Teresa Livoti

Your contribution ***Should you wish to make a formal submission, please consider the questions below, noting that you do not have to respond to all of the questions, instead you may choose to respond to only some of them.***
1. What are your suggestions to improve the Victorian community's understanding of mental illness and reduce stigma and discrimination?
> A more streamlined process into the "jungle of mental health contacts, procedures and facilities". *> Further and advanced education for mental health workers. Often, they are only knowledgeable of text-book symptoms and find it difficult to "connect" to "atypical" symptoms. Unlike other illnesses, there are never any "set and concrete" symptoms to the illness. They manifest in a diverse and varied way for each individual.* *> More attentiveness to carers'/family members' input; after all, they know the mentally ill person more than anyone else.* *> More involvement by, and communication to, carers/relatives whilst undergoing in-patient treatment.* *> A more effective, monitored and controlled "Discharge Plan" after a patient is discharged from Mental Health Units after in-patient care.* *> Therapeutic sessions as out-patients immediately after facility discharge, as a slow transition from in-patient to out-patient which MAY lead to a more prolonged time of well-being, rather than there being a shorter time for relapse.*
2. What is already working well and what can be done better to prevent mental illness and to support people to get early treatment and support?
As I have had less contact with mental health illness than that of several years ago, I cannot comment on this as I do not know what the up-to-date support system is, although, in saying this, only last week I was speaking to a friend whose mother is currently an inpatient and being treated at the [redacted] *(Burwood East, Victoria), and her story sounded very much like nothing has changed.*
3. What is already working well and what can be done better to prevent suicide?

4. What makes it hard for people to experience good mental health and what can be done to improve this? This may include how people find, access and experience mental health treatment and support and how services link with each other.

There is still so much stigma attached to mental health illness and people (be it sufferers or otherwise), do not always "open up". It seems to be a "disease" that is always brushed off as nothing – something you "just get over".

Albeit, since the foundation of "Beyond Blue" and public figures "coming out", there appears to be a lot more acceptance and tolerance of the illness.

THE MORE PEOPLE KNOW ABOUT IT, THE MORE PEOPLE TALK ABOUT IT, THE MORE PEOPLE WILL UNDERSTAND IT.

An idea would be to have eye-catching posters printed and posted in public places, including doctors' surgeries, dentists, train stations, etc., such posters with pictures and marked with scales, at different levels, each level describing the symptoms of how mental health manifests itself. At each scale level the appropriate support and service numbers of where to obtain further advice, seek further information to verify that it is a mental health issue, where to be able to speak to staff who can liaise and arrange further information; ultimately, reassurance that once the level of illness is diagnosed etc., that a "relatively normal life can be led" and is something that should be addressed.

Only two days ago I was sitting in my General Practitioner's waiting room and two large walls were covered in posters, amongst which details on "Influenza Vaccination", "Alcohol and Pregnancy", "Skin Cancer Detection", "Pneumonia and the Elderly" and others - … "speak to your doctor" … they read. So right here in a doctor's surgery and where it can be such an eye-catching topic, there were no posters on "Mental Health"? Why not?

Everyone (either a sufferer or not), should be able to feel reassured that "mental health" is not taboo, that it is a real illness and that help is only a "phone call away". There should be a strong message amongst all this that, notwithstanding that some symptoms may be "similar to" mental illness, it may not always be that, but rather just going through a stressful period, the winter doldrums, a part of aging, other medical conditions, etc.

REASSURANCE can change people's attitudes.

More education needs to be facilitated, most definitely!

5. What are the drivers behind some communities in Victoria experiencing poorer mental health outcomes and what needs to be done to address this?

Such communities tend to be lower socio-economic ones and are generally populated with newly-arrived immigrants from other countries. Such people tend to have very low self-esteem and, as they try to integrate, they need to overcome fear, embarrassment and shame, leading to a restrictiveness to seek help and support. It should be made known and understood that this illness is just as important as any other and needs to be treated to ensure a healthy, happy and lengthier life.

6. What are the needs of family members and carers and what can be done better to support them?

Guided pathways and a constant "touch-base" approach from support/allied workers should be realised for those people who live with the mentally ill person.

More attentiveness to family members' and carers' comments and opinions on their mentally ill family member/friend, etc. After all, as previously mentioned, they do know their loved one better than anyone else.

Personally, I experienced quite a few incidents with my mother where my comments were totally ignored. One such incident – she had been admitted into a Hospital (General) when she had a broken ankle and was wailing. I wanted her to be seen by a psychiatrist because I knew that it was not her ankle (which they wanted to operate on) that was the problem. Notwithstanding, they were annoyed that I would not sign paperwork for the procedure to go ahead.

Medical staff at the hospital had abruptly and without consultation, taken her off all her anti-psychotic medications as they wanted to "dry her up". I was forced to arrange a meeting with the Patient Liaison Officer to be able to be heard that the wailing, the constant in and out of bed actions, the "visions" and "voices" were anything but that of a physical nature.

At the other end of the spectrum, I recall one time that the Psycho-geriatric Nursing Home staff ignored my mother's deterioration over several days – the staff had diagnosed this situation as that of a mental one. I visited the facility one afternoon to find her sitting alone in the Arts & Crafts room (segregated and being punished as she was disturbing the other residents) a half glass of water in front of her, incoherent and not cognitive of who I was. Yes, she required immediate hospitalisation – the cause: a urinary tract infection. And … after hospital discharge, she was permanently removed from that facility.

7. What can be done to attract, retain and better support the mental health workforce, including peer support workers?

Providing more complex education and a hand-in-hand health plan approach between the health workforce, the peer support workers, the carers/family members and patient.

Regular contact between the carers, family members, mental health officers and peer support workers exposes them to diverse situations and more understanding of the different modes that mental illness manifests.

8. What are the opportunities in the Victorian community for people living with mental illness to improve their social and economic participation, and what needs to be done to realise these opportunities?

Occupational therapy classes should be made available after in-patient discharge – a place where the mentally ill persons can all come together in a supervised setting (manned by appropriately educated support staff) be it weekly, fortnightly or monthly. This will enable the support staff to gauge how well the person is adapting and coping in an external everyday environment. Their level of wellbeing could be measured by different levels of activities appropriately enlisted.

