



From: Alison Earls via CommunityRun

Sent: Monday, 7 March 2016 8:54 AM

Subject: Caring for young people with severe and complex mental health issues

Hello everyone,

I have met some unique people in the last few years but there's a group that you might be interested to know a bit more about. Because it's easy for these people to be portrayed in simple portraits that can totally discount the journey they've all been on ...

As many of you no doubt know, the life of a parent or carer is never simple – even with young ones who are generally blessed with good health. So to deal with so much more than the typical challenges of childhood and adolescence can totally shape every waking moment of the life of the person responsible for their welfare. If it starts very early on, a parent may have never known a routine day, a time without distress or nightmares. If it starts a little later in childhood, the loss of the carefree years brings a yearning for the easier times that now seem so far away. But for any family whose child suffers from health issues that are severe and complex, it is a long road – lined with dashed hopes, drained energy and desperation.

I have met several Barrett parents and carers and communicated with others over the last few years. And I've been struck by the strength of character, the tolerance and the devotion of each of them. They are people who would do anything for the young person they love but who are also realistic and practical – all too aware that there are rarely perfect solutions.

They learnt compromise long ago. They try to retain hope but keep expectations reasonable. They understand limitations – in people and in services. And those I've met are infinitely calmer and more forgiving of failings in the system than I could ever be. The composure of those I've come to know is quite astounding. They don't rant. They don't make demands. They are very well informed. Especially about what works and doesn't work with the young people they see suffering every day. But they can be despairing. Who wouldn't? When there are obstacles that don't need to be there and attitudes that are unfair. Many have experienced times when, simply because they are family members, they are seen in a light that tarnishes even their moderate actions – genuine concerns can be disregarded, blame can be assigned, unfair insinuations can be made based on little pertinent information.

No family is perfect. None. But those who try their best to help those they love deserve only our best responses. Not rash judgement based on superficial factors.

Or dismissal simply because worry can't be hidden or past disappointments or injustices weigh heavily.

The Barrett families must feel as if they're all running an eternal marathon. With hurdles around every corner. That takes a considerable physical and emotional toll. And still ... they rise every day and do what needs to be done. They apply strategies. They explore options. When they need to speak, most have an astounding capacity to do so knowledgably and fairly – without drama or self-pity. They don't give up. And they get through each day always hoping to get a little closer to a time when their family's life isn't a tidal wave of crises and turbulent emotion.

Of course sometimes they feel bereft. Inevitably there are times they are frightened. They're human. And they've deal with more emergencies than most. But they are, as clichéd as it sounds, fueled by love. And that's a powerful thing.

So they are as courageous as their teenagers. And they need to be. They learnt a long time ago that the world isn't fair. But it seems they must be continually reminded of extremes in that regard.

So now, as some prepare to give evidence in closed sessions at the Inquiry, we're thinking of them. Those who've provided their insights, those who've experienced the pain, those who push on through the days. Those who love their kids and do their best.

Of course, each person is an individual. Each person reacts in their own way to challenges. And no one gets it right every time. But I've met some people in the last few years who are, quite simply, better human beings than I could ever be. So I hope for them that the future might become a little easier. Because they deserve that and so much more. And they deserve understanding. And admiration.

And support.

Thanks to you all for providing that. And thanks to the Barrett families for showing us the way.

Alison