In mid 2010, when he was 34, Michael Butterworth moved into his own home for the first time.

Ruth Gerzon supported him to record this story of learning to live on his own, and managing individualised funding, in 2012.

Teia Burney was a support worker for Michael Butterworth for 13 months, coming into his life at the time when he moved from agency support to Individualised Funding.

Teia played an important role in Michael’s life. Her part in the journey they shared follows Michael’s story.

Michael Butterworth

15.8.1976 – 25.10.2012

I am the youngest of eight. I am 36 years old and I was born and raised in Whakatane. I wasn’t always disabled. It started at the age four. The disease set in. The doctors were able to diagnose it fairly rapidly. Dermatomyositis. It was a life changing diagnosis not just for me but for my family also.

The disease moved fast when it set in. It was hard for me and my family to keep up. By the age of nine I was off my feet completely, in a wheelchair and in hospital for two and half years. The calcium was breaking through the skin in all places – shoulders, armpits; back of my legs from the buttocks to the back of the knee was one open wound, as well as the length of the spine. The treatment shifted from maintaining muscle mass to keeping the wounds clean and getting them to heal. At the same time I had schooling at the hospital, and physiotherapy. The physiotherapy started to ease off because I couldn’t really move and they were struggling to move me. I was constantly on my back. I couldn’t sit because of the sores. I couldn’t wear clothes because of the sores. It was tiring. It was painful.

In 1987 the doctors said there wasn’t much they could do. They said I wouldn’t make it to the age of 15. They suggested putting me into a rest home in Auckland where all my needs would be taken care of and the family wouldn’t have to watch me die. My parents left that decision up to me. I said that if I was going to die I wanted to die at home.

When we decided not to go to Auckland the hospital washed their hands of us. The family was glad to have some kind of control even if it was going to be the last thing they did. They had seen their son deteriorating from a healthy four year old boy into the body of a dying 11 year old and they had no control during this time.

We’re home. Mum’s having to do everything for me now. The days are long and extremely painful, only now the neighbours can hear it. They’re hearing screaming from the house as Mum’s trying to wash me. It was difficult for everyone involved but it was stuff that needed to be done. She stopped giving me the medications. Everything went in the bin. I was going to die so why were these needed anymore? A family friend, a bushman, suggested an ‘alternative’ form of treatment. We decided to give it a go. We had nothing to lose. We stripped the leaves from koromiko, boiled them in water and washed the wounds with the water. My mother rendered down pork fat as a poultice and rubbed it in the bandages. It stunk and stung but was a hell of a lot nicer than the stuff in the hospital. I don’t know if it was because of these treatments or because we stopped taking the hospital medication, but by 1990 the wounds were healed. I was wearing clothes again. A big step in the right direction.

What to do next? None of us knew what to do. Suddenly we have a measure of control over my life but we found ourselves in time and a space where we never expected to be. I was due to die in a year and I wasn’t. It seemed like the disease had stopped, run its course. By now I couldn’t walk and my arm movement was very limited.

In some respects I was a moody normal teenager. The only friends I had growing up were the doctors, the nurses and my family. They were constantly there. I didn’t really have friends my own age. It wasn’t so much of an issue then because my life was so much about the experience of the disease, the physiotherapy, the hospital. But at the age of 19 or 20 I didn’t really know much about being around other people and about life. So I preferred to stay at home and play video games and watch movies. I loved reading. This was what I did for the next 15 years. The most experience of the world I ever had was through a book or another person.

I never really had any aspirations for myself, any sort of expectations for myself. That was the hardest thing. I can’t say that there was one defining moment that caused that to happen. I suffered from a lot of depression in my twenties that’s just from loneliness and dissatisfaction. I got tired of watching movies, you know, watching my nieces and nephews pass me by, seeing them being born, watching them grow up and move on and do things I should have done. So I think it was a cumulative thing. I guess you got to a point where screw it you may as well just die. I kept myself isolated for part of my life, the greater part of it. It became a vicious cycle. I am angry, I’m depressed, and by choice, I am isolated.

At the end of 2003 my mother was diagnosed with breast cancer. She was in her 70s at this stage and was still my sole caregiver. This scares the hell out of everybody and causes people to finally think about the future and what’s going to happen to me. We sold the family home and moved in with a sister and then a brother. For the first time I had paid carers.