A discharge from in-patient facilities with an appointment for follow-up in six weeks' time is hardly the first approach to take. The transition process from in-patient to out-patient, I firmly believe, is instrumental in that it MAY allow a longer period of time between relapses, if at all.

9. Thinking about what Victoria's mental health system should ideally look like, tell us what areas and reform ideas you would like the Royal Commission to prioritise for change?

> Streamlining and easy access to contact numbers and access to mental health assistance at all times. On one occasion this is the response I received when I called for assistance: …"you will have to wait until Monday morning to have your mother assessed by the ACAT team"… And, in the meantime???

> A carer should not be forced to "wait" if they deem their loved one(s) is in urgent need of assistance, especially if the unwell person is having an "episode". I do understand that this would

not be an easy feat, however, a period of 24-48 hours before any attention and/or assistance can be given is quite a feat both for the individual and the caring family.

10. What can be done now to prepare for changes to Victoria's mental health system and support improvements to last?

It should become common knowledge that mental health is just as important as any other illness because of the far and varied manifestations that the illness is wrought with.

More education should be provided for the public in general with regards to identifying triggers to enable care, understanding, diagnosis, and prognosis etc.

11. Is there anything else you would like to share with the Royal Commission?

I would welcome the possibility of the Royal Commission being able to obtain my dearly loved mother's psychiatric file. She suffered with mental illness for a period of forty-eight (48) years. The fact that she was unable to speak English was a major impediment in her life and treatment-wise as she was not able to fully express her symptoms. Notwithstanding the services of interpreters, I somewhat felt that the true reflection of her innermost thoughts never surfaced perhaps because of embarrassment or shame.

I recall on one occasion our family doctor visiting mum at home and him saying to my father "…Mr [redacted] *one does not die from this illness, but one most certainly suffers immensely" …*

She was a woman who was institutionalised for weeks on end in the [redacted] *Hospital as well as the* [redacted] *Hospital (Footscray, Victoria). She was also a patient in the* [redacted] *(Footscray, Victoria). She had ENDLESS sessions of ECT – this therapy was her "lifeline" and was the major treatment that assisted her (right up until the age of 82/83 years), albeit there was some reluctancy to give her the treatment. The ECT in conjunction with "Lithium", "Nardil", "Risperidol" and many other trial drugs proved effective for her. Names of treating doctors that I can recall:* [redacted]

My mother's diagnosis was "schizophrenia/paranoia", however, I still have my doubts that this judgment was, in effect, correct. Notwithstanding the "voices and visions" that made her distraught and distressed, she was the gentlest of souls that ever existed and was never violent, a trait which some people incorrectly attribute to being mentally unwell.

I am very proud to report that my mother lived "just that little bit longer" because of my "feistiness" and constant battle with her treating doctors, be it medical or otherwise. I admit that there was a constant barrage, without relent and I would do it yet again!

I recall very well, as a five-year old, visiting my mother at the [redacted] Hospital and I can also still hear the large metal keys turning the locks on the wrought iron gates in the corridors of the institution. I also recall my mother in a "strait-jacket" just as is seen in the movie "One Flew Over the Cuckoo's Nest"!

In July of 1972 I was 15 years old and I recall the excitement over the forthcoming Year 10 school term break of the Olympic Games being hosted in Munich and being able to watch them on TV. Alas no, each and every day of those two weeks I travelled with my mother from [redacted] for the purpose of her participating in occupational therapy sessions – therapy which, I believe, was so momentous to her recovery at the time.

I further recall my father's "shame" of having a wife who was "demonised" – such was people's interpretation of how her illness was described in the 1970's and 1980's and, on several occasions, he was even offered suggestions to have my mother "exorcised" by the Church! My father's home life in having to live with my mother's illness was obviously quite a trialling one. Once he retired from work he would be at my mother's side when hospitalised (he would ensure that he visited her more so at meal times) spoon-feeding her, encouraging her to eat - …"eating will make you stronger"…

I would like to also mention that it appears my mother inherited her "mental illness" from her father who, at the age of 36, passed away in an Indiana (USA) Sanatorium in 1932. This was never mentioned within our family and I only discovered this fact via a letter that I found amongst my maternal grandmother's belongings after her death - such was the embarrassment and humiliation, even within the family, that of being known as a person with mental illness. Notwithstanding this matter, in approximately 1962 whilst pregnant and running to catch a bus in the morning to go to work, my mother miscarried a set of twin girls. This incident would haunt her all her life-long and, yet again, was never spoken about and possibly not even mentioned to treating psychiatrists in the early onset of her illness.

Since Jeff Kennett's establishment of "Beyond Blue", and the fact that some high-profile personalities have "come out" and recounted their battles with depression, have majorly highlighted that the illness can affect ANYBODY and EVERYBODY, however, there is still a very long road to travel along the creviced pathway and I very much look forward to listening and reading what the findings of the Royal Commission will conclude with.

Attached are only some of the letters that I could find that were written by myself to the organisations where she was a resident in a facility. Indeed, these letters are only the "icing on the cake" and were written in the latter part of her life. The occurrences noted in the letters are true and correct and may demonstrate to you only minute issues, however, at the said time they were written, they were major events. Isn't it bad enough to have to succumb to the illness without anyone or anything else making the situation any more difficult?

Due to her illness, she was not able to care for her three children – it became my maternal grandmother's role to do so. Incidents seen and heard in the "Mental Health Units" have also truly left my mind scarred. I was able to speak and document the injustices observed, however, what of those people who could not either speak nor write English? How I truly felt for them!

I would like to at this time also express that I feel very honoured to make noteworthy that my children (who are now 38 and 33) are the most compassionate and sympathetic of young adults – and I honestly attribute this to my mother's illness - in fact I believe that this made them who they now are – and I am so very proud of them. My mindset was, from a young age, not to shelter them from the "facts of life in living with mental illness" as I had been brought up. That misconception that "no-one and more so, young children, should not be exposed to the conduct of mentally ill people" is totally void and holds no weight at all. My children would visit my mother with me whenever she was an in-patient and this undoubtedly proved to the many relatives and friends who distanced themselves because of my mother's mental illness, that they were not affected in any way whatsoever, least of all in having contracted the so-called "contagious disease"!

