

Date: Wednesday, 09th October 2019
Our Ref: MB/SS FOI 4051

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Re: Freedom of Information Request FOI 4051

We are writing in response to your request submitted under the Freedom of Information Act, received in this office on 26th September 2019.

Your request was as follows:

1. What are the current criteria/guidelines used for Ehlers Danlos syndrome Neurosurgical interventions at your hospital?

The criteria for EDS are as defined in Malfait F et al. The 2017 international classification of the Ehlers-Danlos syndromes. Am J Med Genet C Semin Med Genet. 2017 Mar;175(1):8-26. There was a consensus meeting in Niagra in 2019, at which the criteria for surgery in EDS patients were discussed and guidelines proposed. We follow those proposed criteria.

2. What are the current UK criteria/guidelines used for Ehlers Danlos syndrome Neurosurgical interventions?

This does not relate to the Walton Centre Foundation Trust (WCFT), we would direct you to The National Institute for Health and Care Excellence (NICE).

3. Why are upright X-rays used as standard but upright MRI's not recognised?

The clinicians here at WCFT do order upright (flex / extension) MRI when appropriate.

4. How many millimetres Basion Dens Interval, Atlanto Dental Interval, Basion Axial Interval is viewed as abnormal?

A value of 9mm or more has been suggested as abnormal, although the literature is not clear on the evidence to support that figure.

5. What Clivo axial angle is classed as a brainstem compression?

There is no agreed angle that has been proven to cause brainstem compression. An angle of 135 degrees has been suggested as indicative of a degree of hypermobility (rather than instability), although there is little proof that this causes true brain stem compression. Currently it is not thought that brainstem compression is an issue in these patients, rather it is traction forces.

6. What degree of brainstem compression would require a fusion surgery?

Surgery is never based following a single measurement on an image. A clinical assessment is required. One must also differentiate between brainstem compression, visible on imaging, and abnormal angulation, which may or may not indicate brainstem compression, and brainstem traction (which is what is currently suggested to be the mechanism in

EDS patients).

7. How many millimetres of translational instability would be surgical?

Surgery is never based on a single measurement. Surgical procedures are based on a full clinical assessment and review of all the appropriate imaging available.

8. If you do not use any of the above criteria in deciding when an EDS patient requires cranio-cervical fusion, what do you use?

The answers above make it clear that these patients are assessed using all measurements, which are available when they are thought to be of value. There are many people who have abnormal angles and measurements and have no symptoms, or symptoms that cannot be attributable to the proposed mechanisms.

9. How many degrees of rotational atlas instability is classed as surgical?

Surgery is never based on a single measurement. Surgical procedures are based on a full clinical assessment and review of all the appropriate imaging available.

10. Does a Neurosurgeon rely on the report of a Radiologist in making surgical decisions?

A Neurosurgeon uses their clinical assessment, their own assessment of the radiology, and the radiology views in deciding on the best treatment of the patient.

11. Are your Radiologists trained to see skull and spinal instabilities and if so what measurements do they use?

Our radiologists are experts in assessing the radiological factors related to spinal instability. However, the questions above are not about spinal instability, but rather about hypermobility.

12. Has the Hospital published any surgical data relating to posterior fusions? If so what year please.

WCFT does not have a central repository of all papers published unfortunately. There have been publications regarding fusion surgery, We would direct you to Pubmed for further information.

13. Has the Hospital published any surgical data relating to posterior fusions in patients with EDS? If so what year please.

WCFT does not have a central repository of all papers published unfortunately. We would direct you to Pubmed for further information.

14. Since Feb 2017:

How many C0 to T1 posterior fusions have been carried out in total to date?

Due to the minimal number of patients identified, further information relating to a specific body part and the foreign object used will not be released under Section 40(3)(a)(ii) of the Freedom of Information Act 2000, as releasing this information may lead to the undue stress of families and patients as this information may still lead to patients being identified. Therefore this information has not been released for reasons of confidentiality; compliance with the Data Protection Act 2018 and by virtue of the exemptions contained in section 40(3) of the Freedom of Information Act 2000

as the Trust believes that providing the information would be in breach of the Principle (B) of GDPR as well as provisions under Chapter III regarding individuals' rights.

15. Since Feb 2017:

How many C0 to C2 posterior fusions have been carried out in total date?

Due to the minimal number of patients identified, further information relating to a specific body part and the foreign object used will not be released under Section 40(3)(a)(ii) of the Freedom of Information Act 2000, as releasing this information may lead to the undue stress of families and patients as this information may still lead to patients being identified. Therefore this information has not been released for reasons of confidentiality; compliance with the Data Protection Act 2018 and by virtue of the exemptions contained in section 40(3) of the Freedom of Information Act 2000 as the Trust believes that providing the information would be in breach of the Principle (B) of GDPR as well as provisions under Chapter III regarding individuals' rights.

