

“One cannot think well, love well, sleep well, if one has not dined well”: a young adult's right to eat

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Abbreviated abstract: A young adult (YA) with a neuromuscular condition feels their human right to food is being challenged. Food and its gentle enjoyment should be accessible to those who are physically vulnerable.



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Background

- ❑ 20 yr old young adult with congenital muscular dystrophy
- ❑ Frequent chest infections meant a video fluoroscopy was performed in 2019 - their swallow was unsafe and they should not be fed by mouth with immediate effect
- ❑ Physically unable to feed themselves so relies on others to do this
- ❑ PEG in situ but continues to eat and enjoys chicken wings, burgers, fish and chips, and curries



- ❑ Lives with parents but has an extensive care package
- ❑ Mentally low as feels human right to eat and be fed are being violated
- ❑ SHANARRI identified unmet needs in healthy, active, achieving and responsible indicators



Then: actions taken

PPWH continue to play the lead role in ensuring collaboration across health and social care by advocating for the YA to ensure that their right to eat is respected, protected and fulfilled despite their physical limitations. To date:

- ❑ Contact was made with MDDUS to discuss legalities and to seek advice.
- ❑ A MDT discussion was had at PPWH concluding that team could take this forward and involve health board ethics and or lawyers, if required, to reach a conclusion.
- ❑ Consent to assess YA's capacity gained following advice from MDDUS.
- ❑ YA declined referral for second video fluoroscopy – they didn't feel it necessary as it "wasn't going to change (his) eating" – Speech and Language agreed.
- ❑ Consultant neurologist contacted colleagues to discuss similar cases in other neuro-degenerative conditions.
- ❑ Contact made with YA's lead physicians across paediatric and adult services to arrange MDT to discuss case and consider way forward to ensure YA's overall wellbeing.



Now: a waiting game

- Capacity has been assessed – the YA understands the risk associated with eating
- The assessment has been shared with the YA's care provider
- An outcome is awaited from the care provider: meanwhile the YA's mental wellbeing suffers



Learning

- Establish a relationship and **build trust** so they feel listened to and respected
- Identify and address** a YA's unmet needs
- Consider the **impact** of the investigation – if it will negatively impact on quality of life, is it necessary?

