

Parents' Submission to the Statewide Adolescent Extended Treatment and Rehabilitation Strategy (SW AETRS) Steering Committee

Monday 4th November

After many requests and ongoing urging from parents to allow them to have input into the planning for the future model for healthcare for adolescents with severe mental health issues, two parents were given the opportunity to present to the SW AETRS Steering Committee – the group charged with devising the new model of care for this group of young people.

The parents were provided with the briefing document that appears on pages 2 and 3 here and, following their voluntary submission of a comprehensive written document compiled to ensure that the committee would be aware of all the information/insights that parents/carers/patients felt were vital, two parents (one who travelled from Far North Queensland for the day) appeared before the Committee.

Their account of their experience on the 4th of November follows the briefing document.

Statewide Adolescent Extended Treatment And Rehabilitation Strategy Parents' Presentation

Hello and thank you for your submission regarding the Statewide Adolescent Extended Treatment and Rehabilitation Implementation Strategy (SW AETRS). Your input and comments are sincerely appreciated.

We would now like to extend an invitation to parents and carers of adolescents currently admitted at the Barrett Adolescent Centre to present this submission to the SW AETRS Steering Committee.

Meeting Details:

9.30am – 10am (*please arrive a little earlier to be signed in*)

Monday 4th November 2013

Child and Youth Mental Health Services Unit

Corners Roger and Water Streets Spring Hill (*parking is available via the Roger St entrance*)

Frequently Asked Questions

Question 1: What is the purpose of the Statewide Adolescent Extended Treatment and Rehabilitation Strategy Steering Committee?

The purpose of the SW AETRS Steering Committee is to oversee the implementation of the Statewide Adolescent Extended Treatment and Rehabilitation Implementation Strategy, and provide a decision-making, guidance, and leadership role with respect to mental health service planning, models of care, workforce planning, financial management and consumer needs associated with future adolescent extended treatment and rehabilitation services.

Question 2: What is the purpose of the Parents' Presentation?

The Parents' Presentation is an opportunity for parents of adolescents currently admitted at the Barrett Adolescent Centre to engage with the Steering Committee. This forms part of a broader engagement strategy to gather input for the design and development of improved mental health service options for adolescents.

The Committee are very interested to hear your submission to raise their understanding of your experience and perspective, and to inform an enhanced child and family centric model of care for the future. All due respect and consideration will be given to your family's privacy and personal situation.

Question 3: How long will I have for the presentation?

You will have 30 minutes with the Steering Committee, commencing at 9.30am. We would like to suggest you allocate 20 minutes for the presentation and 10 minutes for questions and answers from the Steering Committee to clarify any points of the presentation.

We will also undertake a debriefing session with you immediately following the presentation which could take from 10 – 20 minutes. We will be guided by you on the duration of this debriefing session.

Question 4: Will all of my suggestions be implemented?

A range of stakeholders from across the state, and interstate, have been consulted on adolescent mental health services and contemporary models of care. This has included mental health clinicians across nursing, allied health and medical professions, non-government organisations, carers, consumers, and

families. The aim of this extensive consultation is to consolidate input from all stakeholders, together with evidence-based research, to create a service model to best meet the needs of youth across Queensland. Your submission will absolutely be considered as part of this process, however, it must be noted that some of your suggestions may not be implemented.

Question 5: Does my adolescent need to attend the presentation?

No, your adolescent does not need to attend the presentation. Again, we understand that this could be a potentially unsettling and emotional process for you. Even though we will make every attempt to create a relaxed environment when talking with the Committee, and make you feel as comfortable as possible, it might be a little daunting for a child.

Question 6: Will my adolescent's clinical care team be attending the presentation?

No, your child's clinical care team from the Barrett Adolescent Centre will not be in attendance at the presentation. The current clinical care of your adolescent remains the responsibility of West Moreton Hospital and Health Service and is not the focus of this presentation.

Question 7: Who else will be at the presentation?

Only Steering Committee members and the invited parents associated with your submission will be present during your presentation.

Question 8: What if I freeze up during the presentation?

At any time during your presentation, should you wish to take a break, freeze up, or finish the presentation, please indicate to the Committee Chair, Judi Krause, and she will immediately cease the presentation. A separate break out room will be available for you to move to should this be required.

Question 9: Do I need to prepare anything or do I just turn up and start talking?

You are not required to undertake any preparation for the presentation unless you would like to. If you would feel more comfortable with some notes to prompt your thinking in the presentation then please feel free to do so. The Committee will have read your written submission prior to the presentation, so they will be familiar with the content.

Question 10: Is it up to me to take the lead in the presentation or will someone else assist?

The Steering Committee Chair, Judi Krause, will take the lead in the presentation. When you are ready, you will then be invited to lead on from there.

Question 11: Can I ask questions of the Steering Committee?

The purpose of this presentation is for you to have an opportunity to present your submission to the Steering Committee. The Committee will not, however, enter into discussions regarding future adolescent mental health service options. This initiative is still in a consultation phase and no decisions have yet been made regarding the future model of service.

Question 12: How will you support me through this process?

