

Cyflwynwyd yr ymateb i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol](#)
ar [anhydraddoldebau iechyd meddwl](#)

This response was submitted to the [Health and Social Care](#)
[Committee](#) consultation on [mental health inequalities](#)

MHI 07

Ymateb gan: | Response from: Mr Haydn Morgan & Miss Tesni Morgan



On the 27th of August 2020 our darling Bronwen took her life after a long battle with her mental health.

We as a family truly believe that it could have been prevented. During the last 6 months of her life, Bronwen's mental health deteriorated drastically. She was making multiple attempts to take her life, putting herself in dangerous situations on a regular basis. Bronwen was hopeless, her current care-plan was not fit for purpose and she and the family were begging for something to change.

We begged to be listened to, so did Bronwen. We were ignored.

We are striving for shared decision making and regular reviews of mental health care and treatment plans. We also call for an opportunity for next of kin to contribute to those reviews. The current NICE guidelines state that shared decision making is essential in order to meet the needs of the patient.

NICE states that shared decision making is important for:

- Different choices to be made available to the patient and are discussed openly.
- The ultimate decision to be reached together by the health professional and the patient.
- To help health and social care professionals to tailor the care or treatment to the needs of the individual.

This was NOT the case for Bronwen. Shared decision making is ESSENTIAL for patients to receive the best care that is tailored to their individual needs.

We as a family are devastated by our loss and truly believe that it could have been prevented. Throughout Bronwen's years of struggling, we on many occasions came into contact with multiple different strands of Mental Health services across Cardiff and the Vale. During the last 6 months of her life, Bronwen's mental health deteriorated drastically. She was at rock bottom, making multiple attempts to take her life, putting herself and others in dangerous and risky situations on a regular basis. Bronwen was truly hopeless, her current care-plan was not fit for purpose and she and the family were begging for something to change. Urging the professionals that her treatment at that time was not working and we were scared for her safety on a regular basis. The police and her GP (who came into contact with Bron regularly) were in agreement that the current care-plan was not working and we requested (begged) for a change and this was ignored. Bronwen was left feeling completely hopeless, if her current treatment was not helping her and things were getting worse, yet no individual aspect of her care was changing - how was she ever going to feel better. Ultimately she payed the biggest price and decided that life was no longer worth living. This can not go on.

We as a family were NOT consulted when decisions were made regarding Bron's care - despite having written in her notes to consult the family and Bronwen's personal request to consult us. This never happened. Bronwen told the professionals that SHE is the expert of herself and the second experts are her family. Yet they did not want to hear anything from us, the people who spend 24 hours a day with her, caring for her. Surely we would be able to give valuable information about her current state of mind? This again was completely ignored and inevitably resulted in extended pain and trauma for Bronwen and the rest of the family. WHAT NEEDS TO CHANGE?

We are striving for shared decision making and regular reviews of Care and Support Plans. The current NICE guidelines (National Institute of Health and Care Excellence) state that shared decision making is essential for appropriate care and in order to meet the needs of the patient. Although these guidelines are brilliant and if followed would create an extremely more holistically rounded support system, they are indeed guidelines, which means they do not legally have to be followed.

From our experience and many, many others – these guidelines are not being followed and we feel it is time for this to change.

We are petitioning for these guidelines to be a legal requirement. NICE States that shared decision making is important for:

- o Care and treatment options to be fully explored, along with their risks and benefits.
- o Different choices to be made available to the patient and are discussed openly.
- o The ultimate decision to be reached together by the health professional and the patient.
- o People to feel supported and empowered to make informed choices and reach a shared decision about care.
- o To help Health and social care professionals to tailor the care or treatment to the needs of the individual.

This was NOT the case for Bronwen. She was told by professionals that the treatment she was having was not to be changed and when she requested extra support she was not given any options and was simply told no. This needs to stop. Shared decision making is ESSENTIAL for patients to receive the best care that is tailored to their individual needs. THE SOLUTION. We are requesting for a review in the legal requirements of a care and support plan review in order for shared decision making to be at the forefront of all changes to care-plans.

We desperately wish for this particular issue to be put up for debate and discuss the below points, we wish for this to be attached to a legally signed document during care-plan reviews for all individuals involved in mental health services.

1. Have the person's circumstances and/or Care and Support needs changed?
2. What is working in the plan, what is not working, and what might need to change?
3. Are there any changes in the person's informal and community support networks which might impact negatively or positively on the plan?
4. Is the person, carer, independent advocate or other person involved satisfied with the plan?
5. With the individuals consent - are the family/guardians satisfied with the plan?

I fear that without creating a formality/requirement to complete regular care-plan reviews, as well as a requirement for the comments of the service user and their family – the service users will not be given this opportunity since it is not a legality, so it is unlikely be prioritised. We believe that no matter what recommendations or guidelines are put in place – Care and Support plan reviews will not be completed with the service user and their family due to the time this will take. It is simply easier for it to be completed quickly and without consultation to save time.

However, in doing this they are taking away the patient's autonomy and their right to have a say in their treatment. Also potentially not giving the right support at the right time, resulting in the patient receiving support and care that they do not want or will not engage with – only to be bounced to a different service later, putting more strain on the services. It is about giving the right support at the right time and this can only be achieved by consulting the service user regularly and ensuring the support they are receiving is right for them, as well as hearing from their family – the ones who know them the best. I feel further investigation and research needs to be carried out so that the Minister for Mental Health can see the sheer amount of service users who have no say at all

in their care, and their wishes and requests are being ignored. Resulting in more strain on crisis services and wider. I feel the committee or those responsible need to take time to speak with service users or complete a survey to understand how often the average service user is offered a Care Plan review and how much say they and their family have on their care. This will open your eyes to just how irregular this is and why we are so passionate about making this change. The service users themselves are the ones with the knowledge and truth of their experiences, so I urge you to use them as a resource to find out just how much a change like this would mean to them.

If I may, I would also like to draw your attention to a method named "Open Dialogue " from Finland of which 4 UK Health Board Trusts have taken on a trial period. This involves families, carers and relevant persons in the treatment of mental health at home.

This system has drastically reduced hospital admissions in Finland and the fact that 4 UK Health Boards are considering these methods only goes to show that shared decision making is the way forward and Trusts are considering.