Some people in the community still perceive "mental illness" as that infectious disease and very often rather than support the mentally ill, disengage themselves completely, leaving the afflicted sufferers somewhat even more distressed, with loneliness and isolation overtaking their lives.

I make this point as I myself, have been a person suffering with depression (since the birth of my son in 1986) – fortunately I did not inherit the illness at its worse. I have been on anti-depressants since that time and have consulted psychiatrists and psychologists over the years. Doctors have attempted to wean me off medication intermittently, however, this has been without success. My experience, when mentioning that I take anti-depressants, changes people's perceptions of my being and comments such as …"what, you take happy pills?"…and …"how can you function taking the tablets?"… …"don't they change your brain?"… These are terribly negative, hurtful and demeaning comments and I do forgive the people whose mouths utter such words as they honestly do not know what they are saying. Hence, what people don't know does not interfere with their judgements, however, this is definitely not the correct attitude to have.

Furthermore, I wish to point out that over the last twenty years or so, I have endured medical problems (including cholecystectomy and full hysterectomy) and it's difficult to express what *painstaking efforts that I was forced to undertake over a period of time into ensuring that my symptoms were taken seriously as even doctors perceived my pain as "imaginary! This, without doubt, was due to the fact that I was on anti-depressants and hence I would be shunned away as my endometriosis and gall bladder pains were "unreal" because "I was not coping well with life" and hence it was "all in my mind". (Once diagnosed, my bilirubin levels were at three times the normal reading and my reproductive system was quite severely diseased). In my personal experience I have noted that some of the medical profession don't always consider pain on its own other than "imaginary" in normal people so, without doubt, if one is on anti-depressants, then that pain is truly non-existent at all!*

The PERCEPTION and INSIGHT of the illness needs to be overhauled in its entirety!

I do determine that nowadays the fundamentality of the illness is so much on a grander scale as, not only does it encompass the "inherited genes" population, but demonstrates it also in those with alcohol abuse, illegal substance abuse and domestic violence, with such numbers joining in to increase the make-up of the widespread subject known as "mental illness".

I can profoundly attribute the assistance of medication to my being able to live a fully functional life. I have been in the full-time workforce since I was 16 years of age. I have been a wife, a mother and now a grandmother and notwithstanding having battled some testing times which everyone at some time in their life undergoes, I can wholeheartedly pronounce that medication has been my lifesaver. In no way whatsoever has it done other than make my life as normal as possible.

Thanking you immensely for the opportunity given to express my own personal opinions and comments and I am elated that I have been able to do so: a wish that I have had for many, many years and I do trust and hope that significant changes can be made for future generations – as previously mentioned it is an illness that just does "not go away" by "getting over it"!

Should the Royal Commission require an Authority to enable my mother's file to be retrieved and researched (and that this is possible to be arranged), I would be more than happy to provide such Authority. Her file is a "precedent" one, let me assure you, and would be able to teach the psychiatric profession so much more than they would ever learn from medical text books.

Teresa Livoti

01 July 2019

Attachments:

1. *Letter from Teresa Livoti to Bridget Howes (Aged Persons Mental Health Program) dated 24 July 2007.*
2. *Letter from Teresa Livoti to Bridget Howes (Aged Personal Mental Health Program) dated 10 September 2008.*
3. *Letter from Teresa Livoti to Mary Little (Department of Health & Ageing) dated 05 October 2008.*
4. *Letter from Teresa Livoti to Bridget Howes (Aged Persons Mental Health Program) dated 05 October 2008.*
5. *Letter from Bundoora Extended Care Centre (Department of Health & Ageing) dated 27 March 2009.*
6. *Speech written by Teresa Livoti for the Launch of the Booklet "Affirming Life – a Palliative Approach" dated 09 October 2011. This slightly broaches on "mental health".*

N.B. All the notes and attachments as detailed in this Submission are all based on first-hand, personal experiences.

Privacy acknowledgement	I understand that the Royal Commission works with the assistance of its advisers and service providers. I agree that personal information about me and provided by me will be handled as described on the Privacy Page. ☒ Yes ☐ No

[redacted]

24 July, 2007

[redacted]

[redacted] [redacted]

Dear Ms [redacted]

I acknowledge receipt of your letter dated 20 June **2006**, postmarked 12 July 2007 and received on 13 July 2007 for which I thank you. Unfortunately, however, your letter does nothing to allay any of the concerns I have about [redacted] in fact it only further highlights the serious shortfalls in services within the facility.

1. *Communication/Consultation*

With regards to this matter, you either do not, or choose not, to understand that the shortfall in communication refers specifically to [redacted] "Treatment" and "Care Plan". Hence, it would be of great importance for you to create a Policy and Procedure and/or Induction Program for residents within the facility. Obviously you do not have one set in place or if you do, it is certainly not adhered to in the least.

...2/.

In you mentioning the regular communication telephone calls, it was I who instigated them, the background to same being that when I first noticed of her unwellness, I would call to speak to her on a daily basis to enable me to continually monitor her. As I did not call at the same time each day (and perhaps was calling at an inappropriate time and may I mention sometimes encountering hostile greetings at the other end) - during one of these calls it was suggested by one of the staff members that my mother would call me instead - I had no qualms about this at all. The time stated was at 7pm each evening, but this arrangement was only to last for some six or seven occasions after which time my mother's declining health led to incoherency and I as well as the staff realized how futile the arrangement was becoming. I do agree, it sometimes was during these telephone calls that I would take the opportunity of asking the staff members on an update on my mother's wellbeing - BUT - I could only do so when the staff member had the courtesy to announce my mother's call to me or another member of my family and not when my mother would just be handed the phone to speak. It would have to be my right to be able to ask about her particularly as there was no precedence for contact from [redacted] to myself in this regard.