In 2007 cracks occurred in family relationships. My mother left, I stayed with my brother. 2008 was a nice year for me, regardless. I got to meet a lot of people through my brother. His family opened my world up. People would be over for dinner or we’d go to someone’s for dinner. This year we travelled. There were trips to Hamilton, trips to Gisborne. My life was becoming a life. I found this scary. I had to go out of my comfort zone a lot. My brother and his family and their friends were amazingly supportive. They became my friends. I am forever thankful to my brother for the year of 2008. He had to put up with a lot of shit, and it was nothing he volunteered for. He was just helping me out and this came with huge costs.

In 2009 rifts arose in my brother’s home and I found myself having to leave but this time I’ve got nowhere to go. A disability service coordinator, an independent advocate and a team from different agencies, Housing Corp, the hospital OTs, came together to find me a place to live. I really wanted to stay in the community. My only other option was to go into a rest home. This was absolute last resort. At one point we had to quickly scramble to find me temporary accommodation. I spent one night in a rest home, but if I stayed I could not keep my carers.

One of my carers was a nephew of mine, living with a girlfriend in a brand new three bedroom home in Kawerau. She volunteered to have me stay there until I could find something more permanent. She was only 19 and was working all day. The rent was cheap and it was accessible. They had a one year old child and we all shared the home. They were my first flat mates. I paid board. I knew it wasn’t permanent but would give the agencies time to sort something out.

Because I was now living with a paid carer we had to get permission from Minister for Disability Issues for an exemption to the rule that you cannot live with a paid carer. Otherwise he would have lost his job. The Minister quickly agreed.

I don’t think my family members have ever got used to the fact that I’m still alive. It’s like we’re still stuck in the 1980s and we’re just waiting for me to die and then nobody’s responsible for me. This is what was going on in my head. None of my family visited when I was in Kawerau.

**A home of my own**

Finding a permanent home took a while. All the accessible houses were occupied. We asked about the possibility of altering one of Housing Corp’s other homes. They offered a few different places around town, unaltered. The OTs turned down a couple. I turned down at least one that was in another town. As we got further into the process, it became clear that while Housing Corp would allow alterations, Enable was not willing to pay for them. They had already paid $7500 to alter my parents’ home a few years earlier. Cutting a long story short, sometime in May 2010, Housing Corp came to me with two options. One was a 4 bedroom home. It would be up to me to make alterations. It didn’t have any ramps or a wet area in the bathroom. The other option was to come here, a new accessible unit, one of six Welcome Trust units for disabled people. It has a kitchenette, small sitting room, bedroom and a bathroom very suitable for my needs. It’s close to town, the shops and the riverbank. After seeing it I said yes on the spot. They signed me to a six month tenancy agreement. There was no long term vision. I just wanted to see if I could live here and make it last.

Moving in was like diving into really cold water on a hot day - the shock of it. My heart was pounding, it was hard to breathe. It wasn’t hard in the ways everyone assumed. People were concerned that I would be alone at night and be lonely. I was just happy to have a space of my own. No one hassling me, no one bickering. My carers look after me, I have various groups and meetings during the day, and friends pop over in the evenings. I have the beginnings of a social life here.

The hard part was the day to day things that adults have to take care of. Managing my budget, making sure there was food in the pantry, paying bills, and keeping track of everything. It wasn’t the tasks themselves that were stressful but just the fact that they had to be done and I was in charge of this all. There were the “do your head in moments”. I nearly had a meltdown making a list to go to the supermarket. It took a while to get over these ordinary things. I found them quite hard to deal with. People around me at this time were very patient and let me make the decisions. I finally was able to choose what was in the pantry and choose wisely. I couldn’t just have McDonalds every night.

Now I have proved it to myself. I can work with others, make changes and control who comes into my life. I’m loving that. I meet lots of people and get to talk to them all the time. It’s interesting. Now people can really get to know me. It’s not being filtered by my family. It hasn’t been sunshine and daisies. Have all of the relationships survived? Some of them. Do I consider some of these people my friends? Well yeah.

It was really hard for me to get to know people. There was the fear of how to be, and what to say around them. I’d never been the one to initiate the conversations, it was always through the efforts of the other person. That has changed now. I am a lot more outgoing. I still have my moments when those old feelings and thoughts are still there. At times, I still get an overwhelming feeling, even when I’m around friends or familiar people. I think that will always be there and there’s nothing I can do about it. I just can’t let it get the better of me. They’re just thoughts. They’re just feelings. That’s all it is.