16. Since Feb 2017: How many C0 to T1 posterior fusions have been completed with a primary diagnosis of Ehlers Danlos Syndrome to date?

Due to the minimal number of patients identified, further information relating to a specific body part and the foreign object used will not be released under Section 40(3)(a)(ii) of the Freedom of Information Act 2000, as releasing this information may lead to the undue stress of families and patients as this information may still lead to patients being identified. Therefore this information has not been released for reasons of confidentiality; compliance with the Data Protection Act 2018 and by virtue of the exemptions contained in section 40(3) of the Freedom of Information Act 2000 as the Trust believes that providing the information would be in breach of the Principle (B) of GDPR as well as provisions under Chapter III regarding individuals' rights.

17. Since Feb 2017: How many C0 to C2 posterior fusions have been completed with a primary diagnosis of Ehlers Danlos Syndrome to date?

Due to the minimal number of patients identified, further information relating to a specific body part and the foreign object used will not be released under Section 40(3)(a)(ii) of the Freedom of Information Act 2000, as releasing this information may lead to the undue stress of families and patients as this information may still lead to patients being identified. Therefore this information has not been released for reasons of confidentiality; compliance with the Data Protection Act 2018 and by virtue of the exemptions contained in section 40(3) of the Freedom of Information Act 2000 as the Trust believes that providing the information would be in breach of the Principle (B) of GDPR as well as provisions under Chapter III regarding individuals' rights.

18. Since Feb 2017: How many posterior fusions have been completed in patients with a diagnosis of EDS and Kyphosis?

Due to the minimal number of patients identified, further information relating to a specific body part and the foreign object used will not be released under Section 40(3)(a)(ii) of the Freedom of Information Act 2000, as releasing this information may lead to the undue stress of families and patients as this information may still lead to patients being identified. Therefore this information has not been released for reasons of confidentiality; compliance with the Data Protection Act 2018 and by virtue of the exemptions contained in section 40(3) of the Freedom of Information Act 2000 as the Trust believes that providing the information would be in breach of the Principle (B) of GDPR as well as provisions under Chapter III regarding individuals' rights.

19. Since Feb 2017: How many C0-T1 posterior fusions have been completed in patients with a diagnosis of EDS and Kyphosis?

Due to the minimal number of patients identified, further information relating to a specific body part and the foreign object used will not be released under Section 40(3)(a)(ii) of the Freedom of Information Act 2000, as releasing this information may lead to the undue stress of families and patients as this information may still lead to patients being identified. Therefore this information has not been released for reasons of confidentiality; compliance with the Data Protection Act 2018 and by virtue of the exemptions contained in section 40(3) of the Freedom of Information Act 2000 as the Trust believes that providing the information would be in breach of the Principle (B) of GDPR as well as provisions under Chapter III regarding individuals' rights.

Please see our response above in [blue](#).

Re-Use of Public Sector Information

All information supplied by the Trust in answering a request for information (RFI) under the Freedom of Information Act 2000 will be subject to the terms of the Re-use of Public Sector Information Regulations 2005, Statutory Instrument 2005 No. 1515 which came into effect on 1st July 2005.

Under the terms of the Regulations, the Trust will licence the re-use of any or all information supplied if being used in a form and for the purpose other than which it was originally supplied. This license for re-use will be in line with the requirements of the Regulations and the licensing terms and fees as laid down by the Office of Public Sector Information (OPSI). Most licenses will be free; however the Trust reserves the right, in certain circumstances, to charge a fee for the re-use of some information which it deems to be of commercial value.

Further information can be found at www.opsi.gov.uk where a sample license terms and fees can be found with guidance on copyright and publishing notes and a Guide to Best Practice and regulated advice and case studies, at www.opsi.gov.uk/advice/psi-regulations/index.htm

If you are dissatisfied with the handling of your request, you have the right to ask for an internal review. Internal review requests should be submitted within two months of the date of receipt of the response to your original letter and should be addressed to the Freedom of Information Office at the address above.

Please remember to quote the reference number, FOI 4051 in any future communications.

If you are not content with the outcome of the internal review, you have the right to apply directly to the Information Commissioner for a decision. The Information Commissioner can be contacted at: Information Commissioners Office, Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF.

Yours sincerely

Mike Burns

Mr. Mike Burns, Executive Lead for Freedom of Information