Furthermore, when I refer to lack of communication, I also refer to the lack of contact from the Manager(s) and/or Social Worker within the residential facility, in so far as regular up-dates on the resident's overall comportment, health, etc. Carers are entitled to know if a resident is happy and settled within the facility and liaise with the family concerned about making their stay within the facility a more dignified, and respectable one? Is it that perhaps because the residents are mentally ill that they are treated as second or third rate citizens and because "they would not know the difference" and would be "a waste of time"? My mother often astounds me that despite her mental instability, she can relate to many factual matters, hence there is some truth in her perceptions of [redacted] which initially I disregarded, but as time progressed, discovered that some truth prevailed. I reiterate what was previously said in my letter dated 13 June 2007, that a carer has the right to a full and informed treatment plan/update on their relative. A review with either a courtesy telephone call or meeting on a quarterly basis would suffice, fully taking into account the constant Government cutback in costs and I would think would not be such a huge inconvenience to anybody and, in fact, would enhance the facility's services. So what role does family play within your facility? Perhaps other residents' carers' attitudes towards their relatives are somewhat diverse to what mine are, but on induction to the facility, this information should be discussed, as everybody has different needs. Again I ask, is my role only that of to receive and pay the monthly account and just be content???!!!

You fail to mention in your letter that you would have, in perusing my mother's file, encountered two written complaints - one dated October 2006 - another dated 06 June 2007 - again for this lack of communication/consultation and despite having two separate telephone conversations with [redacted], the shortfall, seven months later, has not been addressed in the slightest way. Obviously not of great importance!!!

You state in your letter that should I be referred to another Psycho-Geriatric facility that you would meet with me and the Social Worker to create a communication plan - is this so solely because of my complaint and only for me? In life we are taught to say ..."never say never"... hence, I cannot say that I would not, or may not, have to reconsider accommodation in another of the Program's facilities but I certainly would need to adhere to the proverb ..."once bitten twice shy"...!!!

2. *Staff Credentials*

You state in your letter that the staff at [redacted] is made up of Registered Nursing Staff with psychiatric qualifications, with very experienced Division 2 Nurses supporting the team. How did it come about then, that I, my husband, my children and other visitors who regularly visit my mother, all people who have no nursing background, could visibly see that over a matter of weeks, not days, at how unwell my mother was becoming, specifically restless, confused, disorientated, hallucinative and noisy - all ***visible signs*** of unwellness - we will set aside the hidden signs of loss of appetite and dehydration - all signs which your so-called "very experienced nurses" should have noticed!!! The nurses' temporary course of action was to sedate her to keep her quiet until their shift ended signing off the problem to the next shift and so forth in the hope that the problem would eventually go away or placing her in her room quoting your Division 2 Registered Nurse's comments ..."as she is disturbing the other residents"..., but in the meantime, my mother's health was rapidly declining - be it physical or mental and our concerns shunned.

My mother at this stage had been a resident of [redacted] for fifteen months and therefore very experienced nurses should have more than seen that this was not part of her normal demeanor.

On several occasions, I found the Registered 2 Nurses to be evasive, arrogant and more interested in displaying their authority and making themselves scarce in the event of raising a question. As a professional in the Mental Health area, you should know and understand that carers of people with mental illnesses suffer immeasurable grief and actually need lots of reassurance, compassion and care themselves, as often they also have failing mental health due to the intense care and support they continuously are challenged with in a supporting role to their mental health sufferer and due to the stigma that always has, and continues, to be attached to the illness, and a little empathy would go a long way. During the telephone conversation with [redacted] on 14 May 2007, I did also discuss with him the matter of your staff's voice tones!!!

In my overall dealings with the staff at [redacted] - I found most of them to be courteous, friendly and supportive and people who work under, most times, very stressful and difficult situations, with extreme time deadlines and frames and I highly commend them - they are people who clearly make a difference to the world we live in. It was often that I would praise them personally for the work they did when I came across them at [redacted]

3. *Cessation of ECT/Ongoing Treatment*

Your letter states that my mother was reviewed by the Registrar on 23 April and then again by the Consultant Psychiatrist on 4 June. My letter dated 13 June 2007 advised you that I had a telephone conversation with [redacted] on 14 May to raise my concerns of her declining health - this telephone call obviously went totally disregarded/and or ignored as from 23 April to 4 June transpires a period of five weeks!!! You do not state whether she was at any time seen by [redacted] visiting General Practitioner for her physical state.

I am overwhelmed at the comment you make ..."your mother did not want to have ECT"... I am so flabbergasted by this comment that I do not find appropriate words to provide an answer or elongation on this comment!!! You refer to an expired Community Treatment Order elapsing in mid April 2007 and yet she is asked if she wants ECT???!!! In her state of mind - It does not make any sense at all!!!

In signing off, I am happy to report that my mother has made a truly remarkable recovery and I must admit that I did think that I would not have seen her live through to the end of the month of June after one of the doctors one evening, after having been admitted to the Medical Ward at [redacted] Hospital, asked me to seriously think about whether I wanted her to be resuscitated in the event that she was going to further deteriorate overnight - she was obviously in such a grave state. I would be able to accept any other form of death other than that of events leading to her absolute and sheer neglect. I was only heeded when the Office of the Public Advocate, namely [redacted] intervened on Monday, 11 June after which time action began to take place, specifically in my mother being reviewed for her severe deteriorating condition the following morning.

I take this opportunity to immensely thank [redacted] the Psychiatric Patient Advocate at [redacted] Hospital, [redacted] for her time and in organizing one on one patient/nurse care for my mother over a five day period when she was quite restless and unsteadily climbing in and out of bed, eliminating the possibility of a fall.

Finally, I wish to strongly emphasise Ms. [redacted] that I am only highlighting quite serious deficits in the system and would like to think that the matters brought to your attention are seen as matters that can in fact improve the services you provide. I am not, in any way whatsoever, looking at seeking anything other than acknowledgement that it is important to listen to family's pleas - she is my mother and I of all people should know when she is well or otherwise; it is quite distressing when concerns are shunned and ignored. I also am advocating for the many lost souls in the system - I can put pen to paper, I can speak the language, but what of the others who cannot or are afraid to? With some 75% of the western suburbs' population being from non-English, low socio-economic backgrounds, makes us no less human than those people who live in the more affluent suburbs.

