

Cyflwynwyd yr ymateb i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol](#) ar [Cefnogi pobl sydd â chyflyrau cronig](#)

This response was submitted to the [Health and Social Care Committee](#) consultation on [supporting people with chronic conditions](#).

CC43: Ymateb gan: |Response from: Unigolyn | An Individual

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My son has a rare autoimmune disease called Juvenile Dermatomyositis. He was diagnosed when he was 8 years old, back in 2013. My feedback is based on our experiences over the last 10 years.

### **NHS and social care services**

The readiness of local NHS and social care services to treat people with chronic conditions within the community.

Getting the diagnosis was difficult – I was lucky that I had private medical insurance through work at the time and was able to take my son to a private Dermatologist who made the diagnosis in May 2013. However, I was horrified to hear that he would not be able to see a Rheumatologist in Swansea until the end of that year! Again, I used my private medical insurance to see a Rheumatologist and that consultant saw us via the NHS at The Heath in Cardiff thereafter. The issues continued however as we struggled to get access to a physiotherapist. Eventually he was referred to Great Ormond Street Hospital for specialist care.

We did manage to arrange for a nurse to come to the house to administer his Methotrexate in the early days. So that was one example of treatment in the community.

Access to essential services and ongoing treatment, and any barriers faced by certain groups, including women, people from ethnic minority backgrounds and disabled people.

My son's mental health has been poor for years, but we've struggled to get support. Great Ormond Street Hospital provided some support early on, but it was not feasible to travel back and fore every week. We had a huge battle to get support from CAMHS and the GOSH psychologist even wrote to them. When he was finally offered support from CAMHS, it was with a newly qualified mental health nurse who did CBT from a book. The approach was not suitable for a teenage boy who just saw it as more homework!

Support available to enable effective self-management where appropriate, including mental health support.

As above, we've struggled to get mental health support for my son for years. He has limped through school and college.

He has recently applied for an autism assessment and whilst he has been accepted for this assessment, the waiting list is 4 years!

### **Multiple conditions**

The interaction between mental health conditions and long-term physical health conditions.

The focus is very much on the physical rather than the psychological. My son had a treatment plan for his JDM which included medication and physiotherapy. If they had included mental health support from the early days of diagnosis, I think he would have had a much better time over the last 10 years. Chronic conditions require a multi-disciplinary team to support all aspects of health. The impact of mental health should not be underestimated!

### **Impact of additional factors**

The impact of the pandemic on quality of care across chronic conditions.

Before the pandemic, my son was being seen once or twice a year at GOSH. He also had quarterly or bi-annual appointments in Singleton Hospital and The Heath, Cardiff and I was in regular contact with consultants via email. During the pandemic, he had a couple of phone calls with GOSH, but everything stopped locally! Both local consultants retired so I lost my contact via email and the consistency of care just stopped. Thankfully, he had stopped medication in 2019 and did not experience any flare ups during the pandemic. He was supposed to be transitioned to UCL from GOSH but that never happened due to cross border funding issues. Eventually the Cardiff team got in touch and did arrange for him to be seen at Neath Port Talbot hospital and we are able to contact them if we have concerns. However, the service is not ideal as you just leave a message and hope someone comes back quickly. If he has a flare up in future, I fear that he will not be able to get the right level of treatment quickly enough and there is a lack of knowledge locally for JDM.

The extent to which services will have the capacity to meet future demand with an ageing population.

Services are already stretched – so I can only imagine it will get worse.

### **Prevention and lifestyle**

Action to improve prevention and early intervention (to stop people's health and wellbeing deteriorating).

As stated previously, mental health should be included at the outset of diagnosis as a matter of course. Ideally, we need multi-disciplinary teams treating all aspects of the disease and not just focussing on the medication. Would also be useful to have more interlocks with education and better processes in place to support children and students. I had to create a pack explaining JDM and what to expect from my son during the academic year. I presented this to every school he attended – every year – and yet there were always teachers who didn't know about his condition and the challenges he faced. He is currently in Gower College, Swansea and his mental health has significantly deteriorated over the year, and the lack of support for neurodivergent students has been astounding! They advertise an Equity and Diversity Policy online but cannot deliver in practice.

Effectiveness of current measures to tackle lifestyle/behavioural factors (obesity, smoking etc); and to address inequalities and barriers faced by certain groups.

A multi-disciplinary team would help to tackle these sorts of issues alongside mental health support. My son has become very isolated, and his depression means he is lacking the motivation to exercise and barely leaves the house. I'm finding it difficult to determine whether his aches and pains are due to a flare up or whether it is his lifestyle.

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