Submission
No 19

INQUIRY INTO THE EXERCISE OF THE FUNCTIONS OF THE LIFETIME CARE AND SUPPORT AUTHORITY AND LIFETIME CARE AND SUPPORT ADVISORY COUNCIL - THIRD REVIEW

Name: Ms Tania Panopoulos
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To Whom it may concern,

I dont know what to do or where to start, all I know is I need advise (help).

I am scared to make complaint of fear my son will be taken away from me,

as I am his only advocate he has no voice and I have to speak for him sometimes I tread on peoples toes,

I am just a mum, I dont have degrees or diplomas but have love for my son.

I thank God that there is a scheme for people with brain injury otherwise I dont know where he would be right now.

I am happy with LTCS, where there was no hope you have given us hope never denying Peter his needs seeing him as a human being that with a turn in fate lost his capacity to a real life, with all your help I can maintain him at home with a plan that is working for him as Peter's injuries are so severe there is no hope of recovery so maintaining him with dignity and love is all we can do. A workable plan was put in place with links such as Rn's, carer's,training my carers for his specific needs, Tilt table for maintaining him with exercises ect. From April 1st he is home and I must admit it was daunting and hard work but with your help everything is now put in place for the care to continue in a secure and safe rythm, forseeing the future no one can but he and we all know we have done our best for Peter. His health offcaurse is not always stable, but he is home where he should be with his family.

Peter is in post coma unresponsive state with no hope of recovery. (But miracles do happen and we will never loose hope.)

My compliant is: I am not heard after his care plan is in place I am told that do to not being able to sustain him in the long term his care has to be cut back such as the Rn's that provide wound care, quick decision making and if possible ways off treating him at home and not hospital where his case is complicated and his routine is disrupted and he then becomes unsettled in his body and that takes weeks to bring him back on track so her RN, is vital for his care as was approved, injections such as desmopressin he has hypoputuaterism, that tablets will be given so cutting back the Rn's will save money, do you give a blind man a quidedog and then take it away and give a cane? This program is there for what is reasonable and necessary and the things that were approved were due to his condition. There is talk of many things been withdrawn I spoke to the Doctor in a meeting voicing my concerns and felt and feel I am not heard as decisions are made solely on her judgement and maybe others but not considering the patient but the funds?

I need to know if this is so? Is the LTCS scheme pressuring them? Is my son costing to much to sustain? Is there a price on the value of life to sustain them? Will you take my son away from me based on the cost of sustaining him?
When a patient is not making progress from the state he was to what he is how can you cut back on his needs nessecary not wants BUT NEEDS, what was approved according to his state and nothing has changed since how can withdraw RNs, active shifts, times turned per night, changing medication that is OF NO BENEFIT TO THE PATIENT? If you can sustain him with tablet form have they asked the other side effects that would cause? There is lack of communication meaning I am heard but they disregard everything I say. I have been by my sons side throughout the whole ordeal from 28/11/2008 till now I am his advocate his mother his nominee his VOICE he has a right to be heard through me we cannot deny him that, he is a life he is alive and nothing should be withdrawn from him based on money otherwise it defeats the purpose of having this scheme, and I f I feel like a criminal every time i speak or ask for something well that doesn't make me very comfortable; it makes me feel like we don't deserve the help.

If there is a benefit to the patient then you can make changes based on those changes individually.

I want to be heard and my opinions considered otherwise why have meetings? Why pay these doctors money? I had absolutely no problems as inpatient but once he became outpatient I feel Peter was just a file the transition from in to out should be done differently so he isnt a file but a person and knowing the person so you then can give the appropriate package of care.

Is there and active and an inactive shift only? isn't there care based on need? for example if patient becomes unwell and needs care during night is that denyed? I was told its either active or inactive and she cannot justify it. How can that be? When peter is unaware? he doesn't always swallow and chokes he vomits doesnt know how to vomit and chokes he needs repositioning from spasticity, he bed wets, the list goes on. Ofcaurse he has some balanced time but in general he has active nights and that will be taken away? How can I then take care of him? He is 24/care what is 24/ care then? I was interviewd whilst in BIU and his case was marked (SPECIAL CASE) WHATS HAPPENING NOW? the case manager has asked only to go through her so now I cant have contact with my LTCS co-ordinator only through her? Everything is a mess. This case must be looked at individually based on his injury and wheather he is getting better to make changes not on $. And ofcaurse if there are other cases like his we must look at what benefits the patient yes reasonable and necessary I agree but what is reasonable? When a plan is put in place and works for a patient and stabilizes him you dont make changes that in the long run will not benefit him/her and probably will cost more money to fix all over again, is this unreasonable? Who decides? You must have in a review consultation from family who are also caring for the patient not base decisions mearly on outpatients Dr's ect that just met the patient or you have been told to cut back. Today I was told that in order for others that come on the scheme we have to cut back, should I have turned off life support machine? A parent should not be treated this way. There are many issues that need reviewing. For example on your list of tenders the company I chose I had to train all staff and the BIU some of them as only overseas students apply due to the fact that pay is lower.

I dont want to ramble on..but i need help clearing all this up and I decided to come to you as you are the scheme which is funding my sons life and his future is in your hands with your help everything can be put in place I know its a new scheme and in time things will change but right now I need help.

What I want is nothing to be changed in Peter's care plan and to stay as is, his case is complex making changes to his medicine or care will set everything back for him as Dr Gurka the Director of BIU knows his case very well. I want to move forward and maintain him as dignified as possible for as long as he is with us in this state he is in, denying him the continued plan is denying him life as this will set him back and cause more problems.

thank you for hearing me

Kind regards

Tania Panopoulos