Yours faithfully,

Teresa Livoti

[redacted]

10 September, 2008

[redacted]

C.C.: [redacted]

Dear Ms [redacted]

Further to a complaint last year (June 2007), it is with much displeasure that I AGAIN need to convey my concern over quite a serious matter which I observed whilst visiting my mother on the afternoon of Monday, 08 September 2008 at approximately 12:30pm.

I will omit elaborating on the other discontentment I have with the staff at [redacted], which was the initial reason for my attendance on Monday (specifically regarding the total disregard of constantly stipulated and underlined instructions given both verbally and written, and the blatant lack of co-operation and respect by the floor staff in adhering to these instructions).

A person (someone who I had not seen in the Home before and who, after I asked who was in charge, claimed that he was), was administering medication from a trolley and calling out residents' names to come forward to take their medication without checking photographs with names, etc. Specifically, he called out one resident's name, who my husband knows and who he pointed out to the person administering the medication; a subsequent name was called out and I overheard a worker within the facility say …"there are two people with the same name"… HOW TOTALLY CARELESS AND IRRESPONSIBLE – these are people's lives at risk!!!

Perhaps this is the reason why my mother was administered incorrect medication on or about Thursday, 28 August 2008, and hence my deep concern and the reason for this letter.

…2/.

I have personally observed what transpires in other Residential Facilities - medication is administered, with photo identification and, very often, by two staff members.

Accordingly, I would be most obliged to receive, at the earliest possible date, a full copy of the written Policy and Procedure Manual for the [redacted] a copy of which should be provided to Carers/Family upon a Resident entering the Facility. We are required, as Carers/Family to adhere to [redacted] Rules and Regulations, are we not, and hence if WE KNEW WHAT THESE RULES AND REGULATIONS WERE, WE COULD ABIDE BY THEM AND NOT HAVE TO LISTEN TO STAFF MEMBERS' BACK-CHATS!!! – most certainly a great cause of DISTRESS!!!, some of whose conduct exudes nothing but pure authority without substance.

I assume that the Policy and Procedure Manual you will be providing me with will include, amongst other subjects, the following:

1. Administration of medication to Psychogeriatric residents.
2. The supply of home-made food to residents in Psychogeriatric Nursing Homes, i.e. can family bring in foods for residents to consume either immediately or to be stored for later use, etc. Each and every time I bring in food, there seems to be a different regulation and I am somewhat confused!
3. Resident Care Plans – it is now fifteen (15) months since my mother entered the Facility and to date I have only perused and approved one (1) Care Plan (February 2008). How often are Care Plans distributed and reviewed?

Ms. [redacted] as expressed in my letter to you dated **24 July 2007** – I again reiterate the contents of that letter, namely that I am only highlighting quite serious deficits in the Mental Health System and would like to think that the matters brought to your attention are seen as matters that can in fact improve the services provided, some of which are archaic, detrimental, inefficient, careless and irresponsible.

Again, I also am advocating for the many lost souls in the system - I can put pen to paper, I can speak the language, but what of the others who cannot or are afraid to? Just because we are from the western suburbs and from a low socio-economic background, this makes us no less human than those people who live in the more affluent suburbs.

I await your response.

Yours faithfully,

Teresa Livoti

[redacted]

05 October, 2008

[redacted]

C.C.: [redacted]

Dear Ms. [redacted]

Re: Further Complaints

Further to my letter of 10 September 2008, I have a few other matters which require your attention, as these points were omitted in that letter, which was written under duress.

On Monday, 08 September 2008 at approximately 12:15pm I attended the aforementioned Residential Facility to visit my mother. Three (3) concerns deeply affected me at this said time, namely:

(1) A sole person (someone who I had not previously seen at the facility) came into Module 1 with a medication trolley. His way of administering medication somewhat caused me alarm; he was calling out residents' names (in an attempt to obtain a response from them in order to administer medication). When I asked him who was in charge he told me that he was. As I did not take to his answer in a serious manner, I did not pursue the matter any further with him. I did make two telephone calls whilst in the Facility: one to Social Worker, [redacted] and another one to yourself. Instantly I thought back to my mother's incident some weeks beforehand and was it any wonder if this was their way of administering medical to mentally ill people.

...2/.

Now when my mother initially entered the Facility, I was requested a signature to consent to photographs being taken for the purpose of identity, one of them being for administration of medication. The shouting of residents' names in an attempt to them identifying themselves to have medication administered is clearly not what the photograph's purpose is.

2. Also on the above day (as also many times before), my husband and I brought into the Facility some home-made foods for my mother, clearly labeled with her name and "use by" date, for her to consume. At this said time we were advised by the Kitchen Assistant that this was an issue – as this was the first time it had become one, I questioned this and yes, I can clearly understand the reasons for it becoming an issue, but if we are not advised of any rules and regulations that need to be adhered to by us, then we are not "mind readers" and hence cannot act accordingly.

3. Prior to my making the telephone call to you, I had requested one of the staff members at [redacted] as to whether my mother's pathology results had been received as I have noticed her unwell for a period of time and had requested for tests to be carried out. The staff member replied that they had not, but yet miraculously after me speaking with you, those results appeared!!!

4. On 03 October 2008, I forwarded an email to [redacted] [redacted] requesting a copy of the Facility's Policy and Procedure Manual in order for me to clearly read, note and understand the Facility's rules and regulations. His response was that we should discuss this, and although an appointment time was arranged this has not yet been confirmed or otherwise and feel that it will be disregarded and not taken seriously.

5. I have, on several occasions, when telephoning the Facility not received a response, i.e. no-one answers the telephone. As I have been advised many times that I can call my mother at any time, I find this to be a farcical and insulting comment.

6. On the week-end of Saturday 27/Sunday 28 September 2008 on calling the Facility I found the telephone diverted to [redacted] My understanding is that [redacted] does not come under the umbrella of [redacted] I reported this serious matter for concern to [redacted] [redacted] on Sunday 28 September 2008 and subsequently received a telephone call from [redacted] that the matter was immediately rectified. I have yet to receive an explanation as to how or why this occurred.

