Question 1 My role as a carer.

My role as a carer of a 36 year old Male who has cerebral palsy and who is confined to a wheel chair is firstly and most importantly that of a mother. It is just that in my case the "mothering role" never ends.

Normally mothers step back as children grow, take on their own challenges, their own lifestyle and their own friends. They gradually make more and more of their own decisions and live by those. In my case, those things have not happened. I still make all the decisions, well more the daily life style decisions. I have to plan for every day, do all the domestic jobs that the mother of small children do but at the same time be aware that there is an adult with above average intelligence, that is affected by every move you make. You also have to be aware that he has no choice in most of those decisions. His physical restraints confine him to a lifestyle not too many of us could deal with (graciously).

He has to be assisted out of bed, his breakfast prepared for him, he has to be bathed(or showered)and dressed by someone then put in a wheelchair from which he cannot escape from, every day.

At the end of every day he has to be undressed and put to bed, again by his mother until the next day and that is never ending.

Everywhere he goes, well almost everywhere he has to have his mother with him whether it is entertainment, shopping, medical appointments etc. We use the family car with the wheelchair in the back. This requires lifting him in and out of the car, with the assistance of a "slide board". As one gets older this constant lifting becomes difficult so of recent times when feasible he goes to functions by cab

However if it is somewhere new, we have to investigate the facilities, ie level access and a disabled toilet. If they are not present then he cannot go, or his "mother" finds a way around the problem if it is important to him.

Also picking him up from a function late at night is something I hate. The time taken to put him and the chair into the car, sometimes in very lonely or dark areas ie in the city can make one feel very vulnerable. The cabs are important at these times.

As I still work full time and he part time, I have to prepare his clothes, his lunch, other drinks if he is home, or his electric chair for going to work and all the things he needs on any day away from home.

Q2 Why

Well as a mother you have no choice. You bring a life into this world and you deal with it the best way you know how. I must admit, I was told by a doctor when Adam was a couple of months old that he was going to be a very handicapped child. She suggested that I put him in a home and forget him and have another one. I have never forgotten that nor have I forgiven her. That child was mine and I would do the best I could to make a life for him.

It has been a very challenging role, nobody could tell you exactly what the prospects were, he started school at 3 and a half years going to the Spastic Centre school and that was particularly traumatic, for both of us.

You learn a lot about yourself and the way people deal with disability as he grows up. You become very very protective, defensive and aggressive when necessary.

I think I was obsessive, I did more physio with him,(under instruction from those treating him) than was probably appropriate for one so small but it was something you felt you could do. There were no miracles in the offing so hard work and very small rewards were the most you received.

My husband was at sea so he was away at that time about six months in every year so it was my job.

Q3

I don't know that the role has any benefits per say. I did not expect to be in this position. I had no training to deal with babies, children , whatever. To be thrown the role of a parent to a child with a disability is a tough call.

As with all parents, you learn as you go along, the children mostly survive, not because of you but despite you. When you are challenged with an extra dimension it is frightening. If I knew what I was in for when I had my son and the road we have been on, I don't think I would have done it. There were many times that thought of ending it for both of us were very close to the surface, it seemed a painful, fruitless never ending struggle to nowhere. I am sure all mothers of children with disabilities would agree, nothing throughout their life is easy. There are none of the milestones other mothers see in their children,. Most of the time, if they are not in treatment or in hospital having some correctional work done (many of those) you are trying to give them as much of the experiences that normal kids get. One thing you don't get is acceptance. I tried to be part of a "play school" for my son to experience interaction with other children. I was frozen out of that because the parents feared him. As if he had something contagious. Not a nice experience.

However, you do get to have a very warm very loving relationship with your child. He is very dependant on you and that does not decrease as he grows. But the close relationship does give you great satisfaction every time there is a small gain. The trial and error is continual so when he does something new it is amazing.

Q4.

Challenges, my god, every day is a major challenge.

Getting out of bed every day, knowing what is ahead of you, before you actually start the day as every one else does, is the first challenge, knowing that every day thereafter it will be the same. Whether you want to, whether you feel like it or not, whether you are well or sick as a dog you have to be there.

My day starts at 4:30am, I get up, prepare the breakfast, the lunches, his clothes his chair, his other necessities for the day.

I get him up, put him in his wheelchair, take him to the toilet then to breakfast. He can feed himself, so once it is prepared and in front of him he is ok. I get him the morning paper, make sure there is everything needed in the bathroom(for his bath), then take the dog for a fast walk at 5:45am-6:30am. I have someone from home care come in and bath him at 6:00am. (without this I could not go to work)

I return at 6:30, make myself a quick cup of tea and toast, have a quick shower, make the beds, pack his and my lunches, check he has everything he needs for the day, check he is dressed properly(obsessive) get myself organised (and the dog) and all of us are out of the door by 7:10am or else!