**Supports**

Support mainly comes from the Ministry of Health. Have I got what I asked for? Yes. There’s a few things that I haven’t asked for that I’ve gotten but I’m finding uses for. The prime example is something I didn’t ask for, an automatic door opener. In October 2010 an OT asked me, what if I wanted to go out alone? This was something I never thought was an issue. They insisted and started the process of looking for a solution. They found the product. The submission for funding was approved. Now I wonder why it was never an issue for me. Why wouldn’t I have wanted to go out on my own? This went through rapidly from initiation to approval. The problem arose in its installation. Housing Corp agreed, as long as the alterations were reversible in case I decide to move out. It was July of 2011 before it was installed and working. Everything is a slow process. That’s the thing with bureaucracy. There’s a balance between them trying to protect their own interests as well as fulfilling their obligations. That is their job. It becomes an interesting dynamic and conflict between the two needs of the organisation.

The agencies and organisations may look and sound good on paper, but in the real world, as much as they try to be sensitive and helpful, they are often not. Everything has an agenda. There are always rules. Not all, but some of the people I have to deal with, even they struggle to understand their policies and where everything fits in the greater picture. If they’re not changing policies, they’re renaming them. That just makes everything more confusing. Nothing is fixed. The basic problem with the policy or plan is never really addressed. I don’t like having to be confrontational with the people who are at the bottom of the chain- the actual people who are dealing with me. I know they are doing their job. They know me, they’ve seen me and have been in my home. They are my first point of contact. Unfortunately they have no power. Everything that we discuss can get kicked down by someone from a higher power.

**Patience**

I’ve definitely had to learn to be patient. In my mind now, there’s no difference between being patient and waiting for someone to make me a cup of coffee, or waiting for a group to organise an automatic door opener. In my mind it’s the same thing. It’s just going to make you crazy if you think about it too much. You have to try to maintain some sort of perspective on it. I don’t think I’m more patient than other people. If I could have things my way then I would have them my way. I don’t think I’ve always been this patient. I have an easy going nature. I’ve always been quite laid back, especially with other people.

It’s always been myself that I’ve been hardest on. Some people call it being a perfectionist. It’s always been easy for me to see things from other people’s perspective. I still do that. I can’t help it. So when I’m dealing with people from different departments for example with MoH, I see my issues and I also try to see theirs as well. Some people may say I let people walk all over me, or I’ll sabotage myself because of that mindset. I don’t think that is entirely true. I think in these circumstances I don’t handle it the same as them, but that is what I feel is right. This especially happened in the early days. I would watch how my parents dealt with things.

I’ve become a lot more pushy than my parents ever were. A lot of things I just learn as I go. I kind of understand the bureaucracy with the policies and how they work better than I understand normal interactions with people. I feel this is because I was basically isolated from the world as a child. I didn’t get to see how the world works. I’ve learnt that impatience doesn’t get you anywhere. Getting upset with someone does not make them work any faster. They don’t want to do the thing in the first place if you’re angry. No one is going to want to work or want to help you if you’re angry and yelling at them. The only difference is, I know that they’re obligated to work with me and deal with me. It’s their job. This helps me to be more patient with them. As much as I need their help, they need my cooperation to make things work.

Dealing with organisations, there are still protocols and so many different people are involved. Everyone has to do their own job and they’re all accountable. I’m not the only one with a disability in this country. There is only so much money I am allocated to deal with my problems. That’s just something I have to live with.

**Gaining a place in the world**

Things changed for me when I got here. I was finally in a situation where I could make decisions. I’ve started to realise that I have a place in the world. Just the mere fact of me being in my own place started to change my way of thinking, as with the door opener. It was explained to me the practicality of it. It wasn’t until I started using it after I got it that it made sense to me. I joke to people that there is no plan, I just make things up as I go along. In a sense that is what I am doing. There are thoughts and ideas now of things that I want to do and want to try. It’s just a matter of where do I start and narrowing all my desires down. At the moment I want to do everything and go everywhere.

