends there that you will meet again next time you go'*. So it is a nice situation, and my son was okay because because then he was coming and saying, *'I made a friend, he was there too.'*



Pieter

Pieter is primary carer for his wife Maree, who has polio. She contracted the disease in 1953, not long before the vaccine became available.

Maree got polio when she was nine months old and it has affected her muscles and her spine. She is in a wheelchair and hasn't got much strength in her arms so she can't do much, although she can use the telephone and make a cup of tea.

We've been together seventeen years and married for seven. Her disability affects me in that little things that she could do she asks me to do. Maree was brought up in an institution where they had nurses who would go and get things for her. Now for instance she says, '*Can you go to the bedroom and get me that folder*' and I have got to get up out of my chair and walk over there. Most of the time it is all right but when I am tired or when I am a little bit down in the dumps it becomes a big issue. You can't get up in the morning and say, '*I'll go fishing for the day*' because Maree can't get out of bed – she has got to be helped out of bed, she needs a paid worker and then she has got to find somebody to help her go to the toilet during the day. So it affects you in that kind of way.

Maree goes to work four days a week. It used to be five days but due to the polio she is getting too tired to do five days a week now. We have a worker who comes in the morning four days a week at half past five and gets Maree out of bed and gives her a shower so she can go to work.

That's if the worker doesn't have asthma then I have got to get up and do it, but I am awake anyway.

We don't use respite services unless I am away – I feel I can manage and I don't need them. When we want to have a break, Maree needs a break as much as I do, then we hop in the caravan and go away for a week or ten days. About two years ago Maree's brother made a raft with plastic drums and was going to go down the Murray River. He is just as silly as I am! So I went for a week with him, and Maree just brought extra workers in for the time that she was at home, like somebody came in and put her to bed at night. I felt a bit of trepidation about it as I don't like leaving her at home alone. It's not so much that I'm worried that the paid workers are unreliable as that she is my friend and partner. But it worked out well, and I have done it again – I have been up to North Queensland to see my son. So about once a year I go away, and the workers are always organised to come in. They have always been pretty good.

Also when *Carer Links West* have a dinner or luncheon it gives me a break – I go about twice a year, once in mid-June and once before Christmas. Apart from just a break they give me a chance to speak to other carers and see what they go through.

To other men caring for their wives I would say, you are a husband first and a carer second. Once you become a carer first you are going to get ordered around, you don't get asked any more, and that is where I have put my foot down. If it gets too much for you then certainly take a break because you get over-tired, you get depressed, and it will break your family up. It is better to have a week off every three months and revitalise yourself than trying to be a hero and the marriage dies.

Depending on the person you are caring for and how able they are, you have got to try to lead your life as normally as possible. Even if your wife is in bed sick, don't sit in the house waiting for her to call. Go and walk your dog, do your garden and just come in every hour or so and say hello to her. If there is something, then fix it, but don't dwell on her being sick or being in a wheelchair. You have got to treat them as the person that they were. Life changes, so when something changes that bit more you have got to learn to cope with it.

Pieter's wife Maree was present at the interview. She added these comments about her experiences as a care recipient.

My son, Luke, and his wife live here in Melton, so he is always only a phone call away if I need anything or get stuck. Even with personal care stuff he doesn't have an issue with that. Pieter went away on a scout camp when Luke was only about sixteen, and I said to him, *'Will you come and put me to bed or will I get a paid worker to come?'* Luke said, *'No Mum, I will put you to bed.'* So a sixteen-year-old boy out partying came home at 10 o'clock, and I said, *'What did you tell your friends about why you were coming home?'* and he goes, *'I just told them I am going home to put Mum to bed.'* I would have expected him to go, *'Oh I have forgotten something'*, or make up some other excuse. I try not to use my children as carers because that is not what I had them for, but I know that if I need them in an emergency they will be there.

The first time Pieter went away I was in my early forties and had never ever stayed on my own before. It was very daunting to me to recognise what might happen while he was away. I had paid workers in place but there was still the element of what happens if they don't turn up and the taxi is waiting to take me to the station and I'm not ready for work and I've missed the train and then I'm late for work, so everything just snowballs from the one issue. Also it was the time when the big gas accident happened and I ended up with no hot water and no cooking facilities, so I was home on my own with only workers coming and going. My son Luke was home, but they were things that we had never had to think about before.

'I realise that we both need a break from each other because we probably spend more time together than a normal married couple.'