7. That in light of the above matters I feel that there are huge "cover-ups" for short-staffedness and that carers are left hanging on a string and on-call only to pay for their loved one's accounts and are shown a complete lack of respect and care. No common courtesy appears to be afforded clearly displayed when telephone calls are not returned and if an appointment is made, there is the possibility of the carer turning up for same, without the person with whom the appointment is made not being present. I need to travel 40 minutes (off-peak) each way to attend the Facility and yet no-one in the Facility can offer a 30second telephone call to advise of their impending absence to a scheduled appointment – how thoughtless.

Please be aware that I find it quite perturbing that I am meant to fell assured and confident that my mother is in the best of care while matters like the above are allowed to occur.

Yours comments on the matters contained herein would be appreciated.

Yours faithfully,

Teresa Livoti

[redacted]

05 October, 2008

[redacted]

[redacted]

I wish to relay the following matters of great concern in relation to my mother, [redacted] [redacted] a resident at [redacted] situated at [redacted] [redacted]

1. That on or about 28 August 2008 I received a telephone a call from [redacted] [redacted] Unit Manager, at the above [redacted] to advise that an error by an Agency Nurse had been made in administering medication to my mother. At the said time, I understood this to be a genuine case and cause of error and did not think any further of the matter. He emphasized that apart from her being drowsy, all her vital signs showed no reason for concern.

2. That on Monday, 08 September 2008 at approximately 12:15 pm I attended the abovementioned Residential Facility to visit my mother. Three concerns deeply affected me at this said time, namely:

   (i) a sole person (someone who I had not previously seen at the facility) came into Module 1 with a medication trolley. His way of administering medication somewhat caused me alarm: he was calling out residents' names (in an attempt to obtain a response to administer medication). When I asked him who was in charge he told me that he was. As I did not take to his answer in a serious manner, I did not pursue the matter any further with him. I did make two telephone calls whilst in the Facility: one to Social Worker, [redacted] and another one to [redacted] (Operations Manager of the Aged Persons Mental Health Program) to report this matter of great concern. (Instantly I thought back to my mother's incident of having been given the wrong medication herself some ten days beforehand and was it any wonder if this was their way of doing so)!!!

   When my mother initially entered the Facility I was requested a signature to consent to photographs being taken for the purpose of identity, one of them being for the administration of medication - the shouting of residents' names to identifying themselves to have medication being administered to them clearly is not what the photograph is being used for.

(ii) at the above attendance at the Facility, (as also many times before), my husband and I brought in to the Residential Facility some home-made foods for my mother, clearly labeled with her name and "use by" date for her to consume. At this said time we were advised by the Kitchen Assistant that this was an issue – as this was the first time it had become an issue I was clearly taken aback. I am able to fully understand the reasons why bringing food into the Residence can be a concern, but I do not take to it lightly at being reprimanded. If we are not advised of the Facility's rules and regulations in reference to same, we cannot abide by them – we are not "mind readers" and accordingly, the provision of the Facility's rules and regulations with regards to the supply of foods for consumption would be gratefully acknowledged.

(iii) I often find that communication from one staff member to the other can change a situation's status quite dramatically. On my attendance on the above day I had requested one of the staff in attendance as to whether my mother's pathology results had been received - and was advised that "no" they had not. Yet, after my call to [redacted] over the medication saga, the results miraculously appeared, and became available to me.

4. That I find it quite disconcerting that I am meant to feel assured and confident that my mother is in the best of care whilst matters like the above are allowed to occur. Clearly, directives from management are lacking within the Facility and this in turn then filters through to floor staff.

5. That on numerous occasions when calling the Facility the telephone rings out as no-one answers same On querying this matter I was advised that this may occur because the telephone cannot be heard??? or that staff are busy??? As I have been advised that I can call my mother at any time of the day or night, I find this to be a farcical and insulting comment.

6. That on the week-end of Saturday 27/Sunday 28 September 2008 on calling the Facility I found the telephone diverted to [redacted] [redacted] and that staff answering the phone were impolite and unhelpful in assisting me with ascertaining what the problem was and why this was occurring. My understanding is that [redacted] does not come under the umbrella of [redacted]". I reported this serious matter for concern to [redacted] on Sunday 28 September 2008 and subsequently received a telephone call from [redacted] that the matter was immediately rectified – the telephone had been switched over incorrectly.

7. That in light of the above matters, I feel that there are huge "cover-ups" for short-staffedness leaving much to be desired.

8. That I would gratefully appreciate a response to the matters raised herein with a view in ensuring that they do not re-occur.

[redacted]

Friday, 27 March, 2009

[redacted]

c.c.: [redacted]

[redacted]

[redacted]

[redacted]

[redacted]

Re: [redacted]

I refer to a completed Aged Care Client Record dated 02 February 2009 in relation to the abovenamed and to events which followed due to the incorrect completion of same. Due to its inaccuracy my mother was placed in the "Dementia-Specific" unit of the [redacted] Residential Facility – a place where she was far from appropriate for.

I owe immense gratitude and appreciation to three people who, collaboratively, changed the situation or, at this very moment in time, my mother would be back in a psychiatric unit requiring a heavier dosage of anti-depressants. The whole exercise of the change in residence from [redacted] (her last place of residence) was that she no longer required to be in a "psycho-geriatric" facility – and instead of her graduating to a more healthier and quiter environment, she was actually placed in one to her extreme detriment so much so that, over the two days that she was in the wrong unit, she was whimpering, asking God to please let her die and asking me how I had the courage to place her in a place clearly not for her. Now, if she was YOUR MOTHER, how would that make YOU FEEL?

Upon immediate entry to the "dementia-specific unit" [redacted] the Unit Manager, was clearly taken aback as she could clearly see the error made – she, in association with [redacted] Social Worker ([redacted]) and the person who was transitioning my mother, were quite concerned for her well-being, clearly acknowledging and identifying the inaccuracy of her placement.

I need to also extend my indebtedness to [redacted] the Regional Operations Manager at [redacted] who then actioned upon this misplacement as evidently it was in my mother's best interest and well-being that she needed to be transferred out of that specific unit and into a more appropriate one for her.