The way my family feel about me has stayed the same. They still love me and care about me. What has made it difficult is that their expectations haven’t changed. They still see me as that little boy who’s on the cusp of dying. He needs to be looked after and made as comfortable as possible until he’s gone. They’re stuck in that moment. This is hard. They have a really hard time visiting here. Just the sheer realisation that I’m out on my own, living independently. It brings those who do visit me to tears. It’s a punch in the head to them. It’s such a big shift from what they’re used to and what they perceived. They can’t believe that people are allowing me to do this. They believe I should be in some sort of care. Some members think that I have fallen under the influence. That people are using me to get ahead in their career or make some sort of point. Some think I’m doing it out of recklessness. They imagine that I’m getting wasted and having orgies - that I’m being allowed to do things I shouldn’t be allowed to do. That’s their mindset. “We know Michael best and who are these people who are letting Michael do whatever he wants?” This makes it difficult for me to spend time with them, because that’s all they want to talk about. It’s been five years since I left the care of my mother, and my sister’s house. I have managed not to kill myself in that time. I’m still alive and I still pay my bills on time. There is a perception that these things are only happening because the carers are keeping track of it all and doing it all for me. No one is. I’m doing it on my own. No one is doing it except me. I don’t get any acknowledgement of that from them. Does that annoy me? Yes. Does it make it difficult for me to be around them? Yes. It doesn’t seem to be improving with time regardless of the fact that people keep telling me it will.

**Reflections on power**

My parents and the health care professionals all had different reasons for feeling they were entitled to make the choices they were making. I was disempowered by professionals from right at the beginning. I got to experience one year at school- that first year. From the following year onwards, I was schooled at the hospital in the children’s ward and from 1.30-4 would be spent at the hospital physiotherapy. I didn’t have much say in the matter. Everyone thought that was going to be the best thing. It wasn’t just my education that was compromised by not going to school, it was everything, meeting your peers, being social. I wish I had had the choice.

I’m still scared a bit by the power I do have and the day to day decisions. On a bad day I have trouble picking out which shirt I want to wear. I’ve learnt now that if there’s things in your life that you don’t like that you can change them. This is something I’ve only recently got a grasp on in the last couple of years. I need to keep things in perspective. I wasn’t in control then, people weren’t listening then. I am in control now and people do listen to me. It’s about getting over yourself. Leave the past in the past and see forward.

**Support workers**

When my condition stabilised I was left with some movement in my fingers and my head, and I have feeling the length of my body, but I am all skin and bone, unable to put on any weight. My immune and renal systems function normally now and on a day to day basis I am healthy. I can’t do anything without my support workers, can’t get out of bed. My day starts when they get here.

There is power in the relationship with support workers. It goes both ways, in the sense that I am dependent on them but also they are dependent on me. I am their job. I had one of my siblings be a support worker for me. It was hard to have power in this relationship as she thought of me as her little brother. This was when I was in my independent home. This not the same as living with my other sister, because I was in her house under her rules. This was my house and my rules and acknowledging that was hard for my sister to deal with. She is my sister, how much more familiar can you get in terms of knowing and being comfortable with one another? But it can be the reverse. It was the fact that she was my older sister. Her level of love and wanting to help was strong but also she is a mother and has lived independently on her own. *Why should I do anything the way you want it to be done?* The arguments we were getting into were stupid domestic stuff about the washing powder I buy, how the towels are folded and the cutlery drawer in the kitchen. Things you would never have with another carer. It was driving her nuts to come to work as things weren't the way she wanted, losing sight that it's my home. It was because of my disability and because I was her little brother. She could not get around that, she wasn't going to stop until things changed. She chose to leave after three months. I'd rather deal with strangers, because then I can establish the relationship from the beginning. It all comes down to communication. Clear understanding is key. Sometimes you just have to realise that me and the carer are not going to get along and there’s no point in struggling.

I have had seven staff over an eight year period. I don’t think age really matters. There’s a limit at both ends of the scale as to their suitability. The main requirement is that they need to be willing, and actually capable of getting the job done. I have had carers who have been in their 50s. The current staff are both in their 20s. I don’t think the gender matters essentially. The gender thing can be interesting. The work that is required is very intimate. There is a huge level of trust involved. I think that both genders bring something different to the job and it’s good to get both.