Before Pieter went I really wanted him to go so I didn't say, *'What if this happens or what if that happens when you are not here?'* I recognised that he needed to go and have a break. He certainly was told about it when he came back, but not to the point where I don't want him to go again because I can't cope with all this stuff happening. I realise that we both need a break from each other because we probably spend more time together than a normal married couple. There are more things that he needs to do for me, you are pushed together more. You do need that break from one another.

I didn't want to make him feel guilty and think, oh I can never go away again because of what might happen the next time. So the more times he goes away the easier it gets for me to have the confidence to know, okay I can cope. I have got enough contact numbers to ring people and the network is there to call people if I get stuck. The last few times he has been to his sons up in North Queensland, so it's time for him to have with his family and grandchildren and get back on a level with them. They don't have a lot of contact because of the distance and it is a good opportunity. One grandson has just turned eighteen and Pieter was able to go up for his birthday. He needs to be able to do that and not feel, *'I can't go anywhere or do anything because Maree needs me.'*

He is at the moment thinking about going over to WA because his mum is in hospital, and we are now considering that he might go over there for a couple of weeks. It takes time to work out, it is not like you can say today *'I am going tomorrow'* – you need to plan it more than that. If an emergency came and he said, *'I have got to go tomorrow'*, okay go, and then I'll start making the calls and work out what needs to be done.

After the respite he breaks his neck to come home, he misses me.



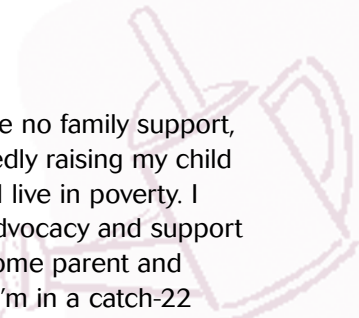
Sally — *not her real name*

Sally's son Harry is now nine years old but he was not diagnosed with autism until he was eight. They live together in an outer suburb where Sally enjoys gardening and other creative pursuits. She is also resourceful in finding ways to help her son reach his full potential.

My son Harry has autism spectrum disorder which is a higher functioning variety of autism. He can read and write and do all that. He doesn't have an intellectual disability, which is more of a problem in some ways because if you have an easily identifiable disability you get sympathy, attention and assistance. I find there is a lot more discrimination – it is harder for people to deal with and there is a lot more denial. It is harder to get medical people and other people who could support him on board to help him.

At first I wasn't aware that Harry was a child with special needs, but it became increasingly obvious as he got older. An autistic baby is probably the easiest baby in the world to look after because they self-entertain. I have seen other people run ragged looking after kids and mine was happy just to play on the floor – as long as I was nearby he didn't care, he was really happy. But as he got older, especially when he had to interact with other people, issues became obvious. By the time he was in school I was being called a bad mother by the school – they were blaming my parenting. Eventually it became clear to a few professionals that he was autistic. And then I finally saw a specialist that I have a lot of respect for to this day, and that's the specialist who diagnosed my son.

That was about a year and a half ago, and now my life has completely changed. I was a single parent with a disabled child who I didn't know was disabled – I just thought all kids were like that! Before the disability diagnosis there was no respite, no time off, no help with any of his issues. When he was diagnosed there was still no help, but at least I had a diagnosis and it meant I could go out and look for services and therapies to help him. The paediatrician gave me a list of phone numbers and through that list I got more lists of phone numbers, so I have gone through and rung every one that was relevant. I have rung probably thousands, I don't know how many people I have rung – I've spent days on the phone just ringing people. I literally ring up and say, *'This is my situation, are you someone that is relevant and can you help?'*



For me the main effect of all this is exhaustion. I have no family support, I have no support from friends, so I am single-handedly raising my child and I have been a single parent since he was born. I live in poverty. I can go out and get a job and not give my son the advocacy and support and all the treatments he needs, or I can be an at-home parent and provide him with what he needs but live in poverty. I'm in a catch-22 situation. Harry is at a mainstream school, but because he doesn't have an intellectual disability he can't get any funding for the services he needs. With autism there are a lot of behaviours that aren't accepted by society, and those behavioural issues are causing problems every single day at school.

'For eight years I had no help and no break at any time – it didn't matter how sick I was.'