We understand that this could be a potentially unsettling and emotional process for you. Our aim is to provide every available support to you at the Committee meeting and directly after. Prior to the committee meeting we will contact you to ensure you are clear about the purpose of the Parent Presentation and to identify any support services that you may require. During the presentation, the Chair, Judi Krause will introduce you to the Committee and be a moderator throughout the presentation. Immediately following the presentation, Stephen Stathis, the Clinical Lead on this initiative, will undertake a debriefing session with you. At the end of this debriefing session, we will discuss whether you think you might like any additional support assistance and, if required, we will make the appropriate arrangements. Finally, and if agreed by you, we will contact you one week after the presentation to see how you are. It is at this time that further support services can also be arranged if required.

PARENTS' ACCOUNT OF PRESENTATION

It began with the Committee Chair reminding us of our 30 minute time limit - 20 to talk and 10 for them to ask questions of us. She also stated that whilst they were aware of the problems at Barrett, this wasn't the forum to voice our dissatisfaction.

The other parent and I told the Committee we would work on the premise that they had read our submission.

1. The other parent presented her account of how her child ended up at Barrett. It was very powerful and emotional but we wanted to make sure the Committee was left in no doubt for whom they were designing their model. We wanted them to hold that front and centre of their minds the whole time and also to realise the extremely trying and distressing process that young people and parents go through just to get to Barrett. And how many times the existing system fails young people and their families. The parent drew attention to the fact that parents have been passed around when they ask questions – CHG, WMH, Minister etc.: we are always told it's someone else's area/responsibility. She also told them there is nothing but private alternatives being offered to young people and their parents as transition options at this stage; that the alternatives outside Barrett are inadequate and there must be recognition of that – that's why her child is there in the first place;

2. I explained that my presentation focused on making the Committee aware that whilst they have a particular task to do, they are part of a bigger process and that I felt it was important that they were aware of what was happening at the same time as their work. I started by stating that the Committee's work started with and is based on the ECRG's recommendations; that initially the two processes – Barrett closing and a new model of care to replace Barrett – appeared to be linked: one closes, the other opens. It has been regularly stated the alternative would be available in early 2014. I quoted from letters and statements from WMH, the Minister etc. to verify that. I said that the further the process went on, there seemed to be a gap appearing between the two processes, to now when it seems like they are two completely independent events. I referred to Recommendation 3 that acknowledges the RISK if BAC closes before Tier 3 available: this recommendation states 'wrap-around care' "ESSENTIAL" and that The availability of BAC funds was a "significant benefit". At this stage, wrap-around care is non-existent, and risk is significant because of that.

I said that our respective presentations may be slightly outside what the Committee was expecting, but that I could not live with myself if I did not tell them of the concerns for the kids because of this process, in case one of them might have been able to do something about it. I gave them examples of some of the things that have happened to kids in this process (I had permission from respective parents to share this information- nothing identifying either parent or child).

I referred to poor consultation and stressed the need for consultation with young people and all stakeholders – the reason we were able to submit to the Committee and talk to it was because of processes initiated by us, not offered by WMH; the bad PR that Barrett has received from some people – describing what Barrett really does and how incredibly successful it has been and is!; how important the school and its staff are to the whole treatment and rehabilitation process – so onsite schooling is crucial as per the ECRG recommendations; even though it wasn't their decision to close

Barrett, to be aware that the decision to close – and the reason they are now charged with deciding on a new model – was not based on an analysis of the outcomes produced by Barrett and therefore there is no way of knowing if whatever they come up with will provide better outcomes. It did not start with 'how can we do better for these kids'. I told them Barrett is much more than the sum of its parts – it's the 'community' it provides and the power of the relationships the kids form with educators, nurses and other staff that makes rehabilitation and recovery possible.

The room was deafeningly quiet when we finished. There were no questions. We expressed our gratitude at being able to provide our perspectives to the Committee.

Afterwards the other parent and I met with Stephen Stathis (head of Children's Clinical Services Children's Health Queensland) for our 'debrief'. We had a very positive discussion with Stephen, again highlighting the gap that will be gaping wide when Barrett closes with no Tier 3 available. He was very interested in many aspects of our parent submission. The parent from FNQ was able to give Stephen a good regional perspective – lack of services, lack of coordination between existing services. We discussed the link between education and treatment: especially how both might be accessed and delivered in regional areas, the need for extended inpatient elsewhere, but at least in Brisbane as a minimum. The objective of providing care close to home is just not feasible for some young people (i.e. they actually need to leave their home to escape abuse and/or stigma) or because of lack of resources (funding) mean only one could be provided but we made sure we clearly stated that there must be a Tier 3 service, and that must include onsite schooling. We raised the issue of unqualified/inexperienced staff, the difficulty attracting said staff to regional areas and the lack of continuity of care because of staff turn-over. We didn't solve anything, and Stephen couldn't provide anything specific for us, but I feel very certain that he is very clear on the issues, and keen to consider the concerns we raised in the Committee's work.

We didn't – and couldn't – expect solutions to the current issues of closure, but we made very certain all the Committee was aware of them, and that we put forward everything that we could think of that is relevant to being considered in the new model. It is very possible that Stephen will consult with us again, especially the parent from FNQ, to get the regional perspective.