Personality is a big factor due to the trusting nature of the job. If personalities don’t mesh, it will be horrible for everyone involved. I’ve learnt that the hard way. Listening skills from the staff goes both ways. The work is pretty simple. After the technical side of getting me out of bed and washing me, the rest of the day is more domestic stuff like cooking and cleaning. We do a lot of chatting throughout the day. We know a lot about each other. It gets to the point where they can read me. They know when I’m upset and know what’s going on. And I feel the same way, it goes both ways. They can talk to me about their issues and I can talk to them about mine. You tend to talk to the person who’s there and they’re always there. It’s building a relationship with the staff which is almost friend-like but still respecting the employee-employer relationship. We both have to remember it is a job, and a professional relationship first and foremost.

When we are together during their paid day the relationship is a professional one, but there are times where we just kick back and hang out. I am connected to these people through the job. That’s what that relationship is built on primarily. Other people hang out with me because they’ve gotten to know me. I meet them over various different circumstances. Some of them have become friends. The one common thing between the two groups at the end of the day is they just see me as Mike. Everyone is seeing and hearing the same thing. It is sometimes hard to remember to maintain the professional relationship with my staff.

**Individualised Funding**

The concept of Individualised funding is excellent. It is not always communicated clearly to potential clients. It can sound complicated and intimidating. Manawanui in Charge wanted me to nominate an agent even though I was practically managing and coordinating my staff under the old system, and six months into living independently and being responsible for my own finances. Still from their point of view it was a risk for me to manage my care.

It took a number of people to help me speak up about this. Someone new came to see me and believed in me. In the end it comes down to someone listening rather than trying to imagine themselves in my situation and what they would do, or strictly adhering to their understanding of the guidelines. I got advice about becoming an employer from an advocate and also from friends. Some of the people who help me are Jehovah Witnesses. There are a lot of small business owners within the congregation who have given me insight into managing staffing situations and things like that, been useful to me in that way. Also they have been very supportive of me and everything I have tried to do for myself, so they are part of my network, people I can go to and talk to about the IF, or just management.

It’s the whole concept of Individualised Funding, I’m finding for a lot of people it’s a very hard concept to grasp. It can seem very scary having to deal with the paperwork side of things but there are a lot of resources to help you and they are not too hard to access. You’ve just got to be willing to ask people, whether they be in your own personal network of friends or family, or you know, Google helps, or even just the company itself, Manawanui.

Some of the issues I have had in the past were through having support workers employed by providers. The providers carry out community home based care and are contracted by the Ministry of Health. I had support workers who didn’t see me as their boss, they saw the provider as their boss. When one support worker became aware that I was applying for individualised funding, and exactly what that would mean, that she would have to see me as her boss, that was difficult. I would no longer be the cripple that she comes in to help. The job itself wouldn’t change it was simply a personality clash between me and that particular worker. I made the decision not to contract her.

I’ve been fortunate up to this time. I have not yet advertised but found support workers on my social networks. If you tap into a network someone knows someone else who can help you out in some way. It's having a point of contact with someone in the community and being vocal that makes it work.

Relationships are key. My two key workers have cared for their family members before they came here but had no formal training. My previous staff gave them training, and they got some verbally from me in interview process. Then I invite them back to show them the practical side of job, personal cares, washing me. After they have seen that they have option, I ask “*Do you think you can do this?*”

You can't really know how someone will be through an interview, but you can use questions, asking whether they would be comfortable being asked to do certain things. I look for their use of eye contact, listening for their response, but most of it comes down to giving them a chance. It's not certification or years of experience that qualifies them for this work. It's attitude, life experience. This is not a nine to five, because of intimacy and personal nature of the work. They come to work in my home, it's not an office or institution, so you want people you are comfortable with and for them to be comfortable here too. Communication is key from the start. Helping them to understand that I am going to be as clear and blunt as I have to be in order for us to spend time together, and encouraging them to do the same, an environment where they can do that.

My relationship with my support crew - it’s good, you know. I have always told them, that basically they are like my arms and legs when they come on board, but they are so much more than that too, all of them. We share a lot of experiences and moments, they are right there with me. They seem to take a measure of joy in being able to help me to do things, achieve things. They seem to enjoy just hanging out, a lot of the time it feels like, we are just hanging out, doing stuff. It’s been good.

It is possible to live a life with a disability with the systems we have in place. But it is difficult. As I said, there is the balance of bureaucracy and freedom of choice. Money is a huge factor. I’ve had a taste of a life operating between the rules of the Ministry. It’s more than I ever expected or thought of.