The way I see it, I am really being pushed to adopt my son out, because if you are poor they are not going to give you the services, so you either crumble or you adopt your kid out to someone who can afford to give them the services. Because of my very restricted budget, half of my income goes onto my mortgage, so I'm already on a very low income. The help that I get is help that I have to pay for. I am allowed four nights respite a year from the council if I pay for them. So again I would have to pay for that plus pay to go out, so to me it turns into a very expensive night. For eight years I had no help and no break at any time – it didn't matter how sick I was. I have often been sicker than him but I have still had to look after him.

I am facing some big issues with *Centrelink* – I am going to be forced to look for work. The problem with that is that I spend easily 90% of my days dealing with all Harry's problems. I am training myself in all the services he needs, trying to educate myself in the absolute best way to help people like my child. Now, because of his condition, I have to drive him to a school that is not local – a school that is better able to help him. So I will end up working in a job the whole time and looking after him and not having time off ever, or going and grovelling to *Centrelink* every few months explaining why I am trying to help my son. They said I can apply for the disability pension. I went to the doctor one day and explained my situation and we filled out the form but I haven't been able to bring myself to hand it in to *Centrelink*.

I am not going to jump from one frying pan into another. If my work with my son was valued I wouldn't have to go in and justify every second of the day to anyone and I would be paid properly for the work that I am doing. As far as I am concerned I deserve the minimum of a wage, just the minimum of a wage. I am saving the government huge amounts of money by doing all this therapist training that they should be paying for. I am preventing him from being in supported accommodation. From a young age he was self-harming and suicidal, so I suppose it would have saved the government money if he had gone through with that. Without the help I am giving him his future looks terrible, and they are just making it as hard as possible.

I did have some help from *Interchange*. When Harry was about seven we got matched up to a host family, and they were just brilliant. It worked out roughly once every six weeks that I was able to go out. I would drop my son off and he would be dropped back at my home in the morning. Occasionally if they were going to the movies they would take him – they would ring up to say, '*We are doing this or we are doing that*'. They are just the nicest people. I've had them over for Christmas Eve lunch – I'm just so grateful to them.

Unfortunately about a month and a half ago Harry suddenly developed an allergy to their dog. He had a severe reaction and now that whole arrangement has fallen into a heap. We are both feeling terrible about it because they have made it clear that they care for him a lot and want to keep seeing both of us. Unfortunately I think the host family situation is going to fall in a heap, but I can't imagine them not being in our life.

'...no one really cares for my son, and they care. I think it is the cruellest thing to have a child that no one else wants.'

It's not even just that they were looking after him, it's just no one really cares for my son, and they care. I think it is the cruellest thing to have a child that no one else wants.

We also had a driving holiday organised through *Carer Links West*. It was only a couple of days in a motel in a country town but we had the best time. Harry thought it was so extravagant! We saw the local sights and they gave us a credit for meals at the local hotel. In country pubs there is always stuff going on and there were some other kids who were really kind to him. It wasn't a big deal, but it happened after we'd had a lot of

major difficulties with one medical visit after another and being told I had to find the money for all of these assessments that are really expensive.

The only advice I would give to others in this situation is: choose your friends wisely. If people put you or your child down just dump them immediately – you don't want to have people dragging you down even further. I have found the people that have been the most help to me – friends, people I can talk to – are the people I have met through the sole parent community. My biggest issue isn't the disability, it is being a sole parent. All the services that I am coming across in the disability area are simply not available for sole parents and yet I believe that being a sole parent is a much harder road than just disability. Because when you have got someone to help you, it is a load shared.



Helen and William — *not their real names*

Helen and William came to Australia from Greece. They are in their late sixties and have three adult children, a son and two daughters. Their eldest daughter Lina has a rare neurological condition which affects her physically. She still lives at home with her parents.

Helen:

These days things are improving but in the past, my story was very distressing and sad. But now they help – the *Department of Human Services* has improved a lot and gives a lot of support. We go to *Carer Links West* once a month for the support group and I have a paid worker nearly every day for one and a half hours in the morning to prepare Lina to go to the daily centre. And I have a few hours at the weekend for recreational care – the worker comes and takes her out. She enjoys going out sometimes, especially if the worker is all right, but the problem is finding good workers. This is a problem that affects nearly everybody. When we go to the support group most of the people complain. In the beginning I used to think it was the agency themselves – they don't send us the right worker, it's not the right time, something like that. I am still having problems with this.

