

Navigating Qld Health Public Hospitals

If you find yourself in one of our public hospitals and you are having too many cognitive issues or feeling too weak to speak up for yourself - then you need the services of an Advocate.

When a person with Tick borne disease is admitted into a ward to address their immediate health issues the Doctors on the Ward may not understand about how chronic tick borne diseases affect a person, so communication is tedious and can be stressful for all concerned.

Each person's situation is not going to be the same so you must find out what the persons needs are with regards to your advocacy.

Here I will step you through one of my personal experiences with Advocacy - it is specific to my clients needs so please leave out any steps that are not relevant to your situation.

Step 1. Have a signed agreement enabling you to be that persons advocate. You will need to agree on the terms and conditions.

Sample agreement:

I, (*clients full name*), on the (*10th Day of February 2014*), give my permission to (*advocates name*), to be my Advocate in all matters regarding my stay at (*name of hospital*) and in any matters that may arise regarding my care needs and any problems I may encounter as a consequence of my stay at (*name of Hospital*)

I give (*advocates name*) permission to act on my behalf

.....
Name of Client

.....
Name of Advocate

Step 2. Set up clear boundaries of what your advocacy will entail and perform your services without bias or emotional investment. You need to keep a clear head to negotiate your client's needs.

Step 3. Be prepared for resistance. Remember treating patients with chronic tick borne infections is not mainstream Qld Health practices and they will not understand if you go charging in declaring LYME LYME LYME which is simply Politics and will immediately put the Doctors on guard.

Step 4. Keep a clear head and an open mind and learn how to speak in such a way that the information you are sharing is accepted. The best approach I have found is to use Australian Accredited Laboratory results and your clients treating doctor's letter explaining their infections - disability status - care needs and so on ** Remember you are not there to make the doctors understand that LYME is here in Australia - you are there to help your client receive the best possible treatment and make their life a little easier.

Familiarise yourself with your clients health issues and seek appropriate medical advice from the right people. Having the correct information makes this process smoother. I personally asked for Dr McManus's help throughout my Advocacy.

If asked by a Doctor " Are you trying to get me to believe that Lyme Disease is in Australia?" Answer NO .. Remember you are an Advocate and are not there to have a debate on the current politics of Lyme. You say " of course not that would be a total waste of time and is completely unnecessary. You know that we have tick borne diseases in Australia, the zoonoses are well documented. The problem is in understanding that if these infections go untreated long enough then a person becomes chronically ill with many different health complications. That is why *my client* has been admitted into your hospital. We are not here for any other reason than to provide the best possible care for *my client*.

Step 5. Meet the Hospital Social Worker and have a chat about the needs of your client. Be specific. Mobility Needs. Home Care needs. Meals on Wheels. Housing Needs - Assistance for your client to Fill out the Forms to apply for housing. The Social Worker can help your client in many ways but is limited by the Doctors Advice. This is where it gets tricky

Step 6. Request a meeting with the Ward Doctor and Consultant Physician, Head Nurse, Social Worker to discuss what your clients needs are. Take notes and jot down things you need to do to help things along. If your

client is too weak or unwell to attend these meetings you can attend alone and take the stress away from your client and simply provide the outcome after the meeting.

If you look at the PDF tagged 'The Advocate Toolkit' **Chapter 6** *Advocating on behalf of another person to get their health needs met* and also **Chapter 5** is very beneficial for both your client and yourself to read. It clearly outlines the patient's rights while staying in hospital.

Step 7. Stand up for your clients rights and needs. If your client needs a ACAT assessment - Neurologist Assessment - Psychiatric Assessment - Occupational Therapist Assessment for MASS - Mobility Aids. Request them in writing and date and sign. Keep copies of everything you submit. If you are denied these assessments then document what is said and by whom, this can later be used as a legal document. Keeping good account of all you encounter in the process is vital for a positive outcome for your client.

Step 8. Don't be afraid to speak up. Here are some of the issues I have had to tackle in my time as Advocate.

- ↗ The Ward Doctor & Consulting Physician disregarding your clients treating Doctors information
- ↗ The Ward Doctor denying your client their medications to treat the tick borne infections
- ↗ The Ward Doctor denying your client oxygen when having a seizure & saying that it is not Hospital Practice to administer oxygen to a person having a seizure
- ↗ The Ward Doctor raising their voice to you over the phone as you call to ask that your client be given oxygen to assist with their stroke like symptoms
- ↗ Nurses being instructed by Consulting Physician and Ward Doctor to not assist your client with their daily hygiene needs.
- ↗ Nurses telling your client that they quote "prefer their patients to do as much self care as they are capable of" I had a few words with the Head Nurse over Duty of Care and Patients Rights
- ↗ Head Nurse bullying my client because of having an Advocate

- A Meeting where my client was present and watching the *Hospital Team* reduce my client to an emotional wreck of tears and anguish to prove my client was mentally ill. (your client has the right to not attend meetings despite any coercive tactics used to bully the patient into attending)
- Bullying Campaign - be prepared for stacked rooms when having meetings and closed ranks. Don't be intimidated by this as you have your patient rights firmly in mind and the extra folks in the room should signal to you that they are a bit intimidated, because you do have rights as an Advocate. They have to speak with you and explain their actions. You can request a second opinion and nominate your clients Tick borne disease treating doctor. You can question their actions based on the needs of your client and your client's rights. Document clearly any statements made by the Doctors.