Hence, I would appreciate knowing how and from where the ill-defined information for her assessment was gleaned from. I have attached to this letter, the last Care Plan prepared by [redacted] dated January 2009, authorized by myself – I cannot see anything in this Plan that remotely indicates that she would be suitable only for a "dementia specific unit".

When I attended the pre-admission interview with [redacted] on Monday, 16 March and she at that time advised me that my mother was being admitted to a "Dementia-Sensitive Unit", I had no idea whatsoever what that meant and, furthermore, I had no idea what calibre of people the unit was meant for – not having toured that section of the facility previously did not in any way prepare me for anything other than relatively quiet, calm and pleasant ambiance my mother needed to be in after having endured years of fraught surrounds within the Mental Health System because of her illness.

Just a brief history on my mother follows, for your information.

She is an 84-year old (not 85 as specified in the Assessment) who, over a period of forty-seven (47) years has suffered mental health problems and has, innumerable times, been hospitalized for same and undergone countless sessions of ECT. Just looking at her endless volumes of medical and psychiatric history would make one giddy, let alone trying to calculate how much time it would necessitate to peruse her files. In fact, her records are of a historic status – my mother has never had "text-book" symptoms for her illness and hence has created history over the aforementioned period of time. Any health professional who would take the time to read her file would learn more from that than any university lecturer could teach in theory.

Coming forward to today, my mother has been mentally stable and well for a period of over sixteen (16) months, with no ECT treatment for twelve (12) months. Clinical Psychiatrists had assessed and approved her complete readiness for mainstream residence. I was thrilled to finally see a breakthrough after decades of treatment in the Mental Health System; she was finally liberated from a system which over the last fifteen years has seen enormous changes about how Mental Health is dealt with, but one which still requires many more changes so that the stigma and enigma connected to the illness, where some people still think that mental illness is a contagious disease, can be eradicated.

It is quite disconcerting to begin to comprehend that the very people who should be protecting our elderly and vulnerable citizens and rendering the last stage of their lives on earth more tranquil, accommodating and enjoyable are in fact, the very ones making evaluations without comprehending their full background and history which can lead not only to them having to endure difficult and traumatic events, but them relapsing. Quite serious decisions for their future well-being when made incorrectly not only have an intense impact on the actual person but on their loved ones as well - totally unprofessional, negligent and careless decisions can be disadvantageous and unsafe for their health and if most assessments are carried out in the same way as that of my mother then clearly there should be a benchmark overhaul with clear and precise categorizations when these assessments are made. I understand that "dementia" is identified in various forms and this should be clearly established, categorized and documented.

What right does any person who does not know my mother in every respect and aspect, meeting her for one half hour, have to decide on her future? I can certainly understand her being assessed for high-care but I cannot and do not agree to the fact that she requires dementia- specific care.

I distinctly recall the meeting had with [redacted] on the morning of the said date, Monday 02 February 2009, and remember him asking my mother questions to which she was capable of answering – my mother is still cognitively alert –her clinical diagnosis has been depression - obviously Mr. [redacted] was not interested in the interview itself, but based his decision on other comments made and documented by staff – some of whom I have come across as being agency nurses without any specific psychiatric nursing background who clearly do not know my mother in normal situations. My mother is referred to as being "aggressive" in the assessment – a more gentle soul she cannot be and for those who will take the time to offer her a gentle hand, she rewards with such a radiant smile that melts ones heart – we clearly cannot be speaking of the same woman!!!

Another quite serious matter I wish to raise with you is the fact that I was requested by Mr. [redacted] to sign the front cover sheet of the Assessment Form prior to him having had the opportunity to fully complete his perusal of my mother's file, allowing him chance to write whatever without my actually being able to read what was covered in the document. This to me is illegal and a matter which should not be allowed to occur. Family or carers should be allowed to peruse the documentation on their loved one prior to signing.

To summarise, all I really want is for my mother to spend her last living days in peaceful, tranquil and reassuring surrounds that she has so longed for all of her life – because of her illness she has been such a tormented soul. Due to my own personal circumstances, I am not in a position to be able to stay at home and care for her, but believe me, Ms. [redacted] last Thursday week I was so infuriated that I would have been prepared to take her home with me rather than see her suffer and endure situations inappropriate for her welfare.

For inexplicable and miraculous reasons (not known even to the professionals), my mother is now is free from audible and visible hallucinations, has overcome severe depression which for many years plagued her (I as a five-year old distinctly recall visiting her at the [redacted] Hospital – a jail-like institution back in the 1960's with large locks and keys). She has managed to overcome huge adversities on her journey through this earthly life – both from a physical and mental health point of view. Had I even remotely listened to "doctors' orders" and what they thought was good for her, she would have been six-feet under some twenty years ago. In as recent as five months ago, at the [redacted] Hospital in [redacted] I was told to prepare for the absolute worst – in October 2008 due to a severe bout of pneumonia she would not live through 24 hours – in November 2008 that she purportedly had suffered a stroke and that she may be bed-ridden and unable to walk - (definitely not the case) – when in speaking to one of the ED nurses telling her that I did not think this to be case, she told me that many people live in denial and I was one of those!!! I would think that I know my mother far more than anybody else - just by looking at her - I knew this information to be incorrect. I have been told that she has fought through due to my constant nurturing and my disregard to a "non-abandonment" type attitude – perhaps yes - and why would I not be at her side encouraging her and holding her hand? All my life through we have played role reversals and I have suffered along side of her.

I am what I am today because of my mother – I did not have a mother who was a normal one per se - one who would put me to bed – who read me stories – who helped me prepare for my wedding – who was able to attend my children's christenings or my daughter's graduation ceremony – for these and many more occasions she was an in-patient in hospital – but I am proud to say that we have come through the other end more compassionate, empathetic and with a fighting spirit – even more than any other person who has had a normal life and who would have had all the love and care from a mother.

There seems to be little regard for many lost souls in our bureaucratic systems – I can put pen to paper – I can speak the language - but what of the others who cannot or are afraid to speak up – what really happens to them? I shudder just thinking about it. With some 75% of the north-western suburbs' population being from non-English, low socio-economic backgrounds, makes us no less human or apt than those people who live in the more affluent suburbs.