It is getting harder for Lina and harder for us now. When she was a baby we carried her, we could go out every week. Emotion was there, but we could manage. But now because she is taller than me, she is the tallest in the home, it is hard for her and for us. She is even starting to say, *'Why am I like that, I hate myself.'* She has been through a lot, bad depression, thinking about suicide, hurting herself, and she has been on medication for six years just to calm her down.

Caring for Lina has affected my other children, especially the youngest one. When she was young, the poor thing, she is a very good girl, but I feel guilty now, I ignored her a lot, and sometimes she said, *'I am your daughter too.'* And now when I think back I say, *'How stupid I was as a mother.'* I feel the guilt of how I ignored her completely.

William:

That's why we don't want to put a lot of pressure on her when she is only in her twenties, or burden her emotionally. I just want her to enjoy her life.

Helen:

We don't use residential respite any more, not at all, because Lina is very scared from her situation. We tried a few respite places but unfortunately it wasn't too good. The last one was okay with her but the other one wasn't really the best. They had been good and caring, but she had bad experiences there. Somebody attacked her, a disabled client. She couldn't move and she couldn't scream or talk, but thanks to the Lord somebody from the staff came into the room. Anyway, nothing serious happened. So she wasn't badly hurt but it was very distressing. We questioned them, we talked to the department and they said, '*No, no, no, nothing happened in this house at all,*' and when I talked to the coordinator of the house, as soon as I phoned she said, '*No, nothing happened in our house like that.*' So I talked to my daughter and I said, '*The coordinator said nothing happened.*' When we made an investigation, this coordinator wasn't in that day and she didn't know what happened though the staff admitted it happened.

The staff were really good but they can't keep their eyes open for 24 hours. So what can we do? So since this incident she said, '*No way am I going to this house.*' That was a few years ago. We haven't put her in anywhere else because they can't meet her needs. The problem probably is the condition or it's Lina, I don't know. So now we are scared to put her in anywhere, even if the people there are really good. It looks like they can't meet her demands.

Another problem is that often you can't book the respite time you need. One day I remember we needed it badly at the weekend. My brother-in-law was in palliative care and we needed to visit him. He lives in the east, so I said we better put Lina in a respite house because my kids had to go and see their uncle – the whole family had to go. I couldn't find respite. Usually there would be an emergency bed because every respite house has one. I said, '*Where is this emergency bed?*' and they said, '*Sorry, we haven't got it because many people are homeless now.*'

When we want a break, usually only one of us can go. *Carer Links West* were really good to encourage us to go for two nights to Marysville and we went. But even when we were there, my other kids still had to look after Lina. We only had a paid worker for a couple of hours and my daughter came home to look after her. So when I realised she had to do so much I said, '*No, not any more, not worth it, not worth it.*'

William:

One of us has to go and one stay. I go to Senior Citizens by myself and maybe out to other places. Sometimes Helen goes to church or here and there or *Carer Links West*. So somebody has to be here.

Helen:

When we do take a break it is terrible because I don't want to burden my other kids who have a lot to do, and at the same time I feel guilty because I am having a lovely time and I don't know what is going on at home.

William:

One break was not bad when we went together through *Carer Links West*. We went for a weekend away and there was a paid worker one-to-one. During this weekend Lina was with us but not with us at meal times.

'I wish she could accept it because it is a mix of nice feelings, to have your own daughter with you and at the same time you are resting.'

Helen:

This was a beautiful time. *People Outdoors* take the clients and their families. So the families enjoy themselves together, all together, and the clients with their paid workers enjoy themselves. It was fantastic, I loved it! But my daughter didn't enjoy herself and that is why she doesn't want to come again. I wish she could accept it because it is a mix of nice feelings, to have your own daughter with you and at the same time you are resting.

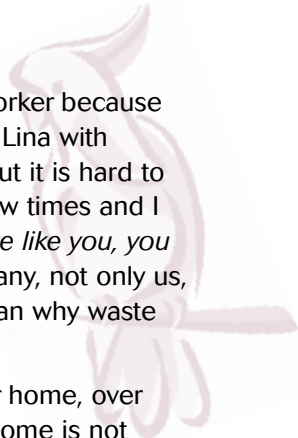
William:

It was one-on-one there, and still in the same group but not with us at all.

Helen:

We can't plan ahead for breaks. I would like to go back to Greece, because I haven't been for fourteen or fifteen years because of Lina. Every year we say we'll go but how we can arrange it?

