

## SUBMISSION TO CARER ENQUIRY

When you are a carer, your life is not your own. You are tending to the needs of another before your own.

As a carer you are suddenly forced into situations where you become a medical expert, centrelink consulatant, secretary, project manager, scientist, politician, Diploimat – just to name a few.

You feel you almost have to beg, borrow, justify why you need help and support

It takes a toll.

You lose your own identity, your friendship group dwindles, your health declines, your financial status weakens

I am a full time carer and this is a glimpse of what it is like

I commend you for starting the conversation rolling about the very important needs of a carer.

I don't need to give you the statistics and facts, you already have them, all I can bring is a lived experience.

Before I begin looking at your proposals and commenting on them I'd like to share with some recent experiences I have had with the Carer Gateway Service to date. The advertising about the program made it sound fantastic and something everybody should access. In conjunction with several agencies I run a Carer walking group where we have 'guest walkers' attend every month and chat to carers about services and supports available in the community. Carer Gateway sounded like something that many carers would benefit from hearing about. So with that in mind I

contacted the number on the flyer. I might also add normally I would email the services to explain a bit about the walk, who was involved and send them a copy of our facebook, website, flyer and you tube clips so they are able to get an understanding of what we are about. But there was no email available on the website, only a phone number.

So I contacted the number provided and spoke to the person on the other end of the phone. I explained my request and she took all my details and said someone would be back in contact with me. Can I tell you I had to contact your office four times as not once was my phone call returned. Each time I was on the phone for approximately 30 minutes mainly on hold whilst the phone operator made enquiries only to have them advise they would pass it on to management and someone would be in touch. At the last call, I asked for the complaints procedure as I was now very unhappy. The phone operator was not aware of any complaints procedure but would pass on my details. I am sure you can imagine my frustration.

The next day I spoke with the manager, James. James was able to explain to me that it was a small set up for a national roll out and they couldn't offer to come and attend the walk because there was no staff to do that. He was very clear about what the organization could and couldn't do and something that should have been explained to me from the start.

So I hope that as this carer gateway expands so too does the staff and visibility levels. You need to be more than just a call centre. In my experience of caring, the most successful encounters have been face to face. I have felt valued, supported and encouraged and haven't felt like a number on the phone. So raising awareness about carers and your organization means you need to be visible at things like

expos, schools, residential care centres, centrelink, not just a voice at the other end of the phone.

Imagine what a profile would be if you were seated at every centrelink office in Australia. That would certainly raise your awareness and that of people in the community particularly working side by side with social workers and others who hear the real life stories of people coming into the centrelink offices. I know myself when I registered for the carer allowance, and I asked the centrelink staff was there anything else for carers to help support me and the children I was caring for, they couldn't answer the question so I left feeling disempowered and despondent. Having a set up would encounter you with such a large range and diversity of the community to have access to fill your criteria of intake, education, peer support and what services could be offered to help support the carers. I believe Lifeassist trialled something similar last year in Box Hill Centrelink and it was successful.

Whilst I could write a very long diatribe of life as a carer and the challenges/hurdles I'm constantly trying to overcome to make it a better life for my children and my husband and I, the point then will be lost. We cannot change the caring role of the carer but we can find way to make it easier and that in turn has a flow on effect to the people they care for.

I also feel that carer needs to be involved in partnerships and feel connected to their community. This will give the carer a totally different perspective of how they view the world.

It is also great that you are starting the discussions but you are also assuming carers needs. Every single carer is different. The person they are caring for is different to that of others. The need to be heard for what they need is very important. For example It may not be respite, it may be

family activities. So please don't assume you know what a carer needs.

Imagine the vision

I wish carers knew .....

I wish service providers knew ....

Together we can ....