Finally, ensure that your Assessment Team employees take more appropriate care and feed-back from family and carers and if they are inconveniencing people to attend an appointment for assessment, then allow them the proper and due feedback.

In having had to express my negative thoughts on this matter, I again reiterate my thankfulness to the three angels as mentioned above – [redacted] – Unit Manager of the [redacted] Unit at [redacted], who was vigilant and concerned for the incorrect placement – [redacted] for her assistance in transitioning my mother and for sitting, talking and holding her hand over the two days when she was quite distressed – and finally to [redacted] [redacted] for listening to her subordinate and understanding the change that needed to be implemented for the safety and well-being of my mother.

In light of the information contained herein, I would appreciate a review of the assessment initially made on my mother, even if for file purposes only.

Should you need to contact me, you may do so on [redacted].

Yours faithfully,

Teresa Livoti

Encl. APMHP Resident Care Plan dated January 2009

P.S.* *Food for Thought:
"BE KINDER THAN NECESSARY, BECAUSE EVERY ONE YOU KNOW IS FIGHTING SOME KIND OF BATTLE".

09 OCTOBER 2011

SPEECH GIVEN AT ASCOT HOUSE
BY TERESA LIVOTI

AT THE LAUNCH OF THE BOOKLET "AFFIRMING LIFE – A PALLIATIVE APPROACH"

A very good afternoon to all of you here present.

My name is Teresa Livoti and I feel quite overwhelmed to have been asked to say a few words on the launch of "Affirming Life – a Palliative Approach" and what it will mean to family members of all creeds and culture, in giving them the ultimate confidence that when their loved one will be going through the process of passing, the information will assist in clarifying any uncertainties.

I am no professional or academic, nor come from any health-related background, but am simply what now can be called a "Past Carer" specifically for my dear mother who passed away early last year. My mother had a mental illness spanning 48 years and spoke no English. Hence, our relationship was a role reversed one from the time I was 5 years old and her emotional reliance on myself was quite innate and meaningful. I endured immense trials and tribulations throughout her life with the associated stigma that has been, and still is, associated with all types of mental illnesses without even thinking or looking at any palliation.

I can vividly recall how, when and where I was at the time I was told that, due to my mother's deteriorating condition and frailty, that I would no longer be able to care for her at home and that she would be requiring palliative care from thereon. Palliative care? My heart fell to my knees. I had heard of such care being available only for people with terminal illnesses such as cancer and other life-threatening conditions - and my mother did not have any of them. My head spun and I could only feel myself spiralling into a lifeless burrow - that was in the year 2006.

My mother received palliative care not only in one or two, but three separate residential facilities. Each time she entered a new residence, I would be asked to fill in the necessary paperwork and be verbally advised of so-called Care Plans with which I would participate in but, ultimately, that involvement became a matter for me to seek, investigate and pursue – there were no clear guidelines to the sequence of events that would follow in the ensuing time of my mother's care, which ended being over a period of 4 years.

I would visit my mother a minimum of three or four times per week and wander through the facilities' foyers and passageways looking and searching for an induction booklet or brochure or some other form of literature – something to which I could refer to. I had so many unanswered questions – who was the best person to speak to? I had not been informed. The care staff was always busy – was I meant to interrupt their routine? For quite some time I felt an emptiness beyond expression! Was this a normal reaction or was I being overly sensitive due to my emotional relationship with my mother? Was I feeling like this because I no longer personally cared for my mother? I felt alone, dismissed, inadequate and even depressed.

Was it because my mother was a mental health patient, that were we left out of the "normal" sequence of events as, after all, it is well known in the community, to think and believe that "one day we will get around to writing something". But like so many broken promises that had been made to me over the years by medical professionals and associated staff alike, I did not ever think that this would come to fruition. I recall at one time even asking whether a Policy and Procedure Manual existed – I needed tangible information on which to rely upon.

As with any partnership, be it personal or business, it is absolutely vital that communication and trust become the key essence of that team game. How utmostly important it is that a carer's views and wishes are taken into account as a positive step in the process of their loved one's journey, and that each step of that progression at hand is seen and dealt with as a co-operative relationship involved in achieving the ultimate and purposeful result for the wellbeing of that loved one whose care you have surrendered. A sense of belonging – a sense of significance – a sense of progress – a sense of perspective – a sense of history – a sense of being unique and special – a sense of still being an attachment to the family – these are all vital issues needing to be highlighted.

Today, I stand here with immense gratitude and sincerely praise, admire and congratulate all those people who were involved in the preparation of the booklet "Affirming Life" – seen by myself as a massive step forward in "partnership in care" – a guiding hand to each and every carer or relative who will be told that their loved one is now entering another stage of their life's journey – a compassionately written resource, powerful in its contents - which can be referred to at any time.

It becomes absolutely crucial that a carer knows that the sequence of events that will progressively occur need not be doom and gloom – but that if approached diligently and correctly, it will become another indelible chapter. I always say that death is a part of life and as such, life continues on ... and we will want to retrospectively live that chapter in our lives time and time again, without any doubts or regrets as those who leave this earthly life live on in our memories.

Thank you all for listening.

"mentally ill people" do not have the same feelings or thoughts as "normal mainstream ones"?

Simultaneously to this course of events, I had another series of inevitable trials within my own family circumstances at home – my husband had contracted encephalitis and was in hospital – my daughter was in university and my son was studying for his VCE – therefore not only did I not have any tangible reference to refer to, but neither personal contacts with whom I could discuss my dilemmas and instigate me on finding the right course of action.

In the latter half of the year 2007 I encountered quite serious deficiencies in one of the psycho-geriatric facilities where my mother was being cared for after which time I was "allocated" a Social Worker, Lynn Bugeja (whose superior was Bridget Howes) to "look after me" – this purely, because of my outspokenness on the shortfalls and inadequacies I could see and hear (and possibly because of the many threats of reporting to a higher level). Both of them are present today and I wonder whether Lynn can recall my desperate plea and plight when I complained to her of the lack of information provided to Carers, at which time I was told