In the beginning I didn't accept the paid workers. Years and years ago the case manager made a lot of effort to help me accept a worker, because I'm from a different culture. At the moment I have three



good workers, at last. But before, it depended on the worker because sometimes I don't feel at peace or comfortable to leave Lina with anybody. But now with those three, yes, I feel all right. But it is hard to get reliable paid workers. Sometimes they come for a few times and I say, 'Are you going to stay with us?' and they say, 'Yes we like you, you like us.' Then after a while they leave – the whole company, not only us, all of a sudden they leave, so they are not reliable. I mean why waste our time, their time, all that.

I feel angry about this. Many people have come into our home, over 36 from different agencies! You can imagine I feel the home is not our home, it is more the paid workers'. Of course I have no objection because they have to go to the kitchen, other rooms and bathroom because they are helping us, but I mean when they come for a short time just to invade the house then after a while it's 'bye bye' and they have to go on to their next job. I am not against the workers but I'm talking about what you feel, imagine they come to your home nearly every day for an hour and a half.

If anything happens to us my kids are going to stay in the home and take care of Lina, and the workers will come and go as it is. It's her home so we can't feel right to put her in another house. But the problem is now, while we are getting older and older, and still we say we have to look after her but we can't do it. We have a big room here attached to the house, and I wish the government can convert this big room to a small little flat for her and make the paid workers come in and out to look after her while we are here. So it would be nothing to do with the house here, and at the same time we know what is going on, they don't abuse her, she is in good hands, she is good, she is close to us. We would give them the property, we'll give them everything, so why can they not do that to help parents who have the facilities to create this idea?

William:

I think the main point for any parent, they have to accept the situation as it is, that their child has a disability. That is at least 50% of the problem out of the way, and gradually it will become easier and you can manage. Otherwise you wouldn't be able to manage at all, and you are going to suffer and you are going to be miserable for your whole life.

'To other parents in this situation I would say, accept that you need a break. Don't be silly like me.'

Helen:

To other parents in this situation I would say, accept that you need a break. Don't be silly like me. If your son or daughter likes to go to a respite house by all means. I would encourage parents to do that or in the end they are going to be like me, stuck at home.





Amber

When Amber first became a mother she also took on a high level of responsibility. Her baby daughter Pandora suffered cardiac and respiratory failure due to a breakdown of her immune system. Amber spent many months in hospital constantly by her baby's side.

Pandora was born in 2004, by emergency caesarean. She came into this world pretty much screaming and that's basically what we lived with for two years. For the first three months I would get up to feed her from

expressed breast milk – feed her for an hour, settle her for half an hour or an hour and then express, so I was just a walking zombie. At 3 ½ months she stopped drinking milk. She was never a rosy-cheeked kid – she was always this pasty little child, but I was a new mum and I had nothing to compare it with, nothing at all. When she stopped feeding we took her to the *Children's Hospital*, which was just a complete shock to me. When we arrived she went into cardiac and then respiratory failure right there in emergency, and ended up in intensive care.

For the first three months after Pandora was admitted to hospital I slept by her bed every day – every day I was living in the hospital and I honestly don't know how I did it. Then I got to a stage where I just had to trust the hospital. It was very hard going home of an afternoon and coming back in the morning, but I needed to do that – I needed to be able to go, *'Oh okay, I've got to go home and rest'*, and it took me a long while to know in

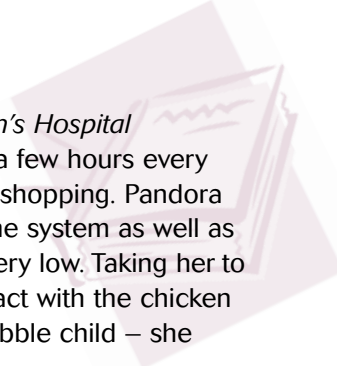
myself that it was okay to do that. At one stage I came home and was sick for four days because I picked up the bug that she had. You sit there and go, *'You need to not stay in hospital, you need to come home.'*

After we left the hospital we moved into temporary accommodation in the city provided by the *Bone Marrow Donor Institute*, which looks after a lot of people who have had transplants. We were in a one-bedroom apartment over there because we were going to the hospital every day. They were fantastic to us – whenever I needed help they were there. When we left there I moved into my rental property in Werribee.