Returning home after work, there is shopping (always) but once home then the reverse goes into gear. He needs to be put on the toilet, he need to have dinner cooked and served to him, we need to go through the day and any outings for the night(there are a few he goes to regularly) clean up afterwards and if he is home then undress him get him into bed by 10pm.This requires physically lifting him into his bed, positioning him properly before you are ready to deal with your own preparations for the night.

If we are lucky to have a night at home then I get to bed about 10:30pm. I need to do this as I need 6:00hours a night. Any less, I struggle.

There is only the two of us(and the dog) so the routine does not change much at all.

Other challenges are that you constantly make sure he eats properly, gets sufficient liquids, his medication daily, that he is safe and always arrives at the place you expect him to be at. He travels to work by bus, as long as the correct disabled access bus arrives, otherwise he is left at the bus stop. Once in the city his journey is hazardous to his place of work as he has to cross several major intersections, his vision and speed to negotiate these are limited. You must be aware that when he is out that the cab he has ordered turns up otherwise he is stranded. That then requires a pickup late at night somewhere!

I think that is enough of the challenges.

Q5

Support is not the easiest thing to get. I do however, as was discussed earlier, have Home Care attendants come in daily for 1 hour to bath him. That is it.

I made the grave mistake a year or so ago of being a part of a so called pilot program looking at “aging” parents of disabled children. I presumed the program was to look at future needs in this area, something I think of regularly, not because I have any solutions, just problems that are just too difficult to solve.

This program, was run by DADAC(department of aging, disability etc). We found that these people were actually service providers, wanting to direct services to us that we didn’t actually require at this stage. We found them to be intrusive, to the point of bullying, to do what they thought we should be doing.

It was an extremely unpleasant experience and we eventually sent them packing. Not because the concept wasn’t acceptable, it was just that the people involved thought they had some God given right to take over our lives.

We both know that sometime in the future something like this will happen to us, we just have to delay it as long as possible.

The informal type of help I have is my daughter, who will help when called upon but not when it comes to anything physical with my son. They have a typical brother and sister relationship which means in this case as little as possible contact is good.. She will do anything for me however.

Any other assistance is from friends and they will help if called upon. I have one particular friend who also has a disabled son so the bond and the understanding is amazing.

If by support you also mean money, let me assure you Centrelink where you apply for Pensions or Workstart allowances or anything else is woeful. We have been through that process and realised very quickly that they set up their processes to fail. In other words they make their processes so complex that most people give up before they complete the applications, and this is what they want.

Q6

This probably is the most important question of all because carers do the job they do mostly because they have no choice. Most people are carers because they are looking after a family member of some kind.

In my case and I am sure many others, it is the future that worries me mostly. There is no process that can set out a plan for the future. Even if you have enough money to provide for the disabled person you are caring for you cannot organise with any confidence what is going to happen when you are incapable of looking after him any more.

All these departments, ie DADAC who provide services on a needs only basis and not future planning are not the solution

What you need is a plan.

A plan that discusses what exactly what services will be needed when I am incapacitated. From my son's point of view as much as mine and how they are going to be provided . A plan that will be put into action quickly and efficiently when required. How many people will be needed, what services he will require, where and how all this will be put together, what it will cost and what he is able to pay.

In my situation he will have the home he is in for as long as he can stay there. That is in my Will but I need to know that he will be looked after properly. That is something I worry about on a daily basis.

The program that I entered into (big mistake) should have been looking at this long term plan. I think it all got lost in the paperwork trail. They lost the plot. They wanted to take over, no one wants that.

Unfortunately, this will not happen. Government departments are unable to do things easily. They make the processes so complex they become unworkable. Nothing gets done because no one can make a decision. Everything and everyone has to fit into a neat box so that the box can be ticked. If not they go into meltdown.

My son and I would very much like to have a pact. A pact that says, when I go he wants to go with me. Now as silly as that might sound, think about it for a minute. He has been totally dependent on me for his very existence. He knows he is safe with me he knows that every day and in every way while I am alive his life will continue comfortably. When I am gone however, he will have to find people to d o what I was doing but they will have to be paid. They may not want to do the jobs that are unpleasant and therefore make life difficult because all of those jobs are ongoing. There will be many of these people assigned to him over a period of time and he will be restricted in what he can do depending on their ability and/or desire to do them. Not a pleasant thought for either of us, to know that that is exactly what is ahead.

Of course it is not an option so all of the above will happen. I need to keep myself as fit and healthy as it is possible to be for as long as I can because there is no one else who cares for him as much as I do.