Being on IF has motivated me to have high expectations for myself, and from the world around me. It’s made me want to do more and be more. It’s challenged me and I like that, you know. It’s been a good time. My idea of fun was always stuff I do on my own, most of it inside my head, reading books, watching movies, , listening to music, that is how I experienced things, that’s how I learnt about things. Now I am instigating that, I am right in the middle of it, and IF has been a big force as far as that’s concerned.

Did anything make me want to stop or give up? Um, I have come close. I always tell people that I don’t know how long I can sustain this. I don’t know how it’s going to end. I am thankful for every opportunity and I am thankful for this life. As hard and as stressful as it is at times, I wouldn’t change anything.

 [Going to the Imagine Better Conference] means a lot. I really enjoyed listening to other people and their experiences. I have enjoyed that more than hearing from different agencies and from the Ministry. It’s the real world stuff, from other people, who, I am finding, were sharing a lot of the same experiences and feelings that I had. That’s what I really enjoyed.

I just want to live as ordinary a life as possible. I have my first home. I hope it’s not my only home in this life. And coming next? Hopefully some sort of career. What that career is, I have absolutely no idea at this point. Currently I’m looking at starting tertiary studies. That was the goal of this year. That has been put on the back burner at the moment for a number of different reasons. It’s been hard to organise myself and my carers to get it done. It’s a work in progress. I was looking at studying anthropology. People and culture interest me. Studying is definitely on the to-do list. I would like to start earning money. I want to see how independent I can be, how much of an ordinary person I can be.

**Teia Burney’s part in Michael’s journey**

When I came to work for Michael, I had not worked for long in the disability field, just six months for a man who had tetraplegia. But because of my life in Australia I had life experience, knew about people and how they behave. I knew what I could do to keep myself safe in a multitude of situations, whether physically or psychologically demanding.

Because Michael was fresh to life I had to share that knowledge with him. It helped him have a different level of understanding. He would listen to what I said, he saw me as a worldly person. At times he wouldn't accept what I said, but he might acknowledge my view as possible.

I am very open. Even at our first encounter I didn't restrict myself or him. He could ask any questions, and if things I thought needed to be said about myself, I said them, so he could free himself up to decide to have a relationship with me. He took the professional part of our relationship very seriously at first, less at the end. It came from his lack of trust in his own abilities.

When I came with my openness and my love, it was hard for me to see a man in his situation, to realise he chose not to have support from his family. I felt like love needed to be there some way or the other. So we had a family type of love, but I had to be careful and be clear. “I love you too, but it's a ‘bro’ kind of love.”

There were hard times, times when he did resent that. And sometimes he felt he would never have that intimate love. All we could do was talk about it and be clear about it, setting those boundaries. It was good when he had a counsellor, he could talk to him about it. He needed a third party to explore those thoughts.

A lot of his life experience came from fictional stories. Now he began to experience things himself. We had arguments, because he was learning how to cope in the world. I am a very honest person. It was probably inappropriate in this working environment but he needed to have those conversations, because in some ways he was sheltered from the truths of the world. He was a clever man and he did inform himself, for him it was practical. Some things needed to be said out loud for him to grasp.

Michael was always cryptic, not straight. Often I had to listen and decipher the feelings behind things and make decisions myself. He never directly spoke about important things. It was always hypothetical. He would quote someone else, not stating his own feelings. It took quite a bit of guessing to work out what he might be thinking.

I had to understand the reasons why he had put restrictions on himself. In order to fulfil the job I had to help him through that. It seemed like instinctive paranoia from his earlier years, not necessarily to do with his disability. “It's not your disability it's your fucking brain cells, man,” I would say.

In order to truly utilise the resources of Individualised Funding and the freedoms that came with that, he couldn't really allow his family to come in and influence his ideas about what he wanted. It was not that their opinion would be bad, but he wanted the opportunity to make his own mistakes. I told him “It is not because of your disability. It's not that you’re special. Your family might be like this, but others go through this stuff too.”

It was difficult for him to see how his life might be once he left home. It was not just him, but his family, who could not believe he would be safe. He was concerned about his own safety and well-being, that he may push himself too much or, that at the end of it all, he would still not be able to complete anything he started.