My mother lives just around the corner and she is a great support to me and Pandora, even though she finds it a little difficult having to be a grandparent without the fun and games that a normal grandparent would have. It is very hard for her, and I think that if it was reversed and I was the grandma and she was the mum I would find it hard as well. Even though she is not a hands-on grandma, Mum is keen to be involved with the resuscitation and things like that. We have done a first-aid course together which was fantastic. She learnt the basic resuscitation skills. I did a whole-day course which included wound-care, bandages and all that sort of stuff. That was a great confidence builder for Mum, so now I can ring her and say, *'Listen, can you please come over and watch Pandora for an hour, I've got to duck out.'* I moved here because Pandora is so unreliable with her illness. Mum can look after my dogs and keep an eye on the house if Pandora has to go back to hospital, so it was basically a win-win situation for me to come out to Werribee. Mum is that kind of support for us.

Pandora's father and I separated in 2006 because of the stress of having a sick child and being in hospital for such a long time. We separated two weeks after she had a bone marrow transplant. Pandora sees her dad every Wednesday and Saturday. I believe that every child should have an active relationship with their father, and he is still very active in her life.

When we were at the hospital *Very Special Kids* got involved and they gave me a volunteer who came every Wednesday for a few hours. At that stage I was still living with Pandora's dad, so I could have that one part of the week when I could get the house in order and know that it was clean and all that sort of stuff. The volunteer would come to the hospital and she still comes now to my home. She and Pandora get along extremely well, so that is a great thing to have.



When we first left the hospital we had a *Royal Children's Hospital* package. They would send out a nurse who came for a few hours every week and looked after her so that I could do the food shopping. Pandora had chemotherapy, which wiped out her whole immune system as well as a bone marrow transplant, so her immune system is very low. Taking her to a shop or having a kid sneeze on her or being in contact with the chicken pox virus is just too risky. It was like Pandora was a bubble child – she never went anywhere.

It was still frightening to leave her in respite, but I knew that there was a nurse there if anything happened. The hospital service carried on until we came to Werribee. Then just recently I interviewed some council people – we chose three of their workers and they underwent specific training from the *Royal Children's Hospital*. They had to do all the assessments on resuscitation and everything else, and later the hospital staff will come back and do a six-week assessment on them again. The council are fine, they are great – there is a woman who we deal with one-on-one and she is fantastic. I have a great case manager from *Abercare* and she is brilliant, she does everything for me.

'...and if she did stop breathing while a worker was here it would be very hard for them to act straight away.'

I am now getting respite every week on a Monday for three hours and on a Thursday afternoon for three hours. I have subsequently gotten rid of the three hours on a Thursday every second week, only because one of the workers ...it's not a dig at her, it is nothing like that – it's just I need to be absolutely certain. Pandora is a special needs child – one minute she will be playing very happily and the next minute she is not breathing, and there is no sign to say what is triggering it. Unfortunately I think even though she is so little and tiny she can be pretty scary, and if she did stop breathing while a worker was here it would be very hard for them to act straight away. I think Pandora feels the nervousness of certain people and really plays on that, so I would rather take away the danger than have to worry about it, and that is what I need to do for her.

I think to anyone who is looking at having respite, I would say, '*Do it*', even if it is only for an hour. As a carer you forget about you, and I think that is the whole thing about respite. You need to be confident to trust your child or the person you care for with someone else because that is what they are there for. They are there to help you, even if you just go to the library

or go for a walk. If you get respite for three hours you might want to stay for the first hour and have an hour off in between.

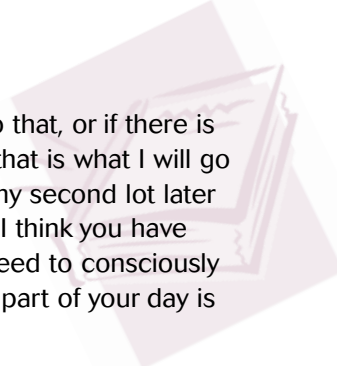
My respite on a Monday was designed so that if Pandora had been ill over the weekend and I hadn't been able to go anywhere, then Monday morning I knew I could go and have that coffee and step back into civilisation and say, *'You know what, I have had a cracker weekend but I'm okay.'* You need to do it no matter what, even if you are nervous or frightened. It is just basically putting one foot in front of the other – that is how you learn to walk and that is how you have to do it.

‘...you have to realise that council workers are trained, they don't just walk in off the street...’