Here are Some of the Statements I have collected

- “ I can speak on behalf of all Qld doctors when I say that no one will write that your client has a permanent disability nor request an Assessment from Disability Services Qld” (not really true is this as we have people in our community on PD Pensions in Qld)
- “There is nothing I can treat your client for. Your Client has no fever and needs no medications and is ready for discharge”
- After I handed my clients mobility needs letter from her treating doctor to the Hospital Doctor “ well this can change in a year and we do not assess people in the same way here in Qld. We have our own way of doing things and it may not provide the same outcome as this *other states* assessment”
- “ Well we have run a lot of tests on your client and there is nothing wrong with them. All the tests are good” (here you need to understand autoimmune and test results)
- “ I am your clients treating Doctor and I can make decisions on what medications they can have. And I will not be giving your client any Bicillin LA injections as they have no infections” or “ not allowing your client to take xxx whatever medications their treating doctor has prescribed” (read your Advocate Toolkit pdf - sudden stopping of long term medications and the adverse outcome for the patient &

document this & provide this documented evidence to the Hospital Doctor in mention as evidence of your request they not experiment with your clients medications as they do not understand your clients disease enough to make an appropriate decision)

↗ “ We will not be requesting an ACAT assessment. They are only for the elderly. Nursing Homes do not care for young people” (not true of course so don't let this put you off)

↗ “ We don't admit people into the Ward just because they are Homeless “ (no you admit them because they are sick)

↗ “We have tested your client for Epilepsy and they do not have it so they are free to be discharge” (not really the point is it when you have tick borne diseases)

↗ “ How dare you complain to the Hospital that I am not caring for your client. You'd have them believe that the patient is sitting in filth and the patients bed is filthy” (it is important that you do not validate this, be careful with your wording. Of course this was the emotionally charged response of the Head Nurse to my request that my client be washed once a day - I explained that no such complaint was made regarding the laundry as far as I knew & that the issue remained with her nursing staff being neglectful - after more complaining from the Head Nurse I pointed out that all nursing assistance offered to my client was documented - was it not? And then asked ' how many times have you washed my client in the past 3 weeks - the answer - once - not really good enough is it & it is a blatant failure to provide duty of care') Result - My client was offered to be washed the next day

To be a successful advocate you need to understand the roles of each person who comes into contact with your client and what their Duty of Care entails. If you encounter a problem, document it well and make a complaint to the relevant body.

Each hospital has a complaints department and they will take your concerns very seriously and will act to pass on your observations to those that need a reminder of their Duty of Care

If you have issues with the Consulting Physician and Ward Doctor and any other person involved in your clients care and you have enough documented evidence then you can contact the Queensland Health Complaints Commission QHCC with your complaint against the hospital naming the people involved and the circumstances. The QHCC will then assign your case an Officer who will contact the Hospital and request an explanation of their actions.

As you document your client's medical treatment at Hospital be mindful that you are making a legal document that will assist your client down the track if negligence is proven and they wish to prosecute.

Lyme Raging & Anger Issues: this is a difficult situation for the advocate to find themselves facing.

You want to help your client but they are angry and when you try to speak with them to find out what the problem actually is - well it is very difficult. Much of your time will be spent calming your client down so that you can communicate enough to assist them with their health care rights. It is important that you remember that it is the disease and not just the client behaving badly, but it is difficult and it can wear you down over time.

From experience the best way forward through this is to remind your client that you are not a social worker or a counsellor and that they need to speak with others about these issues. The use of a Psychotherapist is very helpful and can help keep your client calm. If you can find assistance from within the Hospital Ranks for your client grab it with both hands. It is too difficult to go it alone and it leaves you open and exposed to chronic verbal abuse.

* Make sure that you have someone to speak with to debrief after each visit with your client so that you can go the distance required or alternatively never see your client alone. Take a support person. The support person does make a difference.

Drug Addictions: Please be aware that your client may suffer from angry outbursts when their long term medications are abruptly halted. Your client may appear on edge or tell you they are very angry, but this will not stop them from sudden episodes of rage and you will be the target.

It is not easy to be an Advocate and it is not for the faint hearted. You can expect to be verbally attacked and completely unappreciated and feel used as a consequence. But remember you are not advocating because of any personal desire to be glorified - you are advocating so that the patient is offered medical care appropriate to their level of needs and that is the reward you seek.

Stay focused and committed and once you have succeeded step back. Being an Advocate can create emotional dependence in your client, so it is very important to keep reminding the client what your agreed role is throughout your Advocacy - and also when your Advocacy is to end.

* Please be kind to yourself - ignore the backlash from your clients Lyme rage when it makes it onto the online gossip community. If you are going to work in this field you are going to have to be thick skinned. Remember what you do and why you do it. Regardless of your clients behaviour - if you have managed to assist your client to get the help they need then it is a win!

I am certain that I have much more to learn and look forward to sharing my experiences with you in the hope that together we can make a difference for the most vulnerable in our community. If I can be of any further assistance please do not hesitate to contact me. Confidentiality is assured

Please join with me in showing gratitude to Dr Mualla McManus for her unfailing and untiring duty of care to our community and the many hours of assistance rendered to those in need.

Dr McManus, your knowledge of Tick Borne Diseases & how they affect the human body is invaluable. Your knowledge of the medications we need has been life saving & helped our treating doctors to care for us in ways they never could have without your assistance.

Our Warmest Heartfelt Thanks Mualla