This changed because more people were saying 'you can'. Yet no matter whether others said “You can”, he said, “Don't be silly, I can't. But he slowly began to make choices. He chose to be baptised in his church, to be an Individualised Funding holder and employer, to live on his own. He took all of those things on willingly, but he remained his own worst critic. He was determined not to fail.

He over analysed himself, and internalised things and this tendency made Michael feel very vulnerable. If I saw his mood dropping I would stay longer and watch movies with him. I was probably paid for only 60% for the time I spent and tasks I did, but I was okay with that. It was from love.

Something we shared was reading. We would read together. I would read aloud. I like reading because it practices my vocabulary. He could hold a book, and read on his own, but I think it was comforting for him. He used to be read to as a child. After the first two books, he told me that. I feel he allowed me to read aloud because of that comfort.

Physically the work was relatively simple. Michael had very little movement, so he needed to be showered, toileted and fed, and I had to assist with any other errands he needed done.

I had to be innovative to come up with solutions that Michael might not have considered. Michael only had certain ideas about how to move his body to become comfortable. Other than being baptised he had never been in a bath, so we worked out how to utilise his shower trolley to hold enough water to cover him. I didn’t put in enough for him to feel like he was drowning, just so he could float, and that gave him comfort.

He had never sat in the front seat of his vehicle. On the trip to Hamilton we decided to try this out. It was a long trip, and I figured it would be less bumpy than staying in his chair, and he could see more and enjoy the drive. He was happy. He didn't say much but you could feel and see his appreciation. I had to observe everything going on. When he was making plans with others, I would need to be involved to make sure he had the support to carry them out.

Our relationship grew to the point where there was no need for lists, or for him to tell me what to do. I knew what was needed , and came torecognise the patterns in his diet, and what needed to be replenished, and things like that.

Michael always found it hard to make decisions. We called them ‘executive decisions’, making ‘executive decisions’. He had all this freedom and sometimes just couldn’t make a decision. He would lie in bed and think and not actually voice a decision, so I would have to do it.

We got around it. I would do my best and involve him in the process, as much as was practical. The Individualised Funding issues, such as what he can use it for were hard. There were breakdowns in communication with different coaches and Michael did not know what to do. I would start to write an email and we would talk while writing. We would pick and choose words so it didn't lead to more unanswered questions. Once he felt all the issues were addressed, I would send it away in his name. I initiated the process but he was wholly involved.

At times though, I knew his mood, but would refuse to read him, in order for him to express himself. He was often reluctant. “What do you want?” “I don't know.”

“Well you've been thinking about it since this morning.”

I put that barrier there and would not see. These were not those ‘executive’ decisions but things he could choose, such as when shopping. I restricted his ability to opt out of decisions.

I pushed him to do stuff, pushed him to go out more than he would otherwise. He would just stay home, but he enjoyed going out. It was the effort and fear that kept him in.

Michael was very humble. I guess because of his own humility as well as his beliefs with Jehovah Witnesses, there was no real excitement about much at all. He disciplined himself to enjoy something for its entirety, but not to worship it so to speak.

It was trial and error, the small things he did that he had not done before. If he fulfilled one aspiration, maybe the next would seem achievable. Things like sitting in the front seat of his vehicle, going to a strip bar, building relationships with local businessmen and having friendships with them.

When driving down the street in his motorised chair on his own, people stopped and asked ask how he was, people he couldn't remember, yet they knew who he was. He was not just a fly on the wall or a cripple in a chair. They didn’t treat him like he's special or different. He was recognised and valued.

What helped him move towards his congregation, was that they had that approach. He was not special because of his chair but because he was an individual person with his own beliefs and ideas, and he was treated as such

After he was hospitalised the first time this year he said he enjoyed his life but was okay with dying. I didn’t probe, or ask what to do if he died, but he let me know that it was up to his family to decide, and there was no need to plan for it.

Over the past year he felt he had proved himself to himself. I said, “When you are happy with you, it doesn't matter what others say.” He was supported in this by his congregation.

He felt better this year, especially attending the conference, being involved in something that was so much bigger than himself. This was a real opportunity. It wasn’t something that might happen, but was happening. “I've done something for myself, on my own now.”

Michael overcame so many restrictions in his life. He lived in his family home until he was thirty, and hadn’t had a life outside of that. His experiences were pretty limited. Then he began a journey of his own. That journey was something he could share. He gave us that.