I think my first experience of respite was a little bit easier for me because we went straight to hospital care and had nursing staff as respite workers. We had lived there for nearly two years of Pandora's life so I think that was a great transition. If I had gone straight to council respite I might have felt differently. But you have to realise that council workers are trained, they don't just walk in off the street, they are trained in the specific problems you have with the person you care for. You are never ever told not to be in the house when the paid workers are there. When they are getting trained, you can put in your two cents or five cents worth, whatever it is, but you need to feel confident with who is in your home.

My respite is carefully planned. Mondays are my specific shopping days – the list is written, the respite worker comes at 10am and I am out the door by quarter past, twenty past. I do my shopping and catch up and have a coffee with Mum, so basically it is *Safeway* then a coffee and then on to another shopping centre to get my meat and whatever else and then I come home. It doesn't sound like you can do a lot, but I love even just that twenty-minute coffee break, sitting down in a café and having a coffee. Just the simple things feel great – going shopping and not having to worry about taking oxygen equipment or taking very special care of what Pandora touches or who comes near her and all that sort of stuff. I don't have to think!

My other respite is used either just to go for walks in the park or hanging out at the library. The library is my best friend because it is a quiet place, there are no machines, no sound, nothing, and it is a place where I can just go and sit and relax – just doing what I need to do. If there is a bit



of shopping that I have missed out on I can go and do that, or if there is an appointment like the dentist I need to attend then that is what I will go and do. So my first bit of respite is my shopping and my second lot later in the week is designed for me, for what I need to do. I think you have to plan ahead. I think when you do have respite you need to consciously go, *'Okay, I need to achieve this'*, because every other part of your day is achieving goals with the person you are caring for.

The best respite experience that I have had was the day that council workers had finished their training and it was their first day. It was an achievement for them to know that I was confident they could come into my house and look after my daughter. I have been doing this all along and I have never been trained – Pandora's care is so complex and it was nice to know that someone else finally understood what I deal with on a daily basis. I knew that someone else out there knew, it was like sharing, it was like, you know what, this is great, I am really happy!

Because Pandora is such a well-known little girl, you could actually see how happy they were. They were as nervous as hell when they walked in the door but when they left it was like they had a little spring in their step. They would know that, *'My God, she does deal with a lot'*, but that is what your respite is there for – you know that there is someone else to care.

Don't be tempted to take respite at different times of the week even if they offer it to you. Always book your respite in and make sure it is the same time every week. Every Monday I know I have respite between 10am and 1pm, so I know that I have got to get my bum out of bed, get out of my pyjamas and get organised because I am going out. If you have your respite at the same times every week you get yourself into the understanding that it is okay, it is all right to be able to leave the house at that time and know that someone else understands what you are going through. I've always had a Monday and a Thursday and if I ever deviate from that it is an absolute balls-up.

You are not abandoning the person you are caring for – you are doing it for yourself because you are someone as well, you are not just put on this earth to look after this child. When you think about it, there are twenty-four hours a day and if you take three hours off you have still got twenty-one hours left of the day. And I think people who are thinking about respite really need to bite the bullet and do that big jump and go, *'You know what, this is when I am going to have my respite.'* It is great because

friends ring you up and you can say, *'Listen, I've got respite between 10am and 1pm on a Monday, do you want to catch up and have a coffee?'* and it makes it that little bit easier. You find that it is hard but you need to do it, you need to do it.

I have now got a team of people who understand what I go through, and it is nice to be able to say, *'Can you just take it for a few hours please.'* I think that is your dream respite: to be able to have someone else that you can trust enough to look after your flesh and blood, whether they be young or old.

For someone who is a virgin at respite, you need to just do it – it is very hard at first but once you start it is like an addiction. You deserve it, and there is no one else out there who is going to give you a hand, so if you can do it take it. What is that saying – a problem shared is a problem halved? You know what, you are only human, as much as we think we can just keep going, going and going, we are not Ever Ready bunnies, we're really not! We really need to just take some time to reflect, even if it is only sitting in the backyard for respite. Do it, just do it, bite the bullet and do it.

Being a mother – I never thought it would be this hard, but I can't change it and I never would change it. There were times when the doctors said, *'Turn the machines off, it is not worth it'*, but my daughter lay there with tubes and everything coming out of her and she survived. Pandora has decided to stay here, and you know what, even though I am exhausted and I try and get sleep whenever I can, she is my little miracle. If I can take a little bit of whatever she has got inside her it keeps me going every day. I mean there are days that I can sit on the floor and cry and cry and cry, but I know that I have still got my child and